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Through My Mother's Eyes: The Lifelong Journey of Raising Children With and Without Disabilities

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THROUGH MY MOTHER’S EYES: THE LIFELONG JOURNEY OF
RAISING CHILDREN WITH AND WITHOUT DISABILITIES

A Dissertation
Presented to
The Faculty of Social Sciences
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In Partial Fulfillment
of the Requirements for the Degree
Doctor of Philosophy

by
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March 2011
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Abstract

The purpose of this study was to explore in-depth the journey associated with mothering a child with and without special needs. Through the use of narrative, this study sought to document the life-altering journey of 32 mothers raising children at various stages of development and with a variety of disabilities. The main questions guiding this research study consider the lived experiences of mothers raising children with and without disabilities; what these mothers reveal about the journey with their children; how these mothers define motherhood; and how their definition of motherhood differs for each of their children. To address the research questions and capture the narratives of participants, a two-pronged qualitative methodology was applied, using diaries compiled by participants and in-depth interviews structured by Arvay’s (1999, 2002, 2003) collaborative narrative method. For the diary phase, participants were given bound notebooks and asked to describe their mothering experiences for 4 to 6 weeks. The second phase of the data collection entailed in-depth interviews as part of the collaborative narrative method. The researcher conducted open-ended, in-depth interviews that targeted the perceptions and experiences of the 32 participants. To gain an understanding of the mothers’ lived experiences, the researcher asked mothers to describe their personal experiences raising their children and collected each mother’s story in her own words. All interviews were tape-recorded, transcribed, analyzed, and crafted into poetic representations from each mothers’ own words and experiences. The
narrative, social construction, and symbolic interaction lenses brought to this research study informed the analyses of the mothers’ unique experiences. Through this analysis, significant findings emerged, including negotiating new meanings of motherhood, social alienation, grief, burden, medical scrutiny, the perception of tragedy, acceptance, growth, and absolute love. These findings were embedded in the themes of diagnosis, motherhood, family life, public life, marriage and divorce, personal transformation, advice and recommendations, and the future. The findings from this study uncover key concepts which may be useful to medical and mental health professionals, educators, family members, and society as a whole. The results of this study strongly support the need to educate society about difference and break down the existing barriers. It is clear from this study that society must no longer consider individuals with disabilities as invisible and burdensome, and must learn to understand their differences and accept their personhood.
Acknowledgements

Though their names remain confidential, this dissertation could not have been written without the mothers who shared their deeply emotional and personal stories of their children and their lives to further this research. They spent enormous amounts of time conversing with me; recording their inner-most thoughts in journals; and providing feedback on portions of this study. I am truly privileged to have had the opportunity to hear their stories.

I would like to express appreciation for Dr. Elizabeth Suter, my chair and advisor, who continuously inspired and challenged me to consider new ways of looking at human identity and family dynamics. I would also like thank Dr. Roy Wood, Dr. Mary Claire Morr-Serewicz, and Dr. Bruce Hutton, who also served as members of my dissertation committee.

This research could not have been completed without the constant and unwavering support of my husband, Stephen. To Zoe and Cooper, for forcing me to slow down and see the wonder and amazement in garbage trucks, chocolate popsicles, cartwheels, and temporary tattoos. I thank them for their love; giggles; simple, priceless lessons; and vibrant spirit.

I dedicate this dissertation to my oldest daughter, Laney, who constantly helps me to understand the meaning of motherhood and difference. As a nonverbal child, communicating with the world around her is a never-ending struggle. I am in awe of her courage and tenacity when the obstacles before her seem daunting. She works harder than anybody I know and makes me realize that nothing can ever be taken for granted. Through it all, she smiles and laughs, and teaches our family the true meaning of unconditional love and complete acceptance. She is amazing in every sense of the word. She is our champion. She is an unexpected gift.
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Chapter One: Introduction of Study

“I’d love to have a third child . . . I really would . . . but it’s Doug. He doesn’t want another one.” We are sitting in a local coffee shop sipping soy lattes on a chilly November morning, as my friend Kim describes her predicament. “We already have a boy and a girl, so Doug thinks there’s no reason to try for a third. He thinks we have a complete family as is. Plus . . . well . . . both kids are perfectly healthy so why even tempt fate with another? Why take a chance?”

Suddenly, realizing the significance of her words, Kim stops abruptly. She makes no eye contact. “Uh . . . I’m so sorry,” she says. “I didn’t quite mean it like that. It came out wrong.” She looks down, tracing the ring of foam on the edge of her black, ceramic mug. A thick veil of silence falls between us.

The truth is, I am every mother’s worst nightmare. Just like other mothers, I, too, had childhood dreams of a blissful family life. I imagined myself as a compassionate, doting mother who was an avid cheerleader at soccer games, school plays, tennis matches, and ballet recitals. But my idyllic, fairytale vision of family came to drastic halt on Valentine’s Day 2005, when my 14-month-old daughter’s rare diagnosis was delivered in three, simple words: “We found something.” On that fateful day in a sterile, unfamiliar geneticist’s office, I learned that my happy, uneventful pregnancy had gone horribly wrong, and Laney’s intricate genetic makeup had inexplicably failed us all. Our life would never be the same.
In an instant, I was no longer like other mothers. I was an outsider. When the moms I knew talked of first steps, first words, separation anxiety, and potty training, I could not relate. When they told stories about how Susie did the most perfect plié in ballet class, and how Joey made his first homerun in little league, I listened and said nothing. What story could I tell? How could I be part of this conversation? I could describe Laney’s rare genetic disorder—a tiny deletion of her 22nd chromosome—shared by only 450 other people in the world. I could offer my prepared spiel on the intricacies of the human genetic maze and how it failed Laney. I could recite my analogy of Laney as our dream house and her genetic makeup as an architect’s detailed sketches. How a cup of coffee on the architect’s desk accidentally spilled, smudging his plans, and creating a different dream house than the one we had originally planned. Or I could explain that because of my daughter’s disorder, she cannot communicate and might never ride a bike, talk on the phone, read a book, have friends over for a sleepover, or go out on a date. But who wants to hear that story?

Although I desperately wanted to return to my status of “normal” mother, I couldn’t. I no longer belonged there. I had been thrust into the unknown world of disability, and in an instant, I became every mother’s worst nightmare. I no longer had a place in the world of typical moms. Instead, I began to experience my daughter’s label of “developmentally delayed” as my own. Through Laney’s numerous missed milestones, I, too, missed the same developmental milestones and as a result, became her “delayed mother.” It was as if my identity as a mother changed overnight. The way in which family members, friends, colleagues, and neighbors related to me changed. My newly
gained expertise on the “ins” and “outs” of Medicaid, special education, adaptive equipment, disability law, and therapists challenged me every day. I quickly became familiar with assistive technology devices, absence seizures, individualized education plans, pediatric walkers, and esophageal strictures—all things I knew nothing about before Laney entered my world.

But I had no choice in the matter. I had a child with special needs to care for, and she desperately needed me. I could not collapse under the newfound burden of responsibility. I had to find the courage to accept our unimagined life, try to somehow think of it as a blessing, use it to grow and learn, and work to gain a new perspective on the important and meaningful things in life.

While I was in the throes of struggling to understand what it meant to raise a child with special needs, I discovered that I was pregnant again. I gave birth to a typically developing daughter and several years later, a typically developing son. Before long, I was living in two separate worlds—one for mothers raising children with special needs and one for mothers with typically developing children. There was my younger children’s world—constantly moving, exploring, learning, soaking in everything as fast as they could and moving again. Then there was Laney’s world—a world I constantly struggled to understand, a place so completely different from the typical world. It was much slower and harder to grasp, but still beautiful and amazing at the same time. I found myself a visitor in both of these worlds. There was no place I truly belonged.

Because disability disrupts the expected blueprint of parenthood, childrearing, and family life, living with an individual with a disability greatly influences the lives and
well-being of all family members. Laney’s inability to act and interact in expected ways caused me to turn to my younger daughter and son for the parent-child experiences and interactions that I so yearned for. This caused me constant guilt, stress, and heartache because we were not the family I had always imagined. I never anticipated the emotional, physical, spiritual, and financial toll that disability would take on all of us. At the same time, raising Laney is in no way a negative experience or a tragedy. On the contrary, she is a wonderful, happy, loving little girl. While her growth and development might be very different from that of other children, she is no less human, valuable, or in need of my love and affection.

Laney’s disability does not define her. She is a child with a disability, not a disabled child. Whereas I would never have chosen this complex and difficult life for her—and I would give anything to remove her disability if I could—I would in no way eliminate what I have learned from the experience and the way in which I have grown as a mother and a person. This experience, however difficult and bittersweet, has given my family a genuine gift: the true meaning of unconditional love.

This kind of love is not solely my story. It also belongs to the countless women who are significantly transformed through the mothering of children with disabilities. As individuals, our hearts are soft and unassuming. Together, we have a voice that can help make the world a more tolerant and accepting place. It was important to move beyond my own personal experience and explore the stories of other mothers as a means to understand and appreciate the joys, disappointments, blessings, sorrows, fears, and challenges of other mothers also raising a child with and without disabilities.
Statement of the Problem

Raising a child with a physical or intellectual disability is an extraordinary event from which no parent is immune, and most are generally ill prepared (Seligman & Darling, 2007). As parents mourn the loss of the healthy baby they had hoped for, they experience feelings of sorrow, grief, denial, and profound disappointment (Marshak & Prezant, 2007; McCollum, 1984). These feelings create anxiety, health problems, and depression (Featherstone, 1980; Seligman & Darling, 2007).

The presence of a child with disabilities alters family life and places additional demands and responsibilities on all members of the family (Simeonsson & McHale, 1981). Parents of children with disabilities are at risk for increased levels of stress, social isolation, and stigmatization, as well as decreased marital satisfaction and psychological well-being, when compared to parents of typically developing children (Dyson, 1991; Friedrich & Friedrich, 1981). These stressors require ongoing coping resources to help families communicate with one another and to regain a sense of normalcy in their lives.

In the United States, about 5 to 30 percent of children experience moderate to severe chronic illness or disability sometime during childhood, and the impact of this illness or disability on the entire family is considerable (Cox, Marshall, Medleco, & Olsen, 2003; Newacheck & Taylor, 1992; Stoneman & Brody, 1993; Williams, 1997). While it is clear that having a child with disabilities creates challenges for the entire family, it is less clear how the women raising these children experience motherhood as they care for a child with disabilities.
Despite an increase in paternal involvement and responsibility for some household labor, mothers are still held accountable for the care and emotional development of their children (Hays, 1996). In most cultures, mothers continue to devote significantly more time to the rearing of their children (Leslie, Anderson, & Branson, 1991; Yeung, Sandberg, Davis-Kearn, & Hofferth, 2001) and mothers are seen as ultimately responsible for the way their children turn out (McMahon, 1995). As the primary caregiver, it is the mother who must adapt her life to her child with disabilities and assume most of the responsibility for providing care. The mother is affected significantly with the duties of managing therapeutic services, special education requirements, medical intervention, and behavior management, in addition to the usual tasks expected of the maternal role (Pelchat, Bisson, Ricard, Perreault, & Brouchard, 1999). Moreover, she must struggle with her own personal thoughts and reactions, including feelings of guilt, anger, resentment, despair, and inadequacy (Featherstone, 1980).

Whereas the “normal” woman’s midlife experience represents a decline in mothering responsibilities, the experience of mothers raising children with disabilities is quite different. These moms must continuously maintain their mothering role through close monitoring and care of their child with disabilities (Ogle & Damhorst, 2005). As a result, how these mothers experience motherhood and make sense of their world is very important.
**Purpose and Research Questions**

This study is aimed to understand mothers’ experiences and personal responses to raising a child with disabilities together with a typically developing child, and the effect this has on self-concept, healing process, and daily life. Research shows that coping with a family member’s disability can be extremely difficult (Simeonsson & McHale, 1981); however, it is unclear how mothers successfully navigate these challenges. Lack of understanding of how these mothers learn to cope and reconstruct their identity is a critical problem because it prevents the development of resources to assist these women in their struggle to effectively manage life.

The goal of this study was to explore in-depth the lived experiences of mothers raising children with a variety of physical and/or intellectual disabilities, as well as typically developing children, and better understand the complex lives these mothers lead. By asking participants to share their personal stories as mothers of children with and without disabilities, this inquiry strived to uncover these women’s experiences with their children; how they define motherhood; how this definition differs for each child; how they experience the stigma of raising a nontypical child in a typical world; and how they describe and experience the stark differences in their children.

Through the construction of her narrative, a mother gains perspective, forms her story and identity, and finds coherence in her life (Mori, 1983; Seligman & Darling, 2007). She is able to share her life and connect with others through personal accounts. These stories help people come to terms with difficult events (Weber, Harvey, & Stanley, 1987) and organize their experiences into coherent stories that express individual and
relational identities (Linde, 1993). People use stories to give order to their experiences and to share these with others. This helps them understand their situations and use their common experiences to build community (Frey & Frey, 2001). According to Bochner (2002), stories are how we make our experiences meaningful, how we attach meanings to events involving uncertainty, and how we struggle to do the right thing.

Lieblich, Tuval-Mashiach, and Zilber (1998) assert that narrators bring to light their inner worlds as they describe their lives and experiences. This storytelling is natural for humans, providing an important means for communication. An individual’s inner world can be revealed by uncovering their lives and life experiences. Narratives organize life and convey cultural meanings and interpretations that guide the way people perceive life and the way they interact with life (Daiute & Lightfoot, 2004).

The purpose of this study was to explore the journey associated with mothering children with and without special needs. Through the use of narrative, this study sought to document the life-altering journey of 32 mothers raising children at various stages of development and with a variety of disabilities. The main questions guiding this research study included:

1. What are these mothers’ revelations about their mothering journey?
2. What are the private and public experiences of mothers raising children with and without disabilities?

**Background of the Study**

When a mother discovers that her child has a disability, she embarks on a long journey filled with heartache, strong emotions, and difficult choices. After learning of
their child’s diagnosis, these mothers experience a world of disorientation—full of denial, anger, fear, guilt, confusion, powerlessness, disappointment, and rejection. Eventually, some of these feelings develop into hope, joy, and acceptance (McGill Smith, 2003).

As a mother of a 6-year-old daughter with an extremely rare genetic disorder and two younger children without disabilities, I have first-hand experience raising children with and without disabilities. This knowledge links me to other mothers who have similar experiences. Because of this connection, I was viewed by the other mothers as “one of them” or an “insider” sharing many of the same fears, blessings, traumas, disappointment, and joys. This identification helped the mothers feel safe to tell their stories and created a sense of comfort, trust, and openness. This bond gave us entry into a club that promoted an assumption of understanding, as well as a shared pragmatic view of the world among parents of disabled children (Jenks, 2005).

It is important to note that I shared my personal story only in the introduction of this research study. Instead of treating my story as data and using it for the purpose of interpretation, I applied it simply as a catalyst for this study and let the stories of these mothers stand completely on their own.

Significance of the Study

While all mothers encounter many demands associated with regular mothering, mothers of children with disabilities are confronted with numerous hardships and encounter more stressors and responsibilities. Their lives change beyond anticipation (Park, 1982). Due to the difficult challenges associated with raising a child with disabilities, the experiences of these mothers are unlike those of mothers raising only
typically developing children. But what are the specific challenges and responsibilities for families raising a typically developing child and a child with special needs?

Despite the prevalence of literature on childhood disability, little attention has been given specifically to maternal functioning in families raising children with disabilities and those without disabilities. Because a mother’s development of identity can have a significant bearing on her mothering skills, as well as the mother-child dyad and future child development, achieving a greater understanding of her definition of self is crucial. While there is a consensus in the research that mothers are most often the primary caretaker of children with disabilities (Boyd, 2002; Leslie et al., 1991; Marcenko & Meyers, 1991; Yeung et al., 2001), the effect this has on these parents and their sense of self is not fully understood (Pelchat et al., 1999). The literature calls for further evaluation of mothers raising children both with and without disabilities. In an attempt to address this gap in the literature, the aim of this research study was to evaluate such maternal perspectives.

Conducting research on these mothers’ lives and their unique experiences is essential to better understand the relational nature of family disability and the complex needs of the mother—and the entire family. Studying mothers’ perspectives will help promote the well-being of the mother and her children. Possible benefits of this research include helping mothers effectively manage life when a child has a disability and discovering strategies to keep families strong. The knowledge gained from this research can benefit families in crisis and provide much needed support. Gaining this insight can
address gaps in the literature and inform the development of future programs and policies improving the lives of these women and their families.

In addition, by studying mothers’ adjustment strategies and successful coping techniques, we can help both parents and professionals understand the implications of childhood disability; improve family communication; allow for a better understanding of family strengths and difficulties; and sponsor the development of healthier children. Acknowledging mothers’ experiences with family disability also can assist clinicians in recognizing distress and developing treatment approaches sensitive to coping styles and emotional responses. Moreover, this information may shed light on how practitioners can address the detrimental effects of stigma and develop useful intervention strategies for families struggling to cope with the impact of a disabled child on the family system. Additionally, the important knowledge gained from this research also may help insurance companies comprehend the need to fund supportive services for mothers and families in crisis.

Current research on the experiences of mothers raising children with special needs has been lacking, leaving a gap in our knowledge about these families. The existing literature generates little insight into a mother’s identity and self-development despite the importance of her own development on her child. Research does not adequately provide information about a mother’s view of herself or her experiences dealing with feelings of guilt, anger, burden, resentment, despair, and inadequacy. How she perceives herself and her development are not fully examined. Her journey is not acknowledged or respected. Further research is needed to bridge the gap in understanding her experience and personal
response to the unique challenges she faces, and the effect these challenges have on her self-concept and identity as a mother.

**Overview of Theoretical Framework**

The theories of social constructionism and symbolic interactionism focus on the concepts of self and identity. Social context, language, and interaction are important concepts to both of these theories. Symbolic interactionists believe in the individual subject. They believe the self exists independently of society. According to Gergen (1999), there is a social world that “preexists the psychological; once the social world has made its mark on the psychological, the self exists independently of society” (p. 129).

At the same time, symbolic interactionism stresses the significance of understanding the subjective meanings and interpretations people ascribe to events and relationships (Mead, 1934). For Mead, there is no sense of self that is independent of social process or social interaction (Gergen, 1999). According to Mead (1934), “The self arises in the process of social experience and activity . . . develops in the individual as a result of his or her relations to that process as a whole and to other individuals within that process (p. 135).

While symbolic interaction primarily explores the development of the self in society, social constructionists extend the theory to include epistemological implications and relate these back to theorizing about the self. Schwandt (2000) asserts that human beings do not find knowledge as much as they construct it. Social constructionism is informed by a postmodern approach to identity and self, and is based on a dialectic view
of self and society, where individuals both influence and are influenced by society. These two theories will lay the groundwork for this study.

**Using Symbolic Interaction and Social Construction In One Study**

There exists a range of theoretical perspectives focused on self and identity. Included in this range are the theories of symbolic interaction and social constructionism. Because these theories overlap, I believe it can be useful and appropriate to include both in a single study.

Symbolic interaction is a theory about the development of self in society, with the function of the social highlighted in the process of identity construction. Individuals construct identity as they experience everyday life and interpret their world and the people around them (Baumeister, 1997). Symbolic interactionists believe that to understand human behavior, researchers must take into account the subjective experience of the individual. Part of this subjective experience is the self (Stryker & Vryan, 2006), which consists of multiple identities or multiple relationships to which an individual belongs (Serpe & Stryker, 1987). In the example of mothers raising children with disabilities, disability challenges a woman’s sense of herself as a mother. Using a symbolic interaction frame, a researcher might show how raising a child with a disability can cause the mothers to completely reevaluate the self. Due to today’s advanced reproductive technologies, prenatal diagnosis, selective abortion options, and widespread education on ensuring healthy pregnancies, pregnant woman tend to possess an illusion of control. This false impression leads women to believe in their potential to create a “perfect” baby. However, when this does not happen, and women do not give birth to the
“perfect” baby they had dreamed about, it challenges their beliefs in themselves as women and mothers. Social interaction is a useful frame for studying this recreation of self and identity, and understanding the lived experiences of mothers raising children with disabilities.

Social constructionists maintain that there is not one true understanding of the world. The same can be said for disability; there is not one true comprehension of disability and there are many discourses available as to the meaning of “disability.” The different ways of thinking about disability emphasize the many discourses around disability. This concept of discourse is an assumption of social construction because social constructionists assert that our identities are affected by our cultural understandings, as well as the discourses that are readily available to us (Burr, 1995). For example, in their role as mothers, women raising children with disabilities seem to experience increased public scrutiny when compared to mothers parenting children without disabilities. This scrutiny develops through the socially constructed belief that these mothers need to comply with specific indicators of good mothering, such as attendance at all medical appointments and compliance with special education needs, behavior management, and strict therapeutic regimens. When mothers do not adhere to these cultural prescriptions, they are subject to labels of poor mothering, selfishness, and resistance (Garcia-Coll, Surrey, & Weingarten, 1998; Read, 2000).

The philosophy of social constructionism emphasizes the importance of listening to and learning from those who are (or were formerly) marginalized, who have had their perspectives and voices submerged, or dominated by those with more social power or
privilege. The constructionist paradigm seeks to learn from diverse world views (Hartman, 1994). This entails collaborating with individuals who may be oppressed, listening to their life experiences, searching for meaning within them, and helping to end any type of oppression (Laird, 1993).

At the same time, symbolic interaction examines the self and the effect that social relationships have on the self. Becoming the mother of a child with disabilities results in a complex identity transformation. Upon learning that her child has a disability, a mother must come to terms with the alteration of the many expectations that most parents are able to take for granted (Wallander & Venters, 1995). A mother’s own future is irrevocably changed. She must negotiate a new kind of mothering, significantly different from her idealized or constructed experiences (Nelson, 2002).

There is no question that using the symbolic interaction frame together with social construction can help researchers study these mothers and their unique perspectives. These studies can assist researchers in comprehending mothers’ experiences in raising a child with disabilities, as well as the numerous implications that this can have on their self-concepts and identities.

Role of Qualitative Research

In today’s research environment, evidence and numbers are considered more valuable than a person’s individual experience or perspective. Qualitative research tends to be considered weak, soft, and devalued when compared to quantitative research. As a result, funding bodies are hesitant to use public monies to fund qualitative research.
However, qualitative research is actually quite innovative, useful, and effective—three points critical to the acceptance of qualitative research as a legitimate science (Morse, 2010). With so many different ways in which people can tell their stories, this method is becoming stronger and more widely accepted as a growing number of practitioners embark on this effective mode of inquiry (Ellis, Bochner, Denzin, Lincoln, Morse, Pelias, & Richardson, 2008).

Unlike quantitative research, qualitative inquiry is successful in providing a deep understanding and insight into individuals’ stories (Morse, 2006). Using the example of illness experiences, the qualitative method encompasses not only patients and how they adjust to life with an illness, but also the entire family constellation and social support networks, which are crucial to the study of coping (Morse, 2006). A second example of using individual insight can be taken from the medical perspective. While researchers use quantitative methods to develop medical analgesics, qualitative researchers focus on patient’s experiences of chronic pain and how they actually cope with such pain in their daily lives. This focus allows researchers to incorporate a much needed human element into their research (Morse, 2010).

When discussing the significance of qualitative research, it is also important to take into account the conversation of insider versus outsider research. According to Morse (2010), there are numerous advantages and disadvantages of being an insider conducting qualitative research. Some advantages include understanding and respecting the rules for interaction and having the background to conduct appropriate data
interpretations. Disadvantages of being an insider consist of taking routines and practices for granted.

Kuzel (2010) advocates for the importance of expertise within qualitative research. He asserts that experts (or insiders) have the ability to make sense of what they see and to communicate it effectively, an ability which only comes with experience and specialized knowledge. Because insiders are more likely to be connoisseurs of the phenomenon they research, Kuzel maintains that insider work will outweigh the work of outsiders because these researchers have the ability to communicate in ways that reveal coherence and insight.

Looking into the future, qualitative research will clearly continue to prove its worth and value. For instance, according to Kuzel (2010), the crucial work needed to repair today’s ailing health care system will undoubtedly involve qualitative inquiry. The momentous insights gleaned from this particular research method will pave the way for us to move forward and significantly enhance existing practices, as well as the entire patient experience.

**Outline of the Study**

This dissertation is composed of seven chapters. Chapter 1 introduces the background and purpose of this research and considers the significance of this topic of investigation. Chapter 2 presents a review of relevant literature in the areas of disability, disability as a stigmatizing condition, narrative inquiry, symbolic interaction, social construction, motherhood and childhood disability. Chapter 3 defines the methodology, including the research design, population, procedures, data collection, and data analysis
methods. Chapter 4 offers an introduction to each of the 32 participants. The themes/categories that emerge from the mothers’ narratives are portrayed in Chapter 5, and Chapter 6 considers what these themes signify and describes conclusions. The final chapter, Chapter 7, focuses on the theoretical and methodological significance, study limitations, directions for future research, and suggestions for professionals. Appendices consist of the complete narratives of each mother shared through poetic representation; the informed consent form; interview guide; and diary guidelines.

Summary

The goal of this study is to understand mothers’ experiences and personal responses to raising a child with disabilities together with a typically developing child. This chapter explores the study’s background, significance, research questions, and use of theory and qualitative inquiry. The following chapter reviews the literature on disability and motherhood, as well as focusing on the tenets of symbolic interaction, social construction, and narrative inquiry, which are important in the study of identity and meaning-making.
Chapter Two: Literature Review And Theoretical Approach

Review of Literature

This literature review involves an examination of the central concepts of disability, disability as a stigmatizing condition, and motherhood and childhood disability. In addition to researching and reviewing these concepts, I draw upon the theories of symbolic interaction and social construction, as well as narrative inquiry, to address the fundamental themes that constitute the creation of meaning and the formation of identity for mothers raising children with disabilities.

Disability

About 51 million Americans, one out of every five people ages 5 and older, have a disability (U.S. Bureau of Census, Current Population Reports, Americans with Disabilities, 2002). This number will continue to rise over the next 25 years as the baby boomers approach the age group most vulnerable to disabling injuries and illnesses (Freedman, Martin, & Schoeni, 2004). Several factors contribute to this growing rate of disability, including advances in medicine and emerging medical conditions. Survival rates for spinal cord and severe brain injury have improved dramatically due to improved trauma care. In addition, the survival rates for low birth weight babies have increased 70-fold over the past 25 years, directly influencing the prevalence of developmental disabilities and learning impairments. Emerging conditions, such as chronic fatigue syndrome, autism, mental illness, and attention deficit hyperactivity disorder, appear to
be growing in prevalence, possibly due to greater awareness, improved treatment options, and reduced stigma associated with reporting and seeking treatment (Fujiura, 2001).

According to a 2007 U.S. Department of Health and Human Services survey of children with special health care needs, 13.9 percent of children under 18 years of age, or approximately 10.2 million children, are estimated to have specific health care needs. Overall, 21.8 percent of U.S. households with children have at least one child with needs. This means that about one in five households with children has at least one child with a special health care need.

Among the 11.8 million American children under the age of 3, 235,000 (2 percent) had either a disability with a developmental delay, or difficulty moving their arms and legs, or both. Among children ages 3 to 5 years, 4 percent had a developmental delay and/or an activity limitation involving walking, running, or playing. Among 37.2 million children ages 6 to 14 years, 4 million (11 percent) had some type of disability and 1.4 million (4 percent) had a severe disability. Children in this age group were considered to have a severe disability if they had one or more of the following conditions: mental retardation or some other developmental disability; a developmental condition for which they received therapy or diagnostic services; used an ambulatory aid; were limited in the ability to see, hear, or speak; and needed personal assistance for an activity of daily living. (U.S. Bureau of Census, Current Population Reports, Americans with Disabilities, 2002).

Many children with disabilities or chronic illnesses require the services of numerous healthcare professionals, including physicians, physical therapy, speech and/or
language therapy, occupational therapy, respiratory therapy, counseling, mental health services, and special transportation (Perrin, 1998; Pless, 1998). Many of these children also are considered “technology dependent,” relying upon the use of a ventilator, dialysis, or similar aids.

Due to the complexity of the term disability, numerous definitions have emerged, but there is not one universally accepted classification. However, most population data programs, such as those managed by the U.S. Census Bureau and the National Center for Health Statistics, identify disability as an individual’s capacity to function within a given environmental and social context. An illness or injury may cause disability for one activity, but not another, and for one occupation, but not another. Additionally, disabilities are not static; individuals can acquire short-term disabilities from a stroke, heart attack, or fall, and fully recover (Freedman et al., 2004).

The Americans with Disabilities Act (ADA) of 1990 defines disability as a physical or mental impairment that significantly limits one or more major life activity, such as walking, talking, and independently living (Americans with Disabilities Act, U.S. Department of Justice, 2009). Similar to the ADA’s definition, the majority of definitions of disability refer to the disabled person’s inability to participate in a normal life or perform normal roles. It seems that no matter how progressive the definition, disability is consistently associated with difference and is seen as deviant, due to the individual’s inability to perform typical roles. In addition, people with disabilities are viewed as deviating from core American norms and values, such as independence, productivity, and aesthetics (Ablon, 2002; Susman, 1994).
One of these values, aesthetics, is further described by Hahn (1988) as the fear that people without disabilities experience when interacting with people with visible disabilities. This anxiety is brought on by seeing an individual whose appearance deviates from the customary view of beauty. Another level of fear for nondisabled individuals is existential anxiety, the threat of potential loss of function. This is a perceived threat that a disability might interfere with functional abilities considered crucial to the pursuit of a satisfactory life (Hahn, 1988).

The existence of people with special needs signifies vulnerability. Interaction with people with disabilities forces society to confront their fears of incapacity and the realization that they might experience impairment at some point in the future. Disability also may serve as an unconscious reminder of death, the ultimate symbol of incapacity, imperfection, and loss of control (Martz, 2001). These feelings of anxiety and discomfort drive people without disabilities to separate themselves from people with special needs, creating an “us/them” attitude. This mentality renders disabled individuals as different and inferior, allowing nondisabled individuals to justify their negative stereotypes and acts of discrimination and stigmatization (Link & Phelan, 2001).

**Disability as a Stigmatized Condition**

In Erving Goffman’s (1963) influential work on stigma, he uses the term “stigma” to refer to a discrediting attribute assigned by society to those who differ in some manner from society’s expectations and customs. Stigma results from the identification of those who are different and can therefore be regarded as “others.” Goffman considers stigma to be an interaction between individuals, existing in the relationship between the
evaluator and the evaluated. For stigmatization to occur, difference must be coupled with a negative value judgment that results in an unfavorable reaction to the difference (Goffman, 1963; Susman, 1994).

According to Goffman (1963), there are three major types of stigmatizing conditions: 1) Tribal stigmas are familial and include membership in disadvantaged or devalued racial, ethnic, or religious groups. 2) Blemishes of individual character are devalued social identities related to one’s behavior or personality, such as homosexuality, juvenile delinquency, and substance abuse. 3) Abominations of the body are physical characteristics that convey a devalued social identity, such as physical handicaps, obesity, and disfiguring conditions (Goffman, 1963). Individuals with these conditions are typically devalued in our society, receive disproportionately negative interpersonal and economic results, and face negative stereotyping (Crocker & Major, 1989).

The degree of visibility of the impairment influences the social situation of people with disabilities (Goffman, 1963). This degree of visibility is dependent on the disability itself. For example, mental retardation, paralysis, blindness, deafness, epilepsy, and congenital limb deficiencies, which can be detected in public situations, may pose common social problems of stigma, marginality, and discrimination. At the same time, people with disabilities have different degrees of impairment. Mental retardation can range from mild to severe; amounts of hearing and vision loss differ; and some individuals with mobility impairments can walk, while others cannot (Fine & Asch, 1988). The consequences of any impairment cannot be understood or appreciated
without considering the disabled individual’s physical, structural, social, economic, psychological, and political environment (Hahn, 1983).

Because health, beauty, and independence are highly valued in our society, imperfection, such as physical disability, does not fit this ideal. As a result, individuals with these disabilities are sometimes viewed as bearers of negatively valued traits and undesirable (Barnes, 1996; Krahé & Altwasser, 2006; Ryan & Runswick-Cole, 2008). Faced with these negative traits, others often feel awkward and apprehensive when interacting with those who bear them, and as a result, tend to act inappropriately (Zola, 1993).

Goffman (1963) uses the term “stigma” to refer to a discrediting attribute assigned by society to those who differ in some manner from society’s expectations and customs. He distinguishes among three categories of people relevant to the social interaction: the own, the wise, and the others. The “own” are other individuals who share the discrediting characteristic; the “wise” are individuals (typically family members) who do not share the characteristic, but by virtue of their close association to those who do, provide support; and the category of “others” is made up of individuals who do not bear the trait and who have little or no experience with those who do. Interactions between the own and others define the social experience of stigma (Green, 2001).

Stigma, a socially defined phenomenon, is related to the value placed on social identity. It is a social construction comprised of the recognition of difference based on distinguishing characteristics and subsequent devaluing of the individual. Attitudes
toward disability, homosexuality, AIDS, and obesity differ according to a culture’s
definition and description of valued characteristics (Dovidio, Major, & Crocker, 2000).

Stigma resides in others’ reactions to the stigmatizing condition, rather than in the
stigmatizing condition itself. It is through these reactions that families of disabled
individuals experience “courtesy stigma”—stigmatization based on affiliation with the
stigmatized individual rather than through any characteristic of their own. Relatives and
friends are regarded as normal, yet different. (Birenbaum, 1970; Goffman, 1963; Gray,
1993).

While stigma results from the identification of those individuals who are different,
courtesy stigma is based on an affiliation with the stigmatized individual. Through this
association with an “afflicted” person, one’s own identity may become tainted
(McKeever & Miller, 2004). This stigma takes place when others experience a range of
emotional responses to the disabled individual, including discomfort, awkwardness,
apprehensiveness, curiosity, embarrassment, and sensitivity (Darling, 2003; Goffman,
1963).

Many studies have focused on the experiences of individuals who possess a
discrediting attribute, but little attention has been given to Goffman’s courtesy stigma, the
close association with a stigmatized individual. Goffman (1963) believes that when an
individual is related to a stigmatized individual, society treats both individuals in the
same way. He offers several examples, such as the spouse of the individual with a mental
disorder, the daughter of the ex-con, the friend of the blind, and the parent of the child
with disabilities.
Courtesy stigma is described by Mehta and Farina (1988) as membership in a private club. Just as membership in a private club may be offered to a relative or friend, courtesy stigma is a membership pass into a special group. Through this association with an “afflicted” person, one’s own identity may become tainted. Research on families of individuals with disabilities has found that Goffman’s courtesy stigma does indeed exist (Gray, 1993; Read, 2000; Ryan, 2005; Scambler & Hopkins, 1986; Thomas, 1999; Voysey, 1972). These studies establish that members of such families experience stigmatization because of their affiliation with the stigmatized individual.

The way in which society reacts to disability plays a major role in the consequences of being labeled disabled. The modified labeling theory (Link, Cullen, Strening, Shrout, & Dohrenwend, 1989) proposes that individuals who expect to be subjected to stigma because of their disability or their relative’s disability tend to fear encounters with others. This fear leads to a desire for relationships with individuals who belong to the “own” or “wise” categories (Green, 2001). Mothers of children with special needs seek and value relationships with wise individuals who are sympathetic and can understand the unique challenges of raising a child with disabilities (Birenbaum, 1992).

These relationships are frequently created through support groups, which offer a social and therapeutic resource for the positive reconstruction of identity for the stigmatized and socially alienated (Ablon, 1981; Huws, Jones, & Ingledew, 2001). Mothers’ experiences of stigma are quite powerful and can be characterized by feelings of conflict, guilt, loneliness, self-doubt, being cheated, anger, and self-loathing. Social
support allows mothers to express their feelings, construct their experience, reduce anxiety, reinforce effective coping skills, process information, and reclaim control over their lives (Kerr & McIntosh, 2000; Winterhalter, 1992, 2001). Moreover, through the sharing of her experiences and the construction of her narrative, a mother gains perspective, forms her story and identity, and finds coherence in her life (Mori, 1983; Seligman & Darling, 2007). These narratives are tools for communicating about and coping with the stigma of disability.

**Narrative Inquiry**

Narrative inquiry is congruent with the study of identity. It is through the act of storytelling that individuals construct identity and constitute self (Arvay, 2002; Polkinghorne, 1988; Riessman, 1993). Narratives—often describing a person’s actions, experience, and emotions—provide important clues to the world view and motivations of the storyteller (Foss, 1996).

These stories organize life and convey cultural meanings and interpretations that guide the way people perceive life and the way they interact with life (Daiute & Lightfoot, 2004). Lieblich, Tuval-Mashiach, and Zilber (1998) assert that narrators bring to light their inner worlds as they describe their lives and experiences. This storytelling comes naturally for humans and provides an important means for communication.

As individuals share their lives and connect with others through personal narratives, these stories help people come to terms with difficult events (Weber, Harvey, & Stanley, 1987) and organize their experiences into coherent accounts that express...
individual and relational identities (Linde, 1993). This identity construction is one of the central functions of stories (Kellas, 2005).

Langellier (1989) maintains that personal narrative is part of the study of everyday life, particularly performance in everyday life. “Studying the communication and performance of ordinary people invites researchers to listen on the margins of discourse and to give voice to muted groups in our society” (p. 243). This is especially true for families raising children with disabilities, who cope and heal through the creating/recreating of identities by telling their stories. According to White and Epston (1990), narrative offers hope through telling one’s story and reclaiming one’s identity as a person, and not as a disability or an illness.

People use stories to give order to their experiences and to share these experiences with others. This helps them understand their situations and use their common experiences to build community (Frey & Frey, 2001). According to Bochner (2002), stories are how we make our experiences meaningful, how we attach meanings to events involving uncertainty, and how we struggle to do the right thing.

Narrative is a form of social action that embodies the connection between a lived experience and the social and cultural world the narrator shares with others (Chase, 1995). Frank (2002) maintains that the importance of narratives is not so much that they convey a story, but that they instill in us a belief that the world is a place we can make sense of. “Narratability” means that because events and lives are worth describing, they are also worth living. “Stories give lives legibility; when shaped as narratives, lives come from somewhere and are going somewhere” (Frank, 2002, p. 5).
Frank (1995) writes of the benefits to the self and to others through the sharing of narratives. In the case of children with special needs, this storytelling focuses on the parents’ experiences of raising a child with disabilities and specifically on the parents’ “wounds.” For individuals coping with traumatic life events, narrative construction can be quite beneficial (Orbuch, 1997). The therapeutic value of support groups can be found in disclosing and listening, as well as the validation of parents’ ongoing struggle to live life to its fullest (Romanoff, 2001).

The function of narratives in coping with stigma and constructing identity have been widely studied by researchers. Christian (2005) examined how stepmothers use narratives to address the myth of the wicked stepmother and the stigma associated with the stepmother’s role. Green (2002) examined the narratives of mothering a child with cerebral palsy. In a study of parents who lost a child in a violent death, Murphy, Clark, Johnson, and Lohan (2003) examined how parents found meaning in their child’s death through the sharing of narratives. This review examines the value of sharing narratives and how these stories help to create and recreate identity, giving meaning to the lives of mothers raising children with disabilities.

**Symbolic Interaction**

Symbolic interaction is a theory about the development of self in society. According to symbolic interactionists, identity is a complex social construction evolving from numerous interactions with others in many different social contexts (Baumeister, 1997). As individuals move through everyday situations involving family, work, and
school, they are continuously interpreting their world and the people around them. Individuals construct identity on the basis of these interpretations.

   The theory of symbolic interaction stresses the importance of understanding the subjective meanings and interpretations that people ascribe to events and relationships (Mead, 1934). This is an important theoretical paradigm that brings unique insight into understanding both the individual and society as a whole. Symbolic interactionism focuses on the connection between symbols (i.e., shared meanings) and interactions (i.e., verbal and nonverbal actions and communications). It is essentially a frame of reference for understanding how humans, in concert with one another, create symbolic worlds and how these worlds, in turn, shape human behavior. (LaRossa & Reitzes, 1993).

   From this perspective, society is interaction. Interaction is symbolic, which indicates that interaction exists in relation to the meanings that people develop. People do not respond directly to things, but instead attach meanings (derived from interaction) to them and respond based on that meaning (Blumer, 1969). Therefore, understanding meaning is an important step to understanding behavior. This approach to society and interaction provides a perspective for studying how individuals interpret and relate to other people, as well as objects in their lives, and how this leads to behavior. In this sense, the key to understanding behavior is to identify the meanings behind it.

   Symbolic interaction also provides the opportunity to explore one’s sense of self. “Self” refers to an individual’s conception or understanding of oneself, which arises out of social interaction. As individuals become aware of how others see them, this influences how they see themselves (their self). Mead (1934) theorized that the image we
have of ourselves comes from imagining how we look to others and how others seem to us. Interactionists refer to this as the concept of the “looking-glass self.” The “looking-glass self” refers to our perception of how we think that others see and judge us. Self-feelings emerge out of these perceptions, and we begin to see ourselves as we believe others view us. Cooley (1902) maintains that one’s sense of self develops primarily through interaction with people who are important to us, members of one’s primary groups – small groups in which face-to-face interaction occurs.

For Mead (1934), the self is a social product through and through, an outcome of social symbolic interaction—of emergent, ongoing creation, thinking, feeling, the building of attitude structures, the taking on of roles, all in a quest for coherence and oriented to the social world. A student of Cooley’s work, Mead emphasized how social interaction with others profoundly shapes the development of self (Ashmore & Jussim, 1997). Mead’s conception of the self was preeminently social (Elliot, 2001). For Mead, there was no thinking or any sense of self that is independent of social process (Gergen, 1999). According to Mead (1934):

The self is something which has a development; it is not initially there, at birth, but arises in the process of social experience and activity, that is, develops in the given individual as a result of his or her relations to that process as a whole and to other individuals within that process (p. 135).

Mead (1934) highlighted that once someone is able to view one’s self from the standpoint of others, one also can predict responses and alter their behavior. It is through the experiences of role-taking that a person develops a sense of generalized “other,” or the composite of others’ reactions to one’s self across situations (Gergen, 1999): “By
taking on the role of other, as he or she responds to my action, I come to understand who and what I am” (p. 124).

An individual’s behavior in a given situation arises from his or her concept of self, gained through interaction with others. Individuals behave according to their self-concept. This, in turn, contributes to their sense of self. They take the attitudes of others, arrange them, forming a self-consciousness in the process, and then act according to that view of the self (Mead, 1934).

Mead (1934) saw the self as an “I” and a “me,” with the unpredictable “I,” or what the individual perceives as his or her function or role in society, being very aware of the social “me.” Mead (1934) also contributed to our understanding of interaction, by recognizing the impact of generalized others and significant others on one’s sense of self. Significant others are specific influential individuals, such as family members, with whom people learn to role-take, allowing them to anticipate the significant others’ reactions. Generalized others refer to larger groups of people with whom individuals may role-take.

Faules and Alexander (1978) describe symbolic interaction, as both “essentially a sociological-psychological perspective of the entire spectrum of human behavior” (p. 4) and a “communication theory of human behavior” (p. vii). Symbolic interaction demonstrates the link between language, meaning, and human behavior. Symbolic interaction is a perspective concerned with individuals and their influence on each other. Interactionists study people interacting. They see little point in working with grand sweeping theories, particularly theories about society (Denzin, 1992). To them, society is
not a stable entity that can be investigated completely; it is constantly changing and evolving through the interactions of its basic unit—individuals.

According to Denzin (1992), the focus of study for interactionists is “the intersections of interactions, biographies, and social structures in particular historical moments” (p. 20). They understand society in the present through “face-to-face and mediated interaction that connects persons to one another” (Denzin, 1992, p. 22). Couch (1989) contended that personal interactions are “the heart and soul of social life” (p. xii), while Faules and Alexander (1978) state that organizations and societies “are made up of the interactions of their respective members” (p. vii).

Interactionists are interested not only with how society and its institutions are shaped through the interactions of individuals, but also with the ways people are hampered or confined by constructs that they themselves or people in past generations created in prior interactions (Denzin, 1992). They look at how society and the meaning of social experiences are shaped from within, through the interactions and subsequent interpretations of individuals, rather than by impersonal social forces from outside.

People are the best observers of their own lives, and the narratives of mothers provide a reflection of their interpretation of experience (Denzin, 1992). By utilizing a symbolic interactionist perspective, new insights into the meaning of childhood disability can be made. This is essential given the number of mothers struggling to raise a child with special needs and the potential impact that disability has on today’s families.
**Social Construction**

It is within the narrative matrix that the individual creatively constructs a reality of meaning (Gonçalves, 1997), making social construction theory a useful framework for understanding how mothers of children with disabilities experience and understand their world and negotiate their identities within this world. Through socialization, interaction, and language, these mothers collectively construct the realities in which they live (Stamp, 2004).

Berger and Luckmann (1966) draw upon the tradition of the sociology of knowledge, concerned with “the relationship between human thought and the social context within which it arises” (p. 4) and “knowledge that guides conduct in everyday life” (p. 19). How we understand the world we live in is fundamental to the framework of this theory. Loseke (2003) asserts that we categorize things and people as a way to organize and simplify our complex world. Classifying our world and attaching labels helps us distinguish types of things or people, which in turn informs us about how to act toward these things and people.

Social construction supports the idea that language is essential to social processes and their implications for identity development (Allen, 2005; Leeds-Hurwitz, 1995). Identities are constituted, maintained, and negotiated through communication and interaction with others (Baxter, 2004; Tracy, 2002). Similar to personal identities, familial identities also emerge through communicative practices (Baxter, 2004; Baxter & Braithwaite, 2006) and are created and recreated through interaction and language (Suter, Reyes, & Ballard, 2010). From a social constructionist viewpoint, family identity can be
defined as who and what a family is or is not. This is based on how a family sees and defines itself and how outsiders see and define the family (Suter et al., 2010). Families are discourse dependent in that families are constantly constructing and legitimating the meaning of family (Galvin, 2006). Furthermore, families that depart from the normative standards of what constitutes a “real” family bear an additional discursive burden of presenting themselves as legitimate (Braithwaite, Bach, Baxter, DeVerniero, Hammonds, Hosek, Willer & Wolf, 2010).

Allen (2005) contends that language allows us to make sense of the world and share experiences and meaning with each other. Language and meaning are social productions (Hall, 2000) and how disability is represented in society is important to the public understanding of disability. Mothers of children with disabilities are conscious of and sensitive to the socially constructed beliefs about disability. Public narratives of disability as imperfect and negative become familiar through the socially constructed discourses that frame them. For individuals coping with disability and stigma, interpretations of disability are socially constructed from the ideology of the society in which we live (Greil, 1991). One’s understanding of disability is based on an individual’s experiences and history from within his or her personal and cultural environment.

While the equal treatment and full inclusion of people with disabilities is guaranteed through our country’s legal system, the general population still maintains negative and stereotypical attitudes. Feelings of discomfort, apprehension, and fear during interactions with disabled persons are quite prevalent (Krahé & Altwasser, 2006).
These negative attitudes towards people with disabilities begin early in childhood, with young children categorizing people into disabled and nondisabled, and favoring the nondisabled (Richardson, Hastorf, Goodman, & Dornbusch, 1961). Possible explanations for these attitudes are the existing cultural and social norms that maintain the need for beauty, youth, and fitness, as well as media portrayals of disabled people as sick, suffering, and having “special needs.” Unable to conform to these norms, people with disabilities are therefore marginalized by society (Krahé & Altwasser, 2006; Ruffner, 1990).

Social construction theory is critical for understanding how individuals interpret and narrate their experiences of disability. Using the example of support groups, Lave and Wenger (1991) assert that the role of support groups for mothers raising children with disabilities is to provide a safe community in which members can learn how to convey a story about their lives and construct narratives about themselves as mothers of children with disabilities whose identities are valued within society. Within the safe community of their support group, mothers of children with disabilities develop narratives to explain to themselves and to others what the lived experience of disability means. Applying a social constructionist approach to the study of mothers of children with disabilities sheds light on how these mothers are able to enact and understand their identities.

**Motherhood and Childhood Disability**

Our understanding of motherhood cuts across cultural, social, and historical boundaries (Stearney, 1994). Incorporated within the role of the mother is the idealized
mother-child relationship, as well as the perception that motherhood is a calling; children are fragile and need continuous mother nurturing; and it is mothers who are primarily responsible for fostering healthy child development (Blair-Loy, 2003). This notion of motherhood is understood through the labels that characterize a mother’s relationship with her children, such as being selfless, devoted, loving, nurturing, and protective (Stearney, 1994).

Mothers engage in “maternal practice,” which is the nurturing, protecting, and training of their children (Arendell, 2000). Mothering is a role essential for the perpetuation of a culture. It is crucial in relation to the growth and development of young children, children with disabilities, and children with chronic health problems. Mothering provides a safe environment for those requiring nurturing care (Barnard & Martell, 1995; Medina & Magnuson, 2009).

Not only do mothers offer their children a protected environment, but they also build a “culture” by their relationships with their children. Lightfoot and Valsiner (1992) found that a mother’s role as caregiver is guided by her belief system, which is created from socially communicated meanings acquired from her culture and communicated by other adults and society. Mothers translate cultural messages about childhood, as well as their experiences with children, to their children and to others. This interaction shapes their role as parents (Lightfoot & Valsiner, 1992; Medina & Magnuson, 2009). For mothers raising children with disabilities, this culturally communicated responsibility may create a sense of imbalance and distress in their lives.
Motherhood is viewed by some women as the most important role in their lives (Rogers & White, 1998). In fact, most women are mothers at some time in their lives (U.S. Census Bureau, 2003). This role, defined by the social practices of nurturing and caring for dependent children, is the main vehicle through which women form their identities and learn their place in society (Arendell, 2000). The view of mothers as “little more than architects of the perfect child” (Eyer, 1996, p. 6) has significant implications for mothers’ identities and self-concepts (Collett, 2005). For many women, identity is tied to how well they perform the role of mother. Women’s identities as mothers are a fundamental element of their perception of female roles and responsibilities.

Women become mothers and take on the identity of mother by playing a publicly visible and socially defined role (Collett, 2005). Research demonstrates that many mothers exhaust themselves trying to live up to the culturally determined images of the “good mother,” defined as always energetic, patient, loving, and self-sacrificing (Congo, 1988). These women believe their identity is based on having a clean home and well-groomed children (Houston & Holmes, 2004). To be a decent mother, today’s woman must “devote her entire physical, emotional, and intellectual being, 24/7, to her children and enjoy every minute of it” (Douglas & Michaels, 2004, p. 4). In addition, many women believe that a good mother creates a haven for her family, and understands that she has the power to protect or destroy her child’s well-being (Thurer, 1994).

As women lose their personal identities and motherhood dominates their lives, they obtain a profound sense of meaning, intimacy, and purpose from their children and their role as mothers (Boulton, 1983; Medina & Magnuson, 2009; Nash, 2002). As
prescribed by the idea of essential motherhood, these women are encouraged to bestow all of their physical, mental, and spiritual energies to their families (Douglas & Michaels, 2004). This ideal of essential mothering portrays expectations that are very difficult to meet, which can result in feelings of isolation and loneliness for women (Crittenden, 2001; Douglas & Michaels, 2004).

While mothers see their prime responsibility as supporting the growth and development of their children, mothers of children with disabilities have many more roles and demands than mothers of typically developing children. The responsibilities carried by mothers of children with disabilities are considered the “invisible private workload of caregiving” (Marks, 1996, p. 27). Raising a child with disabilities is quite challenging and requires an increased amount of patience, energy, and time (Crowe, VanLeit, Berghmans, & Mann, 1997). These mothers often experience increased personal distress (Marks, 1998; Plant & Sanders, 2007) and elevated stress levels due to their child’s decreased cognitive functioning, physical limitations, challenging behaviors, and limited social skills (Lessenberry & Rehfeldt, 2004).

Moreover, research supports the fact that child care and household tasks are the primary responsibility of women, with little paternal support (Coltrane, 2004). According to Medina and Magnuson (2009), mothers are typically the caregivers for their children and partners. Additionally, they tend to have overwhelming responsibility for the caring role, consistently carry the greatest total workload, and perform the majority of the caregiving duties for children with disabilities and chronic illness (Boyd, 2002; Cole, 2004; Marcenko & Meyers, 1991; Read, 2000; Ryan & Ruswick-Cole, 2008).
Caregiving for a child with disabilities can be seen as “the endless burden” (Marshak, Seligman, & Prezant, 1999). On top of these copious daily duties, mothers are ultimately responsible for planning medical appointments and therapy visits, as well as managing heavy adaptive equipment, complex daily self-care activities, and general medical management tasks (Coltrane, 2004). Mothers raising these children consistently associate their feelings of well-being with their child’s progress and their ability to meet the day-to-day challenges of taking care of their child with disabilities (Larson, 2000).

Providing this level of hands-on care occupies much of a mother’s time, which limits her ability to participate in the workforce (Hartman, 2004; Kuhlthau & Perrin, 2001). Porterfield (2002) asserts that the disability status of children influences their mothers’ likelihood of participating in the paid labor force. After the birth of their children, married mothers of children with disabilities are less likely to participate in the labor market in a full-time or part-time capacity (DeRigne & Porterfield, 2010; Kuhlthau & Perrin, 2001; Larson, 2000; USDHHS, 2007).

In addition to assuming the highest degree of responsibility for their children’s health and well-being, mothers raising children with disabilities share the stigma and marginalization of their disabled child (Carpenter & Austin, 2007; McKeever & Miller, 2004; Resch, Mireles, Benz, Grenwelge, Peterson, & Zhang, 2010). Because a mother—obligated and committed to consistently provide superb care for her child—is the primary caregiver, she ultimately bears responsibility for how her child turns out. As a result of this absolute power, she is blamed for her child’s limitations, internalizes this accountability, and experiences guilt and self-blame (Dinnerstein, 1991).
Whereas all mothers are potentially affected by the socially constructed role of the “good” mother, mothers of children with disabilities may be subjected to even greater mother blaming. In their role as mothers, women raising children with disabilities seem to experience increased public scrutiny when compared to mothers parenting children without disabilities. This scrutiny develops through the socially constructed belief that these mothers need to comply with specific indicators of good mothering, including attendance at all medical appointments, and compliance with special education needs, behavior management, and strict therapeutic regimens. When mothers do not adhere to these cultural prescriptions, they are subject to labels of poor mothering, selfishness, and resistance (Garcia-Coll, Surrey, & Weingarten, 1998; Read, 2000).

Shu, Lo, Lin, Hsieh, and Wu (2006) conducted in-depth interviews with mothers of adolescent boys with autism and found that these mothers experience a different mothering role from mothers of typically developing adolescent boys. This is due to the fact that boys with autism require a higher level of care and monitoring than typically developing boys. The researchers found that these mothers form new self-identities and seek new meanings for their realities. They must reconstruct their maternal roles as they experience mothering a child with disabilities. In Landsman’s (1998) study, stories told by mothers of children with disabilities suggest that for them, parental adjustment is not about becoming resigned to the tragedy of having a disabled child, but rather about being challenged by, and redefining through experience, the existing cultural understandings of what constitutes “normal” and “perfect.” Landsman examined how these women
struggle to define their identities as mother within the cultural definitions of motherhood that view women raising children with special needs as different and devalued.

Mothers of children with special needs struggle to manage their child’s social identity in a range of settings within the public domain, including family relationships and community settings. Mothers engage these spaces “in an ongoing process of negotiating an identity as parent of an impaired child . . . their child’s impairment is, at least in part, constituted through the activities of managing bodies across private and social spaces” (Kelly, 2005, p. 190-191).

Several studies conducted by Green (2001, 2003) describe how mothers of children with disabilities face a confused world in which interactions with others can be a source of discomfort and social alienation. Prior to their child’s birth, most mothers have had little direct personal contact with individuals with disabilities (Green 2003; Read, 2000). A majority of this exposure has been limited to stereotypes, to stigmatizing images in the media, or to strangers who looked or acted different (Darling, 1988). These mothers must manage a range of peculiar public attitudes, reactions, and behaviors, which fluctuate from kind to cruel and back again (Green, 2003). The reaction of strangers in public places can lead some mothers into a self-imposed social isolation, where they give up the struggle to interact socially with those who do not understand the experience of disability (Green, 2001).

At the same time, other mothers insist that it is important to ignore the sometimes bizarre and inappropriate reactions from strangers and work to maintain a normal life. Mothers raising children with disabilities undergo a process of normalization in which
they try to live up to society’s image of a “normal” family (Davis & Salkin, 2005). They seek to maintain as normal a life as possible, while avoiding individuals who do not cooperate with the family’s definition of the situation as “normal” (Birenbaum, 1970).

Becoming the mother of a child with disabilities results in a complex identity transformation for these women. Upon learning that her child has a disability, a mother must come to terms with the altering of many expectations that most parents are able to take for granted (Wallander & Venters, 1995). A mother’s own future is irrevocably changed. This life-changing experience requires a mother to develop capabilities previously unknown to her (Wickham-Searl, 1992) as she considerably alters her life and carries an “invisible workload” (Marks, 1998). Belenky, Clinchy, Goldberger, and Tarule (1997) maintain that when a significant event occurs in a woman’s life, she “becomes more aware of the existence of inner resources for knowing and valuing. As she begins to listen to the ‘still small voice’ within her, she finds an inner source of strength” (p. 54). She must negotiate a new kind of mothering, significantly different from her idealized or constructed experiences (Nelson, 2002). Mothers who are able to successfully ignore socially constructed ideals and create alternative definitions of motherhood are more likely to experience a happier and more fulfilling family experience.

Summary

This chapter clarified definitions and key concepts related to childhood disability. In addition, this chapter overviewed the lenses of symbolic interaction, social construction, and narrative, which informed the analyses of the mothers’ unique
experiences in this dissertation. The following chapter provides a detailed roadmap of the methods and research design employed in this qualitative study.
Chapter Three: Research Methods And Procedures

Introduction

This study examines the lived experiences and perceptions of mothers raising children with and without disabilities. To provide an understanding of these mothers’ unique journeys, a qualitative study was designed. In this chapter, I explore the research methods and procedures used in this study. This includes the detailed research design; the participants and recruitment process; the procedures, comprised of two phases; and the use of a research journal and pilot study. In addition, I describe my data collection and analysis methods, consisting of diaries and Arvay’s collaborative narrative method. This method is broken down into six stages, which I explain in detail. The chapter concludes with a discussion of my role as a researcher and a summary of the chapter.

The methodology for this study is based on the use of lived experiences. Tennant and Pogson (1995) maintain that the use of lived, rather than created, experience is the primary source for social justice and/or personal transformation. They offer a three-step approach to learning from experience. The first task is getting people to talk about their experiences. The second is to examine those experiences individually or collectively. The third is to identify and take action on the implications of what is discovered. Chapter 4 and Appendix A focuses on the first step of the Tennant and Pogson approach, with a series of personal narratives describing the journeys of mothers raising children with and without disabilities. Chapters 5 and 6 analyze these experiences individually and
collectively, while Chapter 7 addresses the third task of offering conclusions and recommendations.

**Overview of Procedures**

The data for this study came from the responses of 32 mothers raising children with and without disabilities, as they discussed their personal experiences. Participation in this study involved keeping a diary for 4 to 6 weeks, as well as taking part in several in-depth interviews structured by Arvay’s (1999, 2002, 2003) collaborative narrative method. The diary entries and interviews entailed describing the challenges and experiences of raising a child with disabilities and one without, specifically views on motherhood and identity. All interviews were tape-recorded and transcribed. After this step, I read and analyzed the interview transcripts and diary entries and extracted the data into a meaningful and manageable form. Using this data, I crafted poetic representations from each mother’s narrative as a way of organizing and presenting the data (Glesne, 1997; Richardson, 1994). This is the “creation of poem-like compositions from the words of interviewees” (Glesne, 1997, p. 202). Each mother then reviewed her narrative/poetic representation and clarified the data in her story to ensure accuracy and completeness. Next, I carried out four interpretive readings, which included reading for content; reading for the self of the narrator and the researcher; reading for the research question; and reading for relations of power and culture.

Through narrative analysis, the research process attempted to obtain the perspectives of a select group of mothers. These perspectives emerged from each mother’s narrative, which were told in her own voice and written using poetic
representations. To analyze the mother’s poetic representations as a whole, I read and re-read the narratives and noted the significant sections that related most directly to my research questions. I meticulously reviewed these sections for commonalities in the mothers’ experiences and for collective perspectives on these experiences. This is a form of analytic induction described by Bogdan and Biklen (2002). From this process emerged several common themes. I then developed the themes into headings or sections, which group the data, while also allowing each mother’s individual voice to be heard.

**Research Design**

The design of this study begins with my reflections on motherhood. Here, I describe my own personal journey (See Introduction). As a mother of a 6-year-old child with disabilities, as well as two typically developing children, I chose to examine disability through my own eyes by including my personal experiences. Laney’s birth and subsequent diagnosis thrust me into an unknown world. This world—one that I was completely unprepared to handle—is the lived experience of disability. Because this world is impossible for me to ignore, I experience it as a participant and use these experiences to tell my story.

Considered autoethnography, or autobiographical ethnography, this method “interjects personal experience into ethnographic writing” (Reed-Danahay, 1997, p. 2). In qualitative research, it has become widely accepted that the author is placed in the text and “all texts are personal statements” (Lincoln & Denzin, 1994, p. 578). Reed-Danahay (1997) contends that autoethnography is more authentic than traditional research approaches due to the researcher’s use of self, with the voice of the insider being more
valid than that of the outsider. Autoethnography, according to Ellis and Bochner (2000), is an “autobiographical genre of writing and research” (p. 739) that connects the researcher’s personal self to the broader social and cultural context. Using this research method allows me, the researcher, to explore my own experiences and expand knowledge on the social issue of disability. In this study, I answer Ellis’ (1991) call for the use of “emotional narratives” written from a biographical and subjective point of view.

However, I did not want this to be solely my story. I wanted to move beyond my own personal experience because it was important to understand and appreciate the joys, disappointments, blessings, sorrows, fears, and challenges of other mothers also raising a child with and without disabilities.

As a result, I used my impressions and experiences of motherhood as a starting point for this study. I used my own narrative to set the stage for this study and focused my research on the narratives of 32 other mothers raising children with and without disabilities. Ellis and Bochner (2000) consider the blending of personal stories with others’ narratives to be a form of autoethnography. They maintain that autoethnography as a research method can range from examining one’s own personal experience to studies in which the researcher’s experience is explored together with the participants. This method also is embraced by Karp (1999), who blends personal experience with the narratives of others to “study the complexity of everyday lived experiences and the processes through which human beings accomplish the creation of an intersubjectively meaningful world” (p. 604). While it is clear that I did not entirely follow Karp’s method, and Ellis and Bochner’s notion of blending, I did employ these concepts in the
sense that my own personal journey enhanced my understanding of the participants’
experiences and set the stage for this exploration.

The research I conducted here can be considered “insider” research, because I
carried out this study with a group of which I am a member and share social and
historical connections (Kanuha, 2000). Landsman also would refer to my research as
insider research, since the community studied is a community of experience in which the
researcher and others come together from different backgrounds of class, race, education,
ethnicity, and religion to share “a trauma of dashed expectations” (Landsman, 1998, p. 76).
My own in-depth account of my transformative experiences as a mother raising a
daughter with special needs paved the way for these mothers to feel a sense of comfort
and camaraderie as they shared their own descriptive and personal accounts. Although
this insider positionality facilitated the elicitation of the mothers’ narratives, it was not
used as data or as a means to interpret their narratives in light of my own. Rather, I only
used my story as a springboard for the study. My story stopped after the introduction and
the other mothers’ stories began after that point.

To better understand relationships and experiences within families, disability
studies and family communication researchers maintain the need for additional analyses
of participant experiences (Braithwaite, Olson, Golish, Sonkup, & Turman, 2001;
Canary, 2008; Parmenter, 2001). Ferguson (2001) maintains that family researchers need
to “pay attention to the first-person narrative accounts that families offer because there is
a greater need than ever to understand how the accounts that families provide match the
conceptual developments in research” (pp. 389-390). He contends that personal
narratives from parents and other family members have the potential to capture the full range of detail regarding daily life and family history, and can present a fresh examination of an individual’s life.

I chose to use qualitative research methods to achieve this understanding because qualitative data allows for an open-ended exploration of experiences and perspectives (Patton, 1990). To address my research questions and capture the narratives of participants, a two-pronged qualitative methodology was applied, using both diaries compiled by participants and in-depth interviews structured by Arvay’s (1999, 2002, 2003) collaborative narrative method.

Diaries were used for several reasons. Specifically, they provide data that can be as accurate as those gathered through direct observation (Elliott, 1997; Zimmerman & Wieder, 1977). The strength of the method in this context lies in the role of diaries as both a recorder of, and reflection on, personal experiences. Its value is a means of understanding that which is usually taken for granted, or that which commonly lies at the back of people’s minds (Elliott, 1997).

The inclusion of diary methods in this study enabled exploration of the participants’ perceptions of raising children with and without disabilities. In addition, collecting diary data further explained, provided support, and enhanced interview data with longitudinal information about the experiences of mothers raising children with and without disabilities. Participants were given bound journals to keep, but were urged to type entries if they preferred. They received detailed instructions regarding the content of their diary entries (See Appendix C) and were instructed to write about their day-to-day
experiences mothering children with and without disabilities—including all of the high and low points—making a minimum of three entries per week for 4 to 6 weeks. Included in these entries could be participants’ letters; emails; chat room dialogues; and general impressions, feelings, or thoughts about routine/day-to-day interactions with their children, spouses, friends, family members, neighbors, colleagues, teachers, therapists, doctors, or strangers.

In addition to using diaries, I chose to use the collaborative narrative method developed by Arvay (1999, 2002, 2003) because this method encourages full participation. I believe this type of collaboration is a vital component of my research on families and disability. The collaborative narrative method involves six stages: (1) setting the stage; (2) the performance: Co-constructing the research interview; (3) the transcription process; (4) four interpretive readings; (5) the interpretive interview; (6) writing the story.

**Participants**

The participants for this study were 32 mothers raising children with and without disabilities residing in Denver, Colorado. This area was chosen because I am a resident of Denver. I did not plan to include a specific, predetermined number of participants in this study. Rather, I used theoretical saturation (Strauss & Corbin, 1998) as my guide. Theoretical saturation is the point when no new information, properties, conditions, actions/interactions, or consequences are seen in the data. The data analysis can reach closure when all categories are theoretically saturated, the category is well developed in
terms of its properties and dimensions, and further observations yield minimal or no new information to further challenge or elaborate the concept (Strauss & Corbin, 1998).

To be selected, all of the mothers needed to raise at least two children between the ages of 1 and 21 years. One child needed to be typically developing, and one child needed to have some kind of developmental and/or physical disability. Adopted or foster care children were not included. All of the women were birth mothers because I wanted to target only women who gave birth to their children with disabilities as opposed to women who may have willingly adopted or fostered children known to have a disability. I felt that knowingly adopting or fostering a child with disabilities could alter the results of this study.

In terms of ethnicity and background, the sample was comprised of women who identified themselves as Caucasian (29) and Hispanic (3). The mothers in this study hailed from upper middle class and lower middle class backgrounds. Of the 32 mothers, six did not respond to questions regarding income. Fifteen mothers reported household incomes between $35,000 and $75,000 (lower middle class), and 11 mothers reported household incomes more than $75,000 (upper middle class).

At the time of the interviews, mothers’ ages ranged from 32 to 52 with a mean age of 42. The ages of their children with disabilities ranged from 3 to 17 years with a mean age 8. Their children had a variety of medical diagnoses that varied in the level of severity and care. These diagnoses included an array of chromosomal abnormalities, autism, and cerebral palsy. All of the mothers had between one and three typically developing children ranging in age from 1 to 20 years with a mean age of 9. In the
sample, 29 mothers were married, two were recently divorced (within the last 5 years), and one mother was unmarried but living with the father of her children.

Of the mothers, 17 were homemakers, six worked part time, and nine worked full time outside the home. Mothers working outside the home worked in the fields of marketing, finance, telecommunications, health care, education, human resources, public policy, environmental, nutrition, and community activism. The range of formal education attainment included high school graduate (4 mothers), bachelor’s degree (16 mothers), master’s degree (8 mothers), law degree (2 mothers), and doctoral degree (2 mothers).

The study consists of two mothers who knew about their child’s disability through prenatal testing during their pregnancy, and 30 mothers who were unaware of their child’s disability during pregnancy. Of the participants, six reported having significant contact with individuals with disabilities prior to the diagnosis of her child. This contact came from a family member, friend, neighbor, or a job. Each of the mothers in the study indicated a strong willingness and desire to participate in the study and share their stories. Several of the mothers were initially hesitant to keep a diary due to the required time commitment. However, most of these mothers reported being pleasantly surprised by the diary’s therapeutic nature (See Chapter 7). Table 1 (See Chapter 4) highlights each mother, her age, all of her children and their ages, and her disabled child’s specific diagnosis.
Recruitment of Participants

Each potential participant was approached privately due to the sensitive and personal nature of the subject matter and the need to probe into emotional facets of their lives. As an active member of the disability community, I contacted some mothers whom I knew through playgroups, schools, friends, and support groups. Some of these women suggested others whom they knew and who they thought might be interested in participating.

Additional participants were sought through social service agencies (Denver Options and Longterm Care Options) and pediatric therapists. For example, my daughter’s service coordinator at Denver Options (a nonprofit organization in Denver that provides supports and services for people with disabilities) agreed to reach out to her own clients who might be interested in participating in the study. I sent her a brief description of the study, population, and procedures (See Appendix E), so that she could disseminate the information to her clients. In addition, several of my daughter’s therapists, including her physical therapist, speech therapist, occupational therapist, and music therapist work with numerous children on Medicaid and from a lower socioeconomic status. In hopes of obtaining a variety of participants, I asked these therapists to put me into contact with clients who might be interested in the study. I sent these therapists the study description.

Demographically, I can be described as a married, 39-year-old mother of two girls, ages 6 and 4, and a boy, age 2. My 6-year-old daughter is diagnosed with 22q13 deletion syndrome or Phelan McDermid Syndrome. The mothers participating in the study represent children with a variety of diagnosed illnesses and disabling conditions.
The one common thread shared by all of these mothers is their transformative journey through motherhood and childhood disability. Because of this commonality, I, too, am considered an insider who has first-hand knowledge of childhood disability. This camaraderie allowed for access that may be otherwise unavailable and helped to enhance participants’ comfort, trust, and openness, and made them feel safe to tell their stories.

While we all have children with different types of special needs, our experiences are quite similar. We are raising nontypical kids in a typical world, giving us more in common with each other than with parents of only typical kids. This bond gives us entry into a club that promotes an assumption of understanding, as well as a shared pragmatic view of the world among parents of disabled children (Jenks, 2005). Being part of this same “club” changes issues of disclosure (Jenks, 2005). Charmaz (1991) describes the risks of disclosing illness or disability to others who are “healthy” as revealing emotions and vulnerabilities. However, by talking with another parent also raising a special needs child, the risk of disclosure was reduced because the researcher shares the same vulnerabilities, emotions, and experiences.

Because I was using the diary method, as well as the collaborative narrative method, I had to explain the necessary time commitment and ensure that each mother comprehended her role in the study. As the main researcher, my time spent on this project was extensive because I collaborated closely with all participants. It was also imperative for them to understand the time and energy required of them to accomplish this ongoing participation. Not only did I ask them to keep a detailed journal for several weeks, but I also conducted the following: 1) an initial interview to introduce the research
project (introductory interview/setting the stage); 2) a one- to two-hour interview to collect each mother’s story (co-constructed research interview); and 3) another discussion to review the narrative summary and obtain feedback (interpretive interview). All participants needed to agree to this and to sign a consent form.

During the introductory interview, a signed Informed Consent (See Appendix D) outlining the research project, diary method, and interviewing process was collected from each participant in accordance with the University of Denver Institutional Review Board and the University’s human subject requirements. Participants were assigned pseudonyms at the beginning of the project and these names were used throughout the study.

**Procedures**

There were two phases of the study: a diary phase and an interview phase. For the diary phase, participants were given bound notebooks and asked to describe their mothering experiences for a total of 4 to 6 weeks, making a minimum of three entries per week. I requested three entries per week to ensure I would have enough data. The blank notebooks were Mead marble composition books made up of 100 wide-ruled sheets. It was also acceptable for mothers to type their diary entries and print them out or send them to me via electronic mail. Specific instructions were given to each mother detailing what to include in the diary entries (See Appendix C).

According to Zimmerman and Wieder (1977, 1983), the foundation of the diary approach involves the use of the participant as both “observer and informant.” By asking them to keep a chronologically organized diary or log of daily activities, Zimmerman and
Wieder requested a record of their participants’ performances, in addition to reporting that of others with whom they interacted. Completed logs served as fieldnotes and diarists functioned as ethnographers of their own particular situations.

The second phase of the data collection entailed several interviews as part of the collaborative narrative method. I met with the mothers at a time and location that was convenient to them. This location varied, ranging from their homes and offices to local coffee shops and parks. The site depended upon what the mothers deemed most convenient, while allowing for relaxed and unhurried conversation. Children were not present during any of the interviews.

The interviews were open-ended and in-depth, targeting the perceptions and experiences of the participants. Before beginning, I asked the mothers to provide demographic information on their ages, the age of their child with special needs, the age(s) of their typically developing child(ren), their occupation, household income, ethnicity, family structure, and education level. To gain an understanding of the mothers’ lived experiences, I asked a series of open-ended questions intended to focus on particular aspects of the mothers’ experiences, such as details of her child’s diagnosis, specific reactions to the diagnosis, ideas on motherhood, and public and private experiences raising children with and without disabilities. Mothers were asked to reflect upon their perception of their present lives as mothers and spouses, their family situation, and their expectations for the future of each of their children. I collected each mother’s story in her own words, which became her detailed, personal narrative. This approach, described by Gallimore, Weisner, Bernheimer, Guthrie, and Nihira (1993), supports data
in which individuals organize and recall personal experiences in narrative form. The interviews each lasted between one to two hours and were taped (using an XtremeMac MicroMemo digital voice recorder for the iPod) and transcribed verbatim.

**Research Journal**

I began keeping a research journal when I first started conceiving the idea of this research study. The journal included methodological considerations, field notes, personal experiences, thoughts, and frustrations. Following the interviews, I captured first impressions and described side conversations that took place before, during, and after the interviews. I made initial interpretations and conducted preliminary sense-making exercises. According to Riessman (2008), this journal fosters ongoing reflexivity—a critical self-awareness about how the researcher actually conducts the research and the significance of his/her decisions.

The journal was a very successful instrument for analyzing issues, generating insights, overcoming obstacles, posing questions, and developing possible conclusions. Reading through my journal during the entire dissertation process allowed me to record and map what was taking place throughout the research process and to scrutinize my own ideas about family and disability. This was extremely helpful to me during the analysis and writing phases of the dissertation.

**Pilot Study**

To help ensure that all components of the study were organized in an effective manner and that the study was coherent and relevant to the population, I conducted a pilot study prior to beginning the recruitment phase. The pilot study involved one mother,
Deena, who I knew from the local disability community. She has three children: Becky, age 6, diagnosed with a rare genetic syndrome; Chase, age 4, and Melanie, age 1, who are both typically developing. Deena kept a diary for 4 weeks and met with me for an introductory and interpretive interview. The interpretive interview, which lasted an hour and a half, was taped and transcribed. Following the completion of the diary and interviews, Deena was asked to provide feedback on these elements of the study.

Overall, Deena noted that she enjoyed writing in the diary, although it was difficult to find the time, and she found the interviews to be interesting and therapeutic. When asked about writing entries, Deena shared that she struggled with the diary because she needed more instruction on what to include. With this feedback, the diary guidelines were rewritten to include more specific instructions.

This pilot study helped me develop more detailed diary guidelines and allowed me to experiment with various interviewing techniques, as well as refining and clarifying some of my interview questions, which I discovered to be wordy and confusing during the pilot study. This was a valuable exercise and energized me about beginning the actual research journey.

Data Collection and Analysis Methods

Phase 1.

The first phase of data collection involved the diary method. Diaries are used in qualitative research to help the researcher understand a pattern of behaviors through personal reflection. This method is well-suited to research projects that seek to interpret the meanings participants attach to events and experiences (Alaszewski, 2006). Diary
research can empower participants to write about daily experiences in their own words and in ways they feel uncomfortable in sharing during face-to-face interviews (Hyers, Swim, & Mallet, 2006).

Bolger, Davis, and Rafaeli (2003) assert that diaries investigate phenomena as they occur over a period of time, as well as study specific or unique phenomena. The goal of a diary in qualitative research is to capture the participant’s daily lived experience and uncover the meaning created by the individual (Sa, 2002). Diaries provide a window through which the researcher can observe the participant in a natural setting, allowing for a more holistic and contextual research approach (Sa, 2002). Diaries also provide the researcher access to settings where observation is either impractical or creates an intrusion or distraction (Alaszewski, 2006).

Diaries allow participants—through their own written words—to express their thoughts on their lived experiences (Sa, 2002). They capture the “little experiences of everyday life that fill most of our working time and occupy the vast majority of our conscious attention” (Wheeler & Reis, 1991, p. 340). Using diaries as a data collection tool can be useful in helping researchers understand a pattern of behavior and actions through personal reflection. This reflection helps researchers gain “insight into social processes and the rationality which underpins observed actions and events” (Alaszewski, 2006, p. 50).

Diaries can empower participants to write about events and experiences in their own words, and may help them feel more comfortable sharing personal and sometimes difficult information. Therefore, diaries can sometimes be more useful than face-to-face
interviews, which do not always capture the participant’s true feelings and perceptions (Hyers, Swim, & Mallet, 2006). While the thoughts and opinions of participants cannot always be understood through conversations or observations, they tend to be expressed through the written word.

Diaries provide a snapshot of an individual’s experiences of day-to-day living. These “little experiences of everyday life” (Wheeler & Reis, 1991) offer valuable insights into the life experiences of mothers raising children with disabilities. Because a diary can capture the everyday patterns of living that are not accounted for by frequently used data collection methods, this method can be quite valuable in understanding the experiences of these women. A diary allows these mothers to serve as their own measure of accuracy, creating an objective measure of their subjective experience. Since some individuals feel more comfortable writing about personal issues and experiences rather than discussing these issues face to face with strangers, the diary method can be an important technique for examining motherhood and disability.

This notion is supported by Goffman’s (1959) use of theatrical metaphors to discuss the interactions between players. According to Goffman, the stage for the performance includes a front region or “front stage,” the place where the performance is given and where any “discrediting activity is suppressed,” while the back region or “back stage” is “where suppressed facts make an appearance” (p. 112). It is in the back regions where “action occurs that is related to the performance, but is inconsistent with the appearance fostered by the performance” (p. 134). The front stage is intended for the audience, while the back stage is meant to be private and inaccessible.
Goffman’s front stage can be compared to a face-to-face interview, while the back stage can be compared to the diary method. On the front stage—or in an interview—some participants tend to put on a carefully constructed performance, discussing the feelings, issues, and reactions which they believe are expected of them by society; however, these are not necessarily their true feelings. What is observed on the front stage or discussed in the interview often does not necessarily expose the actual truth or the inner workings of the backstage. Actors must be able to keep their secrets if the performance is to be a success. In fact, the front stage performance would lose all integrity and reliability if the back stage maneuverings were exposed (Goffman, 1959).

At the same time, the backstage—or keeping a diary—is where participants are able to give an honest, heartfelt performance, discussing their actual experiences rather than what they believe they should say. This is a place, detached from the audience, in which actors have a private space to construct their true identities. Some might question whether these diaries can be considered a true backstage since participants are fully aware their diaries will be read by the researcher and therefore, not be kept private. However, I believe participants will still feel comfortable writing in their diaries because my “insider” status will help them to be open and honest in their entries. Mothers who share the pain, anger, and disappointment associated with raising a child unexpectedly born with disabilities tend to perceive a sense of community with each other, where they feel free to be candid about their feelings and experiences. This will allow for diary entries that are unguarded, open, and can be considered backstage.
Moreover, due to the fact that individuals sometimes have difficulty expressing their emotions orally, diaries offer a more comfortable and secure way to articulate these feelings. The diary method is valuable in accessing experiences that are otherwise “hidden” or “muted” (Elliott, 1997). For this reason, diaries can take the form of social support for mothers struggling to raise a child with special needs, allowing mothers to express their feelings, construct their experience, process information, and reclaim control over their lives.

Diaries create a space for individuals to compose their life stories. These narratives organize life and convey cultural meanings and interpretations that guide the way people perceive life and the way they interact with life (Daiute & Lightfoot, 2004). Through the construction of her narrative, a mother gains perspective, forms her story and identity, and finds coherence in her life (Mori, 1983; Seligman & Darling, 2007). She is able to share her life and connect with others through personal histories. These stories help people come to terms with difficult events (Weber, Harvey, & Stanley, 1987) and organize their experiences into coherent stories that express individual and relational identities (Linde, 1993). People use stories to give order to their experiences and to share these experiences with others. This helps them understand their situations and use their common experiences to build community (Frey & Frey, 2001). According to Bochner (2002), stories are used to make experiences meaningful, attach meanings to events involving uncertainty, and help us to “do the right thing.”

Frank (2002) maintains that the importance of narratives is not so much by conveying a story, but by instilling in us a belief that the world is a place we can make
sense of. He writes of the benefits to the self and to others through the sharing of these narratives. In the case of using diaries to study motherhood and childhood disability, this storytelling focuses on the mothers’ experiences of raising a child with disabilities and specifically on the mothers’ “wounds.” Narrative theory offers hope through telling one’s story and reclaiming one’s identity as a person, and not on a disability or illness (White & Epston, 1990). For mothers coping with unanticipated, traumatic life events, such as childhood disability, narrative construction and diary keeping can be quite beneficial. The therapeutic value of narrative—in the form of a diary—can be found in disclosing difficult and emotional information, as well as the validation of mothers’ ongoing struggle to live life to its fullest (Romanoff, 2001).

Phase II.

The second phase of data collection consisted of the collaborative narrative method. In an effort to acknowledge both the role my participants play in the research, as well as my role as researcher, I chose to use the collaborative narrative method developed by Arvay (1999, 2002, 2003). This method encouraged full collaboration with participants, which I believe is a vital component of my research on families and disability.

In the pages that follow, I describe Arvay’s method and present an overview of this method as it applied to my particular study. This method involves six stages: (1) setting the stage; (2) the performance: co-constructing the research interview; (3) the transcription process; (4) four interpretive readings; (5) the interpretive interview; and (6) writing the story.
In my study, I switched stages five and six because I wanted mothers to first review their narratives and give me their feedback in a true collaborative exchange. I considered their individual stories to be my actual data, and I wanted their reactions to this data before analyzing it. In order to do this, I needed to write each mother’s poetic transcription in its entirety before presenting the narrative to each mother for review. As a result, I created narratives for each mother based on her transcribed interview and diary entries and then presented her the narrative to review during the interpretive interview stage.

Setting the Stage

Arvay (2003) maintains that the introductory interview (or first conversation) is crucial for several reasons. First, the initial interview introduces the research project by giving a detailed description of the purpose, an explanation of the research questions, and a detailed account of the expectations of participants and their role in the research process. Second, this interview allows the researcher to introduce himself/herself and his/her role and responsibilities in the research process. Third, the researcher is able to access the knowledge level and appropriateness of each potential participant and develop rapport.

This step was important because it allowed me the opportunity to share my own history and personal story of childhood disability with participants. By hearing about my daughter and her disability, participants were able to fully understand my interest in this topic. Because this project was very personal, I wanted to ensure that each mother felt comfortable (and hopefully enthusiastic) with the prospect of having open and possibly
emotional conversations. Some of my questions may have produced intense and private feelings, and participants needed to be comfortable with this.

Additionally, the time commitment on this project was extensive because I was committed to collaborating with all participants. It was important for them to understand the time and energy needed to accomplish this ongoing collaboration. Not only was I asking them to keep a detailed diary for several weeks, but I also would be conducting a one-hour interview to introduce the research project (introductory interview/setting the stage); a two-hour interview to collect each mother’s story (co-constructed research interview); and a one-hour interview to review the narrative summary and obtain feedback (interpretive interview). All participants needed to agree to this commitment of time before continuing to the next stage.

Participants received written and verbal reassurances that participation in the research was voluntary and withdrawal from participation in the research was possible without repercussion. In addition, participants signed a consent form (See Appendix D) in accordance with suggested standards for voluntary participation set by the University of Denver. On the consent form and at the onset of each interview, all participants were advised that they may stop the interview at any time. Interviews were tape recorded and transcribed. The participants were assured that their identity and any personally identifying information would not be included in the interview transcript. To maintain confidentiality of the participants, pseudonyms were assigned.
The Performance: The Co-Constructed Research Interview

Arvay (1999) asserts that traditional research methods restrict participants from expressing their understanding of their lived experience in their own words. She believes it is important to provide opportunities to express and give meaning to personal experiences. By inviting stories through conversation, Arvay believes participants can make sense of their experiences and communicate the meanings of these experiences.

She maintains that interviewing is not just about asking “good” questions, but rather being aware and conscious of the researcher’s role in the construction of the narrative. She “aims to be engaged at both an experiential and a reflexive level—in other words, holding a dual consciousness” (Arvay, 2002, p. 17). She also believes we cannot reproduce past events because “our stories do not mirror the world as lived because our stories are constructed retrospectively and, in this research method, they are co-constructed performances” (Arvay, 2003, p. 167).

I conducted in-depth interviews with participants (See Appendix B for an interview question outline). However, these interviews resembled “focused conversations” rather than formal interviews. While I did have a list of questions, I tried not to use this list in a prescribed manner. I wanted to see what came to each mother’s mind about her life and family. To maintain an informal tone, I interjected statements about my own experiences, just as I would in any relaxed conversation. I recorded the face-to-face conversations with a tiny recorder because I did not want to distract my participants or slow the conversations. In several situations, I did take notes because I feared the tape recording would be unclear due to loud, outside noise.
**Transcription Process**

The exact reproduction of the speech act is impossible (Arvay, 2003). Instead, researchers only can attempt to reproduce the communicative events as clearly as possible. Due to the length and number of my interviews, I hired a professional transcriptionist to transcribe the audiotapes verbatim. I asked the transcriptionist to record each and every word on the tapes, as well as any emotional tone that she heard. This was important to include in order to document all aspects of the interview exchange, such as any pauses, sighs, crying, laughter, and silences. The transcriptionist also noted any inaudible speech on the tapes. The transcribed interviews ranged in length from approximately 25 to 50 pages.

**Four Interpretive Readings of the Transcript**

Arvay (1999) delineated four interpretive readings that she carried out in collaboration with the participants in her study. These included reading for content; reading for the self of the narrator and the researcher; reading for the research question; and reading for relations of power and culture. She asked each participant to take part in these four readings, incorporating her feedback in her analyses and findings. Arvay (2002) insists that without this collaboration process between researcher and participant, the narratives would develop into the researcher’s stories and rely exclusively on the researcher’s understanding of the significance of the participants’ lived experience.

My research design slightly deviated from Arvay’s method in the degree to which participants were included in these interpretive readings. I conducted Arvay’s four interpretive readings; however, I opted not to include my participants in these particular
readings. I chose to alter Arvay’s methods due to issues of time and feasibility. Because my participants were all extremely busy mothers, working to raise their families, I did not believe it was feasible to ask them to commit to the time necessary to follow Arvay’s method in its entirety. Instead, I asked participants to review their respective transcripts and collaborate on the construction and representation of their narratives during the last stage (the interpretive interview).

I conducted the four interpretive readings by working with the written transcripts. Using a different colored pen for each reading, I recorded my analysis, thoughts, and comments regarding these readings in the margins of the corresponding section in the transcripts. The following section details my process of conducting the four interpretive readings:

**Reading for content.**

I reviewed the transcript for content, looking for typographical errors, as well as the need for any further clarification. I looked for the whole picture or the story line.

**Reading for self.**

By reading the transcript and locating the “self” of the narrator (or participant), I paid attention to the person telling the story, how she is positioned in the story, her struggles, what she is feeling, how she presents herself, what she chooses to portray about herself, what she is trying to express, and what parts are hidden. Here, I searched for the participant’s actions, beliefs, choices, and self-representations.
Reading for the research question.

I considered the research questions and tried to determine how the participants answered the following questions in their own personal narratives: What are the lived experiences of mothers raising children with and without disabilities? What do mothers of children with and without disabilities reveal about their lives with their children? How do these mothers define motherhood? How does their definition of motherhood differ for each of their children?

Reading for relations of power and culture.

For this section, power related to power imbalance, issues of powerlessness, oppression, silencing, and disillusionment. Culture related to norms and values that regulate social action, social interaction, social status, and role. I focused on the idea of power for these mothers, or a lack thereof. I also looked closely at the influences of culture, gender, and society and how this related directly to the mothers’ stories of disability and difference. I asked in what ways does the participant struggle with issues regarding power and culture? Where is she silenced? When does she use her voice? Is she aware of the influences of power and culture in her own life? Does she ever find herself trying to live up to society’s image of a “normal” family? Is she conscious of any power imbalances in her life or the influences of culture? How has her reality been changed or challenged? How does she see herself as a mother? How does she think others see her as a mother? How would she compare herself to other mothers who do not have a child with special needs?
The thoughts and comments related to these readings were recorded in the margins of the transcribed text. After carrying out these four interpretive readings, I was ready to write each mother’s narrative.

**Writing the Story**

In this step, Arvay summarizes the interpretive readings into one blended text. She typically writes the stories as first person accounts, creating a joint construction through a reflexive and collaborative research process. By using the first person, Arvay hoped to create an embodied tale that is “coherent, compelling, and revealing of the storyteller’s intentions” (Arvay, 2003, p. 172). This narrative is a story-in-progress, which includes the researcher’s perspectives as well as the collaborative four interpretive readings.

Because I chose not to include my participants in the interpretive readings, I did not create this type of blended text. Rather, I developed the participants’ narratives into first person accounts using their transcribed stories and diary entries. I then revised the narratives by using the feedback I received from the interpretive interview.

While Arvay warns that not including participants in the four interpretive readings may compromise the narrative analysis, I disagree. By asking participants to review their narratives and respond to my questions/concerns during the interpretive interview, I ensured that these stories remained the mothers’ stories—and did not rely on my own interpretation of the meaning of the mothers’ lived experiences. I agree with Arvay that using first person accounts of the life story help to bring participants’ stories to life, and I wrote each mother’s narrative in this form.
I read and analyzed volumes of interview transcripts and diary entries, extracting the data into a meaningful and manageable form. Using this data, together with my analysis of the four interpretive readings, I crafted poetic representations from each mother’s narrative as a way of organizing and presenting the data (Glesne, 1997; Richardson, 1994). This is the “creation of poem-like compositions from the words of interviewees” (Glesne, 1997, p. 202). Richardson (1992) suggests that a poem constructed from the actual words and phrases of individuals being studied connects the reader directly with the individual. This connection creates a situation where the data becomes a powerful and accessible tool. Poems highlight an individual’s emotions, feelings, and moods. The most private feelings are described in order to recreate moments of experience. The poem shows how it is to feel something (Richardson, 2002).

According to Richardson (1994), writing up interviews as poems “honors the speaker’s pauses, repetitions, alliterations, narrative strategies, and rhythms” (p. 522). In creating narrative poems from the transcripts and diaries, I used only words, phrases, and sentences which the mothers had spoken or written in their journal entries. I wrote their experiences in the exact words they had used.

**The Interpretive Interview**

The focus of this interview was to elicit feedback from participants on my initial findings. I considered this to be a form of member checking, or playing back the interview to the participant who provided it to obtain a reaction (Lincoln & Guba, 1985). Participants were presented with their written summaries, asked to review them, and comment on content, ideas, and structure. Based on my feedback from the preliminary
analysis and results from the four interpretive readings, in some cases I developed additional questions. Whenever I found gaps in the data, I asked the mothers to clarify the information. This supports Strauss and Corbin’s (1998) method, which suggests the researcher return to the field for clarification when necessary. My goal in this stage of the analytic process was that each mother be completely comfortable with the presentation of her narrative summary. I engaged each participant in face-to-face discussions to hear her insights and thoughts, and used email and phone primarily for clarification purposes. This stage was exciting and educational as it was truly collaborative for researcher and participant.

Most of the mothers were happy with their narratives and enjoyed being able to read them in print. Below are a few written responses that I received after mothers read through their stories:

Wow! This was amazing. You hit the nail right on the head. I teared up as I read it, because you really summed up what I said and I guess reading it really makes it hit home. I think you did an excellent job. Thank you. What you did with my story was amazing! (Tiffany)

It made me cry. Doesn’t everything? I think I’m less depressed than during this period of time, but I still have a lot of the same feelings and worries. I heard myself trying hard to see the positives. Some of those thoughts aren’t so forced these days. I bet other parents would relate to a lot of what I said. (Maureen)

I think it is a bit more dire than I typically feel, but not to say it isn’t an accurate account of the weeks I wrote about. It makes me realize I need to focus more on the positive. (Georgia)

On several occasions, mothers were unhappy with their narratives after reading them in print because they felt they sounded too negative, off-putting, or depressing. I struggled with these situations because while I wanted the narratives to be accurate and
heartfelt, I did not want to print a story that made any of the mothers uncomfortable or upset (See Chapter 7). In a few scenarios, I did choose to slightly alter the text by changing a small number of words that made participants feel distressed. In one scenario described below, a mother initially asked me to make changes to her narrative, but then actually reconsidered her request a week later (in the second excerpt) in hopes that the “bare truth” would be helpful to other mothers:

It took me a while to read through the narrative. I was in a really bad place at the time of the interview. I was so negative about my marriage. I started to read it to my husband and then stopped because I forgot what was said. There are a few things that I would like changed. I will go back over it and send you items that I would like changed. Thanks.

Things are better with my husband, but we are still struggling. I think it would be good to keep the feelings that I had in the interview and diary as they are here. Maybe it will help someone else in the same situation. (Denise)

**Role of the Researcher**

As mentioned earlier, I am a mother raising a young child with special needs, as well as two typically developing children. My experiences surrounding this unique mothering journey were the beginning point for this study. According to Van Manen (1990), orienting oneself to a phenomenon “implies a particular interest, station or vantage point in life” (p.40). He adds that the starting point for phenomenological research is identifying a deep interest in a meaningful experience. This is the experience of childhood disability.

A researcher must possess knowledge of the research topic, but Kvale (1996) advises that this knowledge must be used carefully so as not to reinforce the power structure often present in qualitative studies. The issue of trust and credibility was vital.
Creating open and conversational questions and allowing the participants to see the person—and mother—behind the researcher helped establish a positive relationship and reduce issues of power (Kvale, 1996).

Self-reflexivity enabled me to share with my participants my connection to the study, as well as the importance I place on sharing one’s story. While my own journey strengthened my understanding of the participants’ experiences, I needed to be aware that not all of my participants had the exact same experiences as me and were in different stages of their respective journeys. I needed to be cognizant of placing myself “in the other’s place” (Canales & Bowers, 2001) as I reviewed the participants’ diary entries and conducted the interviews.

For purposes of clarity and validity, I recognized that I possess personal biases due to my close association with this group of participants and with the topic being studied. However, I was careful not to let my first-hand knowledge about the challenges and demands of raising a child with special needs have any negative impact on my role as researcher. I made every attempt to remain open and receptive to the stories of each mother. Most importantly, I needed to allow each participant’s story to unfold naturally as each woman described it. I kept in mind the philosophy of Moustakas (1994), who argues that authenticity is the main architect of validity in a phenomenological study, and it is the responsibility of the researcher to accurately provide a comprehensive description of the phenomenon.

As I wrote each mother’s narrative, I struggled because I was overcome with feelings of guilt and pressure. These mothers had disclosed personal and heartfelt details
about their families and lives. They had exposed themselves and made themselves vulnerable (Chase, 1995). While I had committed myself to collaborating with each participant, I was forced to detach myself from the intimate relationship I had created with participants during the interviews in order to create a relationship with my readers. Josselson (1996) describes this phenomenon as being an intruder and then a betrayer. She explains that researchers feel they are responsive during the interviews but then use the lives of participants for their own purposes, to show something to others. While I felt as if I were turning my back on participants as I wrote their stories for public consumption, I constantly reminded myself that these mothers agreed to share their deeply emotional and personal stories of their lives to further this research. They willingly gave me the opportunity to hear their stories and trusted me to create and interpret their narratives. And these collective stories have the ability to make this world a more tolerant and accepting place.

Summary

This chapter has presented the research design and procedures. Using a sample of 32 mothers, this research addressed the challenges and joys these mothers encountered, the impact of the challenges on their lives and their family’s lives, and the definitions and meanings of motherhood they created for themselves. While my perspective from within the disability community gives me prior knowledge and understanding of these mother’s lives, I employed strategies to minimize the impact of subjectivity. The following chapter presents brief profiles of study participants and introduces readers to each mother and her family.
Chapter Four: Introducing the Mothers

Introduction

This chapter introduces the 32 mothers in this study by way of a brief profile of each. All names have been changed to protect the confidentiality of the study participants and their families. Appendix A contains the detailed narratives told in each mother’s voice, written in a poem-like form. The poetic representations (Richardson, 2002) are direct quotes excerpted from the mother’s interview transcripts and diaries, and arranged by headings/sections. Reading these narratives in poem-like form enables the reader to understand each mother’s world as told through her own words. The narratives represent the study participants’ actual responses and insights.

While their worlds are chaotic and overloaded, these mothers made time to share their lives with me through in-depth interviews, journal entries, and collaboration and feedback on portions of this study. They laughed and cried as they explored the ups and downs of motherhood and disability. The mothers described the unanticipated and life-altering experience of having a child with a disability—how it has affected them and their families, and the meanings they have gleaned from their journey. As a way of helping others, mothers shared their advice and recommendations on coping and moving forward. Their deeply emotional and personal stories reflect life inside families managing and overcoming the hardships of childhood disability.
Table 1 below highlights each mother, her age, all of her children and their ages, and her disabled child’s specific diagnosis. A brief profile of each mother follows the table.

**Table 1. Special Needs Populations Represented in Study**

<table>
<thead>
<tr>
<th>Mother</th>
<th>Mom’s age</th>
<th>Child</th>
<th>Diagnosis</th>
<th>Child’s age</th>
<th>Sibling(s)</th>
<th>Sibling’s age</th>
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**Alexandra**

Alexandra is a teacher turned homemaker. This 36-year-old, married mother is raising Luke, 10 years old, and Patrick, 8 years old, who was diagnosed with high-functioning autism at age 6. Alexandra describes her family life as constantly revolving around her youngest son. “It always feels as if our life circles around Patrick. Will Patrick be able to handle this? How will he manage? What will this outing look like?” she says. “Often, I feel like Luke gets shortchanged. But what can I do?” Throughout
her story, Alexandra describes herself as having the attitude of, “This is what you got, so just deal with it.”

While Alexandra admits to feelings of grief, she tries not to dwell on them. She insists it is necessary to grieve about the disability, allow yourself to feel what you need to feel, and figure out how to feel supported. “Try and find all of the positive things that you can,” she says. “Because it will be extremely easy to find the negatives. You’ve got to hunt down the positives and then hang on to them.”

Anita

Calm and soft-spoken, Anita is very candid about her experiences raising sons Daniel, 10, and Seth, 4. Daniel is diagnosed with cerebral palsy. He is visually impaired, uses a wheelchair, and has severe scoliosis, which requires surgery every six months to expand the titanium rods supporting his spine. He is unable to sit or stand independently and requires total care.

This 41-year-old, stay-at-home, married mother sometimes wonders what it would be like to have two healthy children . . . how different her life would be. She says Seth cannot yet fully comprehend the severity of his older brother’s disability. Seth prays each night, asking God to “make my brother not have a wheelchair when I wake up in the morning.” It’s a prayer that Anita admits to repeating to herself many times.

While she has generally come to accept Daniel’s cerebral palsy, Anita says she continuously struggles with his disability and all that goes with it. “He is my inspiration and always seems to have a smile on his face,” she says. “But I really wish for him that
he didn’t have the pain, the surgeries, the tight muscles, and all the numerous challenges he faces.”

**Barbara**

A 40-year-old, stay-at-home, married mother, Barbara is raising two sons, Sam, 5, and Tyler, 3. This gregarious, bubbly woman had no experience with disabilities before Tyler was diagnosed with profound Sensory Processing Disorder (SPD) at the age of 2 ½.

Barbara candidly admits to spending a great deal of time, energy, and money on Tyler and his disability because she feels she has failed him. She says she let down her youngest son by somehow “gifting him” with SPD and continues to let him down by not being as patient and tolerant as she feels she should be. Barbara is not as hard on herself where her older son is concerned, which leaves her wondering whether her lack of guilt has to do with Sam, the person, or the fact that he doesn’t have special needs like his younger brother.

Throughout her story, Barbara wonders when she will stop beating herself up over every decision and worrying that nothing she does is good enough. “I am not sure I can realistically continue to live this way,” she says. “I do believe I am this way as a result of Tyler’s diagnosis. Knowing myself and the mother I was pre-diagnosis, I am sure I would be more lackadaisical, not as obsessed with the details, and not as close-to-the-edge as I currently live.” Barbara adds that she is certain of one thing: “Clearly, everything in my life has brought me here, to this precise spot, to be the mother of these two boys.”
**Bonnie**

Bonnie, a 46-year-old, married mother of two, says she had no experiences with developmental disabilities before her son, Joshua, 16, was diagnosed with autism at age 2 ½. But her son’s disability has led to Bonnie’s career as the full-time assistant director of a local early intervention organization. It also has given her many joys and sorrows, as she and her husband raise Joshua and 20-year-old Addie, a sophomore attending college out of state.

Reflecting on her son’s life, Bonnie says that birthdays are very difficult because Joshua’s celebrations are so different from her daughter’s. In all of his 16 years, Joshua has been invited to only three parties, despite having hosted several of his own parties. “When I think of all the parties that Addie has been to, it makes me so sad for Joshua,” she says. “But this is something I can’t control. I wish I could snap my fingers and make everything ‘normal’ for him, but I can’t. I need to resign myself to our reality.” Bonnie is hopeful that eventually her son will have a friend or two to pal around with. “I want him to have this experience,” she says. “It’s part of growing up.”

**Brenda**

At 47, Brenda is a single mother (divorced) to 15-year-old Elizabeth and 12-year-old Bridget, who is diagnosed with Angelman Syndrome, an abnormality affecting her 15th chromosome. Talking with Brenda, it is clear that this is a strong and courageous woman. She works full time as the president of a telecommunications company and is raising two daughters on her own. She is extremely proud of her girls, and, while
Elizabeth and Bridget live in two separate worlds, Brenda finds much to celebrate in both worlds.

Feelings of sadness and regret pervade the discussions about her divorce. Brenda admits that, in some ways, her life would be much easier if she were still married to her daughters’ father. But she candidly describes living in “survival mode for way too long,” where each partner “had no idea how to nurture” the other. “Our divorce is my one regret,” she explains. “But we couldn’t continue living like we were. It wasn’t fair to us—or to the girls. I try not to blame our divorce on Bridget’s disability. Sure, her numerous medical problems were stressful and put a strain on our marriage. They definitely contributed to the divorce, but they were not the one and only cause.” She adds, “Would we have divorced if we did not have Bridget and her disability? I don’t know . . . who knows?”

Catherine

A married mother of three young children, Catherine describes life with 8-year-old Emily, 7-year-old Owen, who is diagnosed with autism, and 5-year-old Molly: “We are always planning or making decisions around Owen. And then the girls have to work around that. At any given moment, he gets all of my attention,” she says. “Because of the mental energy that it takes to raise a child with disabilities, my daughters end up having more needs as a result. And being siblings to a disabled child requires more support as well.”

This 44-year-old stay-at-home mother says she never imagined herself raising a child with special needs and treating her kids differently. “Unfortunately, there is a
double standard for my son,” she says. “Owen gets treated differently than the girls because I don’t want him to have a tantrum or because he just does not understand what I am asking of him. He also demands a great deal of attention because of his special needs.” She explains that, while her older daughter understands this dynamic, her 5-year-old does not. Molly always asks why her brother gets treated differently. “I feel so guilty having to say that we treat Owen differently because he’s different. This goes against what you would normally be doing, which is treating all of your kids in the same way.” Catherine constantly worries that her daughters’ sense of worth is being damaged by the double standard and the greater amount of attention showered on Owen.

Cindy

Cindy is a 44-year-old, married, stay-at-home mother raising three boys. Drew is 12, Paul is 9, and Evan is 7. Evan is diagnosed with Cri du chat syndrome, a rare genetic disorder caused by an incomplete chromosome 5. Its name is a French term (cat-cry or call of the cat) referring to the characteristic cat-like cry of children with this disorder. Evan is G-tube fed and recently began walking independently and learning to talk.

In her story, Cindy reflects on her previous biases about disability. She describes herself as a very sheltered person, who once considered having a child with disabilities to be the worst possible thing that could happen to anyone. When Cindy was pregnant with her second child, a grocery clerk with special needs accidentally hit her oldest son, Drew, in the head as she bagged groceries. “The clerk apologized profusely, but I was not at all nice to her,” says Cindy. “This incident has always stuck with me. She was a human being, too, but I did not tolerate difference of any kind. Now, I have been forced to
accept difference. And I can’t stand it when others don’t accept Evan. It’s funny the way life works.”

**Denise**

Denise, 44, is a married, stay-at-home mother to Samantha, age 11, and Hannah, age 6. A certified nursing assistant, she also takes care of Samantha, who is diagnosed with tuberous sclerosis complex, a genetic disease that causes epilepsy, autism, developmental delays, and “tubers” that grow throughout her vital organs.

In her story, Denise describes how challenging it is to balance life with her two daughters. She says Hannah is everything she ever wanted—a little girl who is typical. However, Denise feels she cannot enjoy all the things she has always dreamed about doing with a daughter because she must spend all her time with Samantha. Moreover, constant mental and physical exhaustion prevent her from thoroughly enjoying life. While Hannah has learned to accept this reality, Denise feels perpetual guilt about her older daughter’s disabilities keeping Hannah from being a normal kid, doing typical things.

**Donna**

Donna, 38 and married, is raising three kids with her husband. She is mother to 8-year-old Jack and 6-year-old Emma, and stepmother to Mary Ellen, 14, who lives with Donna and her husband part time. Jack is diagnosed with shunted hydrocephalus, triplegic cerebral palsy, atrophy of the optic nerve, cortical vision impairment, nystagmus and strabismus, and epilepsy. Donna is home-schooling Emma, working as a certified nursing assistant for her son, and employed as a freelance web development consultant.
On some days, Donna wonders what life would be like if Jack’s oxygen hadn’t been removed too early in the NICU, which caused his massive brain bleed. It would be incredible, she says, to have a healthy boy who could play, run, and learn like everyone else. In so many ways, her life would be much easier. But, at the same time, she also wonders whether she and her husband would still be married and whether she would be half as good a mom. “Before Jack, I was very focused on my corporate job. I wasn’t the least bit family oriented and was not compassionate about people’s needs. I was kind of a witch,” she says. “However, I have since matured and become human because of everything we have endured. I have become a team player. I am now more patient and gentle with others.”

While Donna admits that life with Jack is extremely hard, and the daily heartaches sometimes make her want to give up, lie down, and forget the world, she says that it’s very important not to dwell on these feelings too long. She allows herself a little time to think these thoughts but then forces herself to don her suit of armor and fight the day’s battles.

Ellen

Ellen, 41, divorced her husband of 14 years about one year ago. This single mother is currently pursuing a graduate degree, while also raising 9-year-old Julia and 6-year-old Henry. Henry was diagnosed with autism spectrum disorder when he was 2 ½ years old.

In her narrative, Ellen recalls feeling extremely helpless and unsure about the future after receiving Henry’s diagnosis. She had no idea what to expect from her son
and felt scared and alone. “My husband and I didn’t know how to come together. We didn’t know how to connect with each other or ask for help,” she says. “And we didn’t know how to be there for one another.”

Ellen openly admits that her son’s disability was very hard on her marriage. She says that, while she wishes she had not given up on her marriage, she knows things were not improving. “Instead of coming together as a family, the strain of Henry’s disability seemed to tear us apart.” After 17 years, she ended a relationship she expected to last forever. She adds, “I’m not sure if I would have left had this not happened to our family.”

Emma

An attorney by profession, 45-year-old Emma is a married, stay-at-home mother to Simon, 4, and Holly, 3. Simon was diagnosed with Down syndrome in utero at 15 weeks. Emma recalls that, after her son’s diagnosis, she had very negative feelings about his life and future. “I had really low expectations for Simon,” she says. “I remember somebody giving us a baby outfit from the University of Michigan. My first thought was that he will never be able to go there.” She says she wishes she did not know that Simon had Down syndrome: “Sometimes, when you are clueless about something, you just kind of do what you do without thinking too much about it. I would have liked to have raised Simon in that way.”

Emma opens up in her narrative about society’s expectations of difference. She describes hearing about a woman in rural Ohio with nine kids. The mother didn’t even know her ninth child had Down syndrome until he entered kindergarten. She thought he
was a bit slow, but always figured he would catch up in his own time. “What a great way
to go through life,” says Emma. “To just treat people as they are and address the things
they have, rather than all of the things they can’t do. How great would that be?
Unfortunately, I don’t think that will happen in my lifetime. It’s sad.”

**Gabrielle**

Gabrielle is a 42-year-old, married English professor at a local university. She is
raising fraternal twin boys, Charlie and David, age 5, and Ben, age 2. At 3, David was
diagnosed with partial trisomy 16, a rare chromosomal disorder affecting his 16\(^{th}\)
chromosome.

In her honest and emotional narrative, Gabrielle describes feeling haunted by
having babies later in life. She finds herself wondering whether having kids earlier might
have avoided having a child with special needs. She also portrays a time when she
viewed everything in terms of “before David” and “after David.” She explains: “I would
find an old ticket stub from a movie in my pocket, and I’d think back to what was going
on in my life during that exact time. I would always think of time in terms of before
David was born or after he was born, when life radically changed. It’s as if his birth
represents this incredible milestone that redefined my entire identity. I hate that I think
about my own child in this way.”

**Gail**

Gail, age 45, is a married, stay-at-home mother raising four kids with her
husband. Their oldest son, Ethan, is 16; Michael and Julie are 14-year-old twins; and
Wyatt is 11. Wyatt has a brain injury due to a cord accident at birth. He is nonverbal,
uses a wheelchair, and has very little head and trunk control. In addition, Wyatt is G-tube fed and has breathing and swallowing issues.

Feelings of acceptance and peacefulness permeate Gail’s narrative. She insists it is very important to accept the things you can no longer do as a family, while focusing on what is still possible. Gail describes going on a mountain hike with her family before Wyatt got his wheelchair. “My husband insisted that all of us could hike in the mountains together and pull Wyatt in his wagon. It was so important to him that we participate in this outing together, even though I doubted his wagon could make it. We tried dragging the wagon up the trail, but it was very hard. It took more time and effort than we thought it would. We had to turn around. My husband was absolutely devastated.” Today, Gail and her family no longer hike together on inaccessible trails, but they camp and hike in accessible places because it is important to do family activities together. She adds, “We do not want to deprive the older kids. While it is not easy to always take Wyatt with us, we do our best to bring him along whenever possible.”

**Georgia**

Georgia is a soft-spoken, 42-year-old, married mother of two children. This full-time benefits administrator is raising Phoebe, age 8, and Mason, age 6, with her husband. She describes Mason, diagnosed with cerebral palsy shortly after birth, as a sweet, happy, and brave little boy. Unable to sit up, stand, eat, talk, or walk, Mason is trapped in a body that refuses to cooperate with him. However, this doesn’t stop him from smiling constantly and enjoying life to its fullest. Mason takes great pleasure in swimming,
horseback riding, swinging, wrestling, and cuddling. “Mason is a typical little boy who loves to be roughed up and teased,” Georgia says.

A devout Catholic, Georgia tells both her kids each day that they are a blessing from heaven. She says she loves both her children, but she hates her son’s disease. “I pray that God blesses some scientist with the ability to find a cure. I hold out some hope for stem cell research,” she says. “If a cure is not in the plan for Mason’s time on earth, he should certainly have a direct route to heaven when he leaves this earth. He is paying for something. I just don’t understand it all.”

Jessica

Jessica, age 32, is a full-time production manager for a busy print company. An unmarried mother of two, Jessica lives with the father of her children because she believes “being a single mom is just too difficult.” She admits that raising 8-year-old Grace, diagnosed with both epilepsy and severe autism, and 7-year-old Max is an extremely challenging task. Jessica sees the many sacrifices her son has to make because of his sister and her disability. “It constantly breaks my heart knowing what he is missing out on, even if he doesn’t know it yet,” she says. “Grace’s disability dictates when and where and what we are able to do. We don’t have the opportunity to do typical family activities. Max doesn’t have a normal childhood.”

But Jessica works very hard at being optimistic and viewing obstacles as learning experiences. Adapt and overcome are her constant mantras. She insists that, while her life is stressful and overwhelming, she considers herself blessed. “Before Grace, I was immature and selfish. Grace helped define me as a woman. She gave me life as a
woman, as hard as it is. She taught me strength and confidence. She taught me about priorities and selfless love. She is my guiding light.”

Jill

Jill, age 43 and married, is a former project manager for a financial services company. She has traded her corporate life for being a stay-at-home mother to 4-year-old Sarah and 3-year-old Toby. Sarah’s diagnosis is partial trisomy 21 (Down syndrome) and partial trisomy 10. Because Sarah is missing the “critical region” for Down syndrome, she does not present with the classic features associated with Down syndrome. She has global delays, is fed through a G-tube, and is nonverbal.

In her story, Jill describes her struggles to cope and accept Sarah for who she is without wishing Sarah were a typical version of herself. Jill describes how seeing pregnant women and adorable baby girls is still difficult, crushing her with painful thoughts of what Sarah could have been. While these deep feelings of sorrow are abating as her daughter develops, Jill admits that feelings of extreme sadness still hit her at unexpected times.

Her emotions vacillate constantly. She says that at times she loves Sarah more than life itself and feels enormously proud of her accomplishments. At other times, she feels embarrassed by her and wishes she had never been born. While extreme emotional ambivalence is reflected in her narrative, Jill insists that she prays for strength and courage, not for escapes. She strives to enjoy the present moments with her daughter instead of worrying about the future. “While I do love my dear sweet daughter,” she says, “accepting her disability will be a lifelong journey.”
Kate

Energy and passion infuse 50-year-old Kate, married mother to Dean, age 20, and 17-year-old twins, Henry and Nathan. Born at 28 weeks, Henry and Nathan are diagnosed with cerebral palsy due to prematurity. Today, the twins’ disabilities are considered severe and profound. Henry’s only voluntary movement is hitting a switch with his head. He doesn’t speak, doesn’t use his hands, and has no head control. He has titanium rods from his neck to his hips. Nathan doesn’t stand or walk, but he can talk. Dean currently attends college in a neighboring state.

Kate is open and brutally honest in describing the hardship of caring for two severely disabled boys. She also discusses her struggles in raising her typical son, Dean, and trying to maintain a marriage, as well as her own health and sense of self. Kate tries to be positive about her life. “You can choose to look at the glass half full, or you can choose to look at it empty,” she says. “And there’s no rational reason to look at it half full other than life is just easier if you look at it that way.” She insists that everyone has a choice in how they react to events in their lives. Kate wants to enjoy her life and time with her kids, and accept the fact that some things in her life are not great. She says, “My goals include pushing my boys to their highest level, facilitating them to do their best, being proud of their success, having a peace about whatever may come, and keeping a light heartedness throughout my house. Other than that, I don’t have much control.”

Kelsey

At 47 years old and married, Kelsey has become a no-nonsense person. What you see is what you get. “This is not the life I had planned for, but it’s what I got,” she says.
“So, I try to live a good life with a happy, connected family.” This family is made up of her husband; 18-year-old daughter; 15-year-old daughter; and 11-year-old son, Dillon, who has a rare genetic syndrome that remains undiagnosed.

What upsets Kelsey most is when her family cannot do things together. “Years ago, it was so important to me that the entire family do things together. Through the years, however, I have learned not to expect this because of Dillon’s disability, to do the best we can, and to realize that sometimes it will work and sometimes it won’t. But when it does, it really is wonderful,” she says. “We all like each other in our family. And that’s a blessing we should count.”

Kelsey doesn’t know what the future will bring for her son, but she believes it is important to enjoy each day without worrying about what’s coming next. She says that while life is hard, she has learned to live day to day with Dillon’s disabilities and simply appreciate the good days.

**Madeline**

Madeline is a 50-year-old English teacher and married mother of two. Her oldest daughter, Olivia, age 13, was diagnosed at four months with Osteogenesis imperfecta (OI), a condition causing extremely fragile bones. OI is a congenital disease, frequently caused by a defect in the gene that produces type 1 collagen, an important building block of bone.

Madeline’s family also includes her husband and their typically developing 12-year-old daughter, Abby. In Madeline’s narrative, she recounts the pain and shock in learning of Olivia’s diagnosis. “Olivia had been fussy for several days, so we took her to
the pediatrician. The doctor suspected an ear infection and prescribed penicillin. The next day, her left leg became swollen, and her doctor suggested heading to the emergency room in case it was a reaction to the antibiotic,” she explains. “Next thing we know, we were told that our baby had a broken femur. We were not allowed to take her home because she was in police custody. They actually thought we were capable of throwing her across the room and breaking our own baby’s femur. It was absolutely shocking.”

Shortly after, doctors diagnosed Olivia with a rare bone disease. While it was awful to be suspected of child abuse, Madeline says she would rather be suspected of abuse than have her daughter diagnosed with OI. Looking back on Olivia’s life, Madeline recounts that one of the best things a genetic counselor ever told her was that she would never get over her daughter’s disability. “She said I wouldn’t get over it tomorrow or the next day or in a year or two. Rather, it will come up at different times throughout my life. And it’s so very true. But I still cannot imagine our life any other way.”

Marcia

Marcia is a 52-year-old, married, part-time banking associate raising 17-year-old Sophia, 14-year-old Luke, and 8-year-old Daniel, who is diagnosed with Down syndrome. “You expect your kids to be slightly different from each other, and you expect there to be some challenges, but you never expect to become an expert in something like Down syndrome,” she recalls. “I was very naïve and had no idea what it would be like to parent Daniel. I never thought it would be all consuming. It has been quite an experience, and I have had to wing it as I go along.”
Marcia describes an incident that occurred when Daniel first started playing coach pitch baseball at a local recreation center. In one of his first games, Daniel hit the ball to the pitcher, who threw it to first base and tagged out Daniel. He remained on first base, and nobody said a thing. Marcia recalls not knowing what to do. She finally walked over to the coach of the other team, pointed to Daniel, and asked if he was out. “The coach got real close to me, screwed up his face, and whispered, ‘Well, he has Down syndrome, so we didn’t call him out.’ I couldn’t believe it,” she says. After the game, Marcia told the coach the boy with Down syndrome was actually her son, and, while he might have special needs, he also knows the rules of the game and should be treated just like the other kids. “It made me wonder if I should start every experience with, ‘This is my kid, Daniel. He has Down syndrome, but please don’t treat him any different,’” she says. “But is it my job to train the world? Is it my job to change the way society looks at disability? That’s quite a job.”

Mary Beth

This married, 40-year-old mother of three is a full-time high school special education teacher, a profession she entered because of her son’s diagnosis. Ben is 9 years old and diagnosed with both Down’s syndrome and autism. Rachel, 7, and Max, 3, are both typically developing. Ben was diagnosed at birth with Down syndrome and, at age 4, with autism. Mary Beth describes the Down syndrome diagnosis as devastating and shocking. While she suspected he might also have autism, Mary Beth says the dual diagnosis was very difficult because it was one more “blow” to her family.
In her story, Mary Beth describes her difficulty in creating balance in her life. While her two youngest kids are very verbal and demanding of her attention, Ben needs a great deal of assistance doing almost everything. She feels very guilty about not being able to devote the same amount of attention and energy to all three. While there are many places that Ben can’t go—due to his loud vocalizations and tendency to get over-stimulated—Mary Beth and her husband try very hard to lead a normal life with typical family activities. This has always been a priority for her family.

Mary Beth’s narrative reflects her feelings of social isolation. However, she says that raising two typically developing children—both very active in school activities and sports—has helped connect her to other parents and mitigates the feelings of social isolation created by raising a child with disabilities. Throughout her story, Mary Beth touches upon the fact that many parents fail to teach their children about people with disabilities. After continuously watching other kids stare at her son and make fun of him, she wonders how parents can be so negligent in educating their children about disability.

Maureen

Maureen, age 43 and married, was once a very career-focused IT project manager. These days, however, she works hard as a stay-at-home mother of two children, 8-year-old Joseph and 6-year-old Nicole. Joseph was diagnosed at age one with hypotonic cerebral palsy.

Throughout her story, Maureen discusses her constant worries and struggles raising Joseph and Nicole. While Nicole is a very independent and outgoing child who is frequently invited to parties and play dates, Joseph demands a great deal of mental,
emotional, and physical energy from Maureen. “When Nicole goes over to the neighbor’s house to play, I never worry about her. It’s actually a nice break for me,” she explains. “But I never seem to get a mental or emotional break from Joseph. His play dates are a ton of work for me because I need to facilitate the entire thing. Even if he is somewhere else or sleeping in his bed, I am constantly worrying about him.” She adds that she even worries about him in her sleep, waking up in the middle of the night or having dreams that reflect her fears.

While life can be tough, Maureen tries hard to focus on the positives. She says that both Nicole and Joseph have benefitted from having each other. They share a very strong friendship and consider each other their best buddy. Nicole teaches Joseph, plays with him, and raises the bar for what Maureen and her husband think Joseph can accomplish. “If we didn’t have Nicole, I am not sure we would be aware of what typical kids are actually like. As they both change and grow, we need to readjust our expectations based on their individual levels of development. While this is essential, it hurts to be constantly aware of how much both kids differ. And I wonder what effect this has on them.”

Rachel

Rachel is an energetic, married mother of 4-year-old Chloe, who is visually impaired, and 7-year-old Ava. This 35-year-old stay-at-home mother believes you never know what you’re made of until you are pushed to the limit. “I never thought of myself as a fighter, but Chloe’s disability has taught me to be just that,” she says. “I always saw myself as a go-with-the-flow kind of person, but I need to be very strong for Chloe. I
need to be her constant advocate.” She also insists it’s important to remember that we all have challenges in life. “I try to teach my girls that life may not always be fair, but we can’t wallow in our problems. I tell them that when life gives you lemons, you need to make lemonade. We have no other choice.”

**Rebecca**

Rebecca, age 49 and married, is a former urban planner, turned stay-at-home mother. She is currently raising a 14-year-old daughter, Laura, and a 10-year-old son, Colin, who has Prader-Willi syndrome (PWS). PWS is a complex genetic disorder that typically causes low muscle tone, short stature, incomplete sexual development, cognitive disabilities, problem behaviors, and a chronic feeling of hunger that can lead to excessive eating and life-threatening obesity. PWS is caused by a lack of several genes on chromosome 15, and most cases are attributed to a spontaneous genetic error occurring around the time of conception for unknown reasons.

In her story, Rebecca admits that her life is not what she imagined. She always thought she would live in Manhattan, work as an urban planner, and enjoy a cultured life. “I never believed I would move to Denver, endure the experience of a stillbirth, and have a child with special needs,” she says.

Rebecca feels lucky because Colin is a “great kid who is very loving, cuddly, and interested in many different things.” She constantly wonders why everything has to be so hard for him. Why do the things he loves, such as drama camp, cause him so much anxiety? Why can’t he be like other kids? Throughout her story, Rebecca also worries about Laura, who has neither a predictable sibling nor a normal home life.
At the same time, Rebecca describes the most difficult part of her mothering journey as having no end in sight. Because independent living is impossible for Colin, Rebecca’s parenting responsibilities will never change. She feels trapped by this lifelong burden and the prospect that Colin will always depend on her and her husband. “I resent the fact that this burden will never cease,” she says. “I think about what I have given up already, and what I will have to forego in the future to help Colin. Most parents get a new lease on life after their kids go to college. But that won’t be true for us.”

Sandra

This semi-retired, 47-year-old, married nurse now works as a stay-at-home mother to Audrey, 16, and Nate, 14, who is diagnosed with intractable seizures. “This means that basically, he has seizures that can’t be controlled,” she explains. “I used to live in survival mode, always scared. How do you live like that? Always on alert. Never sleeping so you don’t miss a thing. The worry is quite intense.”

Sandra says she knows her typically developing daughter is affected by Nate’s disability. But she works incredibly hard to make Audrey’s life as normal as possible, such as by pushing her to participate in many activities and not expecting her to assist with Nate’s care. “But she has been limited. We all have been limited. How can we not be?”

Sharon

Sharon, age 39 and married, wears a variety of hats. She is a music teacher, graduate student, board member, and community activist, raising 8-year-old Amanda, 6-year-old Zachary, and 3-year-old Megan. Zachary has Down syndrome.
Sharon says people have confessed to her that they could never raise a child with special needs, and she admits that she, too, used to feel exactly the same way. “I remember being pregnant and thinking, please don’t let me have a child with special needs. I can’t do it. But I think most people just rise to the occasion. This is the human experience. Even though we put all of these labels on it, and we think how awful it must be, you just deal with it.” She adds, “There are certainly times when it’s really hard, and I think it would be so much easier if Zachary didn’t have Down syndrome. But most of the time, I look at this wonderful kid and feel lucky to be his mother.”

Throughout her story, Sharon speaks of people’s ignorance about disability. Those who don’t have first-hand experience, she explains, just cannot understand. Lacking experience, people are afraid of the unknown and so don’t know how to act. “I used to be that person, so I can understand,” she says. As a result, Sharon is a strong proponent of full inclusion at school, which she believes can help bridge the gap. “So, when ‘Joe Smith’ is trying to hire someone, and a person with a disability applies, he might remember my son, Zachary, from school. He might recall that while Zachary wasn’t great at everything, he was a good person who tried very hard. Or when a mom has a kid with Down syndrome, maybe she won’t be so devastated by the news.”

Shelley

This 47-year-old, married mother of two is a full-time theology professor at a local seminary. Talking about Zachary, age 12, and Caroline, age 10, who has Tetrasomy 18P, a rare chromosomal disorder, Shelley’s thoughts are clear and well-reasoned. Her
quiet strength, intelligence, and commitment to her family and church emerge throughout her narrative, in which she candidly shares her reflections and her experiences.

When asked about her thoughts on motherhood, she stops and thinks for a long while. “Caroline completely changed my perspective on the kind of mother I wanted to be,” she says. “I no longer need to focus on the intellectual aspect of motherhood because there are more important things to think about now. I believe in my heart that God does not cause this to happen. Instead, God gives you what you need to deal, and you take it if you can. Caroline is here to teach us about what it means to be human. The life she is living is very meaningful and worthwhile, but it is a very different life. You can either look at this experience as a burden or a gift.” Shelley adds that while she tries to experience Caroline as a gift as much as possible, she also tries to accept that it sometimes feels more like a burden. “It’s all about your perception. Like those pictures where your brain switches between seeing a young girl and an old woman and back again, depending on how you look at it.”

**Susan**

Susan is the married mother of four boys: 24-year old Dillon, 21-year-old Sam, 5-year-old Connor, and 2½-year-old Henry. She agreed to participate in this study to help other mothers. “As a mom, I want as much information as I can get,” she says. “And as I get older, I’d like to learn more about disabilities and services. I want to better understand how other moms out there handle the difficulties of raising their children with special needs.”
Susan and her husband are still searching for a diagnosis for Henry. He is developmentally delayed and does not talk. Because of his inability to communicate, Henry has started to throw frequent tantrums in the form of screaming and hitting fits. “These have become very challenging and frustrating for the entire family,” says Susan. “I know they are not his fault, so we try to deal with them the best we can.” One way is to teach Henry how to communicate using sign language. He is currently using a few basic signs, such as more, milk, eat, thank you, please, yes, and no.

Tessa

A quiet, soft-spoken woman, Tessa is very open and honest about her experiences. She doesn’t believe in sugarcoating anything. “At times, I feel anger and resentment towards Jett because of his disabilities. I get extremely frustrated that he can’t communicate,” she says. “And then I feel guilty because none of it is his fault. I often experience these torn feelings, back and forth, back and forth.” This 39-year-old, married, part-time environmental consultant is raising three children with her husband. Ellie is 9, Maggie is 6, and Jett is 4. Jett is undiagnosed. His numerous medical tests have all been negative, and his current diagnosis is global developmental delays.

Tessa explains that, while no parent wants to resent their child, Jett has changed her family’s life in so many ways. “He makes things so much harder for us all. He takes a great deal of energy—physical and mental. He changes every situation and the way we do everything. I wonder if we will ever adjust. My biggest hope for the future is that I don’t always feel this way. I wish for some level of acceptance. I feel like we must find a way to rise to the occasion or this disability will bring us to a very bad place.”
Tiffany

A mother of two young girls, Tiffany talks about her constant guilt. “Guilt is the story of my life these days,” she recalls. “I always feel guilty about something because balancing the different needs of my two daughters is very challenging.” This 33-year-old, married, deaf educator/early interventionist is now a stay-at-home mother to 5-year-old Rebecca and 3-year-old Abby, diagnosed with Rett Syndrome. Having grown up with a sister with mild cerebral palsy, Tiffany still remembers how tough the disability was on her sister and their entire family. Her sister endured the pain of being made fun of and excluded by other kids.

The memories sting, and Tiffany hopes no one will ever make fun of Abby. She knows firsthand how mean kids can be to each other. “This sounds terrible, but I am almost relieved that Abby is so severe,” she says. “This way, she does not have the cognitive ability to really understand the cruelty or the things other kids might be saying to her. It is one less thing I need to deal with and worry about. I am actually more worried about Rebecca’s reaction and feelings than Abby’s.”

Tracey

This 39-year-old, married holistic nutrition consultant and knitting/crocheting teacher has endured the painful process of learning that not one, not two, but all three of her children had some type of special needs. Her 10-year-old son, Conner, has autism. Her 8-year-old daughter, Cecilia, was diagnosed with a variety of issues, including reflux, severe anxiety, auditory processing disorder, and failure to thrive. And her 7-year-old son, Bradley, has asthma and global developmental delays.
Cecilia has outgrown most of her issues, and Tracey no longer considers her daughter to have any special needs. “These days, I focus a lot of my energy on meeting the complex needs of Conner and Bradley, and making sure my daughter leads her own life, while being understanding of her brothers’ various limitations,” says Tracey. “I work one-on-one with Cecilia to help her develop the strategies necessary to handle her brothers’ issues, especially since her friends do not have any of the same types of problems.”

Tracey remembers when she would sit and cry for six hours after dropping her oldest son at preschool. However, she has since learned how to deal with these emotions and proudly describes herself as a strong and confident mother, who consistently stands up for her children and their needs.

Yvonne

Yvonne is a 34-year-old, married, stay-at-home mother raising Robbie, age 8, and Brandon, age 1. Robbie is diagnosed with autism, optic nerve hypoplasia (underdevelopment), asthma, food allergies, and sensory integration difficulties.

In her story, Yvonne explains finding it very difficult to spend time with family members who do not understand her son and his severe behavior issues. She describes Robbie’s having several major breakdowns during a weekend family camping trip. Already embarrassed and uncomfortable with her son’s behavior, Yvonne had to deal with her niece’s repeatedly asking why Robbie was behaving inappropriately and whether he would ever get better. “I yelled at her and told her that he has autism, and I can’t do anything about it. I explained that he was not like her own kids, and she
couldn’t compare them.” After the argument, Yvonne says that she felt embarrassed and sad that nobody understands what her life is like, not even her own husband.

**Summary**

This chapter provides a brief profile of each of the 32 mothers in this study. Appendix A contains the detailed narratives told in each mother’s voice, written in a poem-like form. The poetic representations (Richardson, 2002) are direct quotes excerpted from the mother’s interview transcripts and diaries, and arranged by headings/sections. Reading these narratives in poem-like form enables the reader to understand each mother’s world through her own words. All the narratives represent the actual responses and insights of the mothers in this study. In the following chapter, I present the results and analyze the themes that emerged from the mothers’ narratives.
Chapter Five: Results: Understanding The Experience

Introduction

This study is an in-depth exploration of mothering children with and without special needs. Through the use of narrative, the study seeks to document the life-altering journey of 32 mothers raising children at different stages of development and with a variety of disabilities. My goals are to document, share, and gain knowledge from these mother’s life experiences. Through narrative analysis, the research process attempts to obtain the perspectives of a select group of mothers. These perspectives emerged from each mother’s narrative, which was told in her own voice and written using poetic representations.

To create each mother’s poetic representation, I began by reading and rereading the transcribed interviews and diaries, noting the significant sections that related most directly to my research questions. I meticulously reviewed these sections for commonalities in the mothers’ experiences and for collective perspectives on these experiences. This is a form of analytic induction described by Bogdan and Biklen (2002). From this process emerged common themes, which I developed into headings or sections. I believe these sections successfully organize the data, while also allowing each mother’s voice to be heard.

In this chapter, I organize the findings of this study into the following seven sections, each pertaining to the broad conceptual themes that emerged: Tales of a
Diagnosis, The Meaning of Motherhood, Still Married and Recently Divorced, Encountering Family Life, In the Public Eye, Personal Transformations, and A Look into the Future. These sections are further broken down under sub-sections, each of which pertains to specific data described in detail by participants. Each of these sub-sections contains illuminative and relevant excerpts from the poetic transcripts of the mothers in this study. The particular excerpts were carefully chosen and hand-picked based on how well they support each theme and sub-theme.

**Tales of a Diagnosis**

Each mother’s narrative begins by describing the circumstances of her child’s diagnosis. Two of the 32 mothers received a prenatal diagnosis of their child’s disability through prenatal genetic testing. In all other cases, the disability was confirmed after the birth of the child—sometime between 2 weeks to 5 years—through a form of genetic or psychological testing. Regardless of whether there was a prenatal or postnatal diagnosis, all of the mothers recalled the event vividly and described their responses in great detail. They share how they learned of the diagnosis and their immediate reactions to the news.

This section is further divided into five sub-sections. The first sub-section describes these mother’s intense emotions of sadness and shock after receiving their child’s diagnosis. They share reacting to the stunning news with powerful feelings of grief and sorrow. The second sub-section deals with the mother’s unfamiliarity with disability and their fear of the unknown. Most of the mothers in this study typically had no experience with disability and were forced to enter a formerly unknown world. While most mothers had no experience with disabilities before their child’s diagnosis, the next
sub-section on firsthand experience focuses on the small number of mothers who actually possess personal knowledge of disability through a family member, neighbor, or a job. The next sub-section, unsupportive medical professionals, describes negative interactions with medical professionals during or after their child’s diagnosis. In this section, several mothers describe coping with off-putting and negative messages from doctors regarding their child’s diagnosis and their subsequent burden of care. Experiencing relief after receiving a diagnosis is the final sub-section. Here, several mothers describe learning of their child’s diagnosis as a relief because they finally had some concrete answers. The diagnosis ultimately explained the behaviors and medical issues exhibited by their child.

**Experiencing sadness and shock**

All of the mothers describe their initial reactions to their child’s diagnosis with heavy emotion and intense sadness. Their child was not what they had expected and the initial grief was overwhelming. They speak of feeling shocked, devastated, traumatized, and heartbroken. Some describe the experience as their worst nightmare and being overwhelmed with immense grief. Some wondered why me and why my innocent little baby? For example, in Mary Beth’s narrative, she describes her son’s dual diagnosis of Down syndrome and autism as a total shock to the family. She portrays a dark time stocked with immense grief and compares this experience to losing her own mother to cancer. The excerpts below are taken from the narratives of two mothers who share similar experiences. They both compare learning of their child’s diagnosis to living a painful nightmare that never ends. In this nightmare, Jill reveals waking up in the
morning only to relive the nightmare, while Madeline shares not being able to wake up from her nightmare for a year:

My worst nightmare was coming true. We had a baby with special needs. I didn’t stop crying for weeks. I couldn’t get out of bed. I woke up each morning and relived my nightmare over and over again. At the time, all I could think about was that I couldn’t handle this. I wanted a diagnosis of cancer or a heart defect, something that could be treated. I did not want a mentally disabled child. (Jill)

After she was diagnosed, I felt like I was living in a nightmare. I didn’t wake up for a year. It was like I was in the dark, like it was always night, and I could not wake up. It was so traumatic. I had never experienced any kind of trauma or death in my family. This was the worst thing that had ever happened to me. It sounds selfish, but it was. (Madeline)

Gabrielle describes feeling devastated by her son’s diagnosis because of the irrevocability of the disability. She had spent the first 3 years of his life believing David was only slightly and temporarily delayed and would eventually catch up to his twin brother and to his peers. Receiving a genetic diagnosis was heartbreaking for Gabrielle because it meant David’s delays arose from a chromosomal abnormality that would never go away. She explains: “It felt final and absolute, in a way his delays never felt to me. He wasn’t going to grow out of it. He would always have difficulties.”

Many of these women had specific ideas—often unconscious—about how the “perfect” mother and child should look and act. As a result, the diagnosis of disability left many of the mothers feeling inadequate and disappointed in themselves. For example, in Rachel’s narrative below, she reflects on her pregnancy and wonders if she did something wrong to cause her child’s disability: “Did I eat something bad? Did I take something I wasn’t supposed to take? You start to question everything.” At the same time, Cindy constantly wonders whether other people think she did something bad during
her pregnancy to contribute to her son’s disability. She explains: “I can still remember one neighbor asking me what happened during my pregnancy to cause this.” For Jill, giving birth to an “imperfect” and “damaged” child makes her feel heartbroken and cheated. These sentiments of failure and despair permeate her narrative below:

I loved Sarah, but a part of me didn’t want her if she were not perfect. I could not look at her without imagining her potential . . . if not for the extra 21st chromosome that was present in every single cell in her body. Looking at her, I saw my failures. My body betrayed me. I failed at reproduction, a basic human function. I felt like I disappointed everyone . . . my husband, family, friends, and most of all, Sarah.

In addition to dashed expectations of the perfect child and the perfect life, many of the mothers felt their futures were hopeless after the diagnosis. These mothers initially believed the disability meant a bleak life for themselves and for their families, with no prospects of happiness or joy. They worried about the lifelong burden of raising a child with disabilities and the negative effects on their families. Fears for their child’s future, worries about what the disability might mean to his or her happiness, and acceptance by others were also common. In the excerpts below, both Anita and Jill paint gloomy pictures of their early fears of a lifetime of social isolation and stigma:

I was absolutely devastated. It was finally clear to me that yes, this was a long-term situation for Daniel. I was thinking ahead to all of the things he wouldn’t be able to do and all of the things he may miss out on. (Anita)

When Sarah was first born, I remember thinking how her full name would look on a business card. But after finding out about her diagnosis, I realized that grocery store bagging personnel don’t have business cards. (Jill)

**Fear of the unknown**

It is clear that some of these mothers’ feelings of shock and devastation stem from their lack of understanding and inexperience with disability. They describe a fear of the
unknown and previously held prejudices, which intensified their distress and fear. These mothers typically had no experience with disability; it was unfamiliar and frightening to them. Suddenly they experienced disability from the perspective of an insider—forced to enter a formerly unknown world, forever changing their lives, homes, and hearts. The mothers in this study reflect on their previously held prejudices and their initial feelings of being miscast as the mother of a disabled child, a role they must step into immediately after the doctor hands down a diagnosis.

For example, Yvonne confesses that she had no experience with disability before learning of her son’s diagnosis of autism. “It was all new to me,” she says. In her story, Cindy ponders her previous thoughts about disability. She describes herself as a very sheltered person, who once considered having a child with disabilities to be the worst possible thing that could happen to anyone. Cindy recalls an incident in which a grocery store clerk with special needs accidentally hit her oldest son in the head as she bagged groceries: “The clerk apologized profusely, but I was not at all nice to her. This incident has always stuck with me. She was a human being, too, but I did not tolerate difference of any kind. Now, I have been forced to accept difference.” In the following narrative, Anita also reflects on her lack of experience with disabilities before her son, Daniel, was born: “I had no basis or guideline. I just assumed that his life was going to be the worst. I just thought he would not be able to enjoy life.”

These mothers’ lack of experience with disabilities also translates into a fear of individuals with disabilities and being forced to confront the horrible stereotypes they once held. In her narrative, Madeline describes growing up afraid of people with
disabilities because they invisible in society when she was young: “I only remember
gawking at them like zoo animals from behind a fence on the elementary school
playground. I was afraid of wheelchairs, afraid to look at the person in the wheelchair,
kind of embarrassed and self-conscious.” Sharon explains that because she was raised to
appreciate different cultures, she has always considered herself to be a well- adjusted and
accepting individual. However, she admits to struggling with the implications of her
son’s diagnosis: “When I had Zachary, I had to confront some terrible stereotypes I had
about people, especially with cognitive disabilities. I had to go through a grief period
when he was first born.”

Firsthand experience

While some mothers had no experience with disabilities before their children’s
diagnosis, six of the mothers possess firsthand knowledge of disability, either through a
family member, neighbor, or a job. These mothers report mainly negative reactions to
the disability experience, which are framed by fear, sadness, burden, and tragedy. For
example, in her narrative, Sandra shares her experiences growing up with a neighborhood
girl who had frequent seizures: “I remember thinking, please not that, anything but
seizures, and look what I end up with. I tried to stay away from that
girl, so I totally
understand why people stay away from my kid. I felt the same way.” Similar to Sandra,
Gabrielle also describes spending time with her husband’s aunt, who had a severe
developmental disability. Through this difficult experience, she learned firsthand about
the negative aspects of disability and stigma, and developed her own stigma attached to
chromosomal abnormalities. She elaborates in her narrative: “We experienced her
disability firsthand. There’s a realization that it is permanent. And that it affects every single cell in his body.” In the following excerpt, Tiffany portrays life with a sister with a disability as difficult and embarrassing: “My older sister had mild CP, so I experienced disability at a young age. I still remember how tough it was on my sister. Kids always made fun of her. I felt embarrassed for her and for me. It was terrible.”

**Unsupportive medical professionals**

It is evident that many of the mothers in this study struggle with their own personal reactions to the disability diagnosis. At the same time, some of them also find themselves wrestling with the negative reactions of medical professionals. In many of the mothers’ narratives, family doctors, pediatricians, and geneticists played a prominent role in the diagnosis of their children. However, some mothers describe doctors who did not manage this diagnosis discussion in a competent or humane manner. Often, their delivery was neither positive nor supportive, and they described a diminished quality of life, as well as a life stocked with heartbreak and burden. In the following excerpts, two mothers portray how their child’s diagnosis was delivered to the family in a manner lacking empathy, sensitivity and compassion. Here, Anita describes being told by her infant son’s neurologist that her son would never be normal:

At 6 months, Daniel started having significant seizures and his development was very delayed. We got a diagnosis of developmentally delayed at that point. The neurologist told us that whatever normal is, Daniel won’t be 100 percent normal. What an awful way to explain what the future held for us.

In Denise’s narrative below, she shares being informed by doctors that her daughter was born with a rare disease. However, her daughter’s doctors were completely ignorant about the disease and could only offer a very brief description from a medical
Unable to answer any questions about Samantha’s life span, they bid Denise goodbye and good luck. She brings to light her experience below:

I was in total shock. I was devastated. It had taken us 4 years to get pregnant. I thought I had done something wrong. The doctors did not know anything about tuberous sclerosis complex. They pulled out an old medical journal and showed us one small, vague paragraph about the disease. I looked them in the eye and asked if Samantha was going to die. They said they had no idea. They handed us that page from the medical journal and told us goodbye and good luck.

Furthermore, mothers in this study vividly describe medical professionals who seemed to lack any understanding of how their facial expressions, as well as their tone and manner, intensified the mothers’ feelings of hopelessness and despair. While these mothers share their need to be encouraged to hold on to their faith and be optimistic about their children’s lives, many actually felt despondent after speaking with their doctors. They insist that greater awareness and sensitivity to the family’s reactions to the diagnosis and prognosis would have helped them to feel more positive and hopeful, and encouraged them to explore all options and support services available to their family.

Some mothers describe doctors who openly conveyed their personal biases toward children with disabilities. These doctors discussed the children in a highly negative manner, speaking in terms of “grief,” “tragedy,” and “hardship” for their families. At a time when these mothers needed encouragement and inspiration, some were actually urged to end their child’s life or begin searching for institutions to avoid a diminished quality of life for the rest of the family. In the excerpts below, Donna describes being advised to end her infant son’s life, while Tracey shares her story of being encouraged to look for institutions for her son with autism:
When I returned to the NIC unit the next morning, the nurses said Jack had been fussy all night. I found him seizing in his incubator. He had a grand mal seizure due to a massive brain bleed. They had removed the oxygen too early. He was put on life support, and we were told to pull the plug. They said he would be dead by age five, he would need to be institutionalized, and he would never interact. They were adamant that he would have no quality of life, and we should just end his life now. We took him home instead. (Donna)

Conner was born six and a half years into a solid marriage. He was breastfed, wore cloth diapers, ate organic food, never watched television, and was never sick. At age two, everything changed. He stopped talking, stopped looking around, stopped eating, and stopped sleeping. One year later, he was diagnosed with autism. We were not given much hope for our son. We were told to start looking at institutions because back then, that’s what parents did. (Tracey)

**Experiencing relief**

Despite the fact that most of these mothers feel traumatized and grief-stricken by the news of their child’s diagnosis, some mothers actually describe hearing their child’s diagnosis as a relief. These mothers—some searching for a diagnosis for a very long time—finally have a concrete label with which to explain their child’s medical problems or behavioral issues. At last, they know what is going on with their child and what to possibly expect in the future. Anita believes that finally having a diagnosis of cerebral palsy for her then 1-year-old son, Daniel, was a big relief. She explains: “We said this is what it is, so let’s do what we can to help our son, and focus on his therapy and his progress.” For Alexandra, finally hearing the diagnosis of autism after several years of searching for answers was a relief because she had always assumed her son had autism. In her narrative, she elaborates: “The diagnosis was a good thing because we were hoping the label would help us with insurance.”

Barbara explains that when she finally received her son’s diagnosis, it was neither a surprise nor an unwelcome confirmation. Here, she describes feeling extremely
grateful to be acknowledged: “What was wrong with my child had a name. I knew how
to look it up, what types of therapies to pursue, and how to explain it to myself and to
others. After all, this is a society of definitions and labels.”

Because Tessa’s 4-year-old son, Jett, is still undiagnosed, Tessa has never
experienced these feelings of relief. Instead, she describes a life of uncertainty and
ambiguity, where her son’s delays have no name. When asked to reflect on this
uncertainty, Tessa speaks of a life of contradiction. In the excerpt below, she considers
her son’s lack of a diagnosis to be both a hardship for her family and, at the same time, a
blessing:

With all the tests we have done, Jett is still undiagnosed. We have never had that
“aha moment” to tell us what is going on. In a way, being undiagnosed is both a
blessing and a curse. It’s a blessing because the sky is the limit. Maybe just
around the corner, Jett will make the turn and catch up to his peers. It’s also a
curse because we don’t know if the road ends. Is it today, is it tomorrow . . . or
was it yesterday? Although we still wonder, we are beginning to accept that we
may never know why Jett is the way he is.

Summary

In this section, mothers describe experiencing grief and shock after receiving their
child’s diagnosis. These feelings are intensified by unfamiliarity with disability and a
fear of the unknown. For the small number of mothers who do possess previous
knowledge of disability, they report mainly negative reactions to the disability
experience, framed by fear, sadness, burden, and tragedy. While mothers must come to
terms with their own difficult reactions to the diagnosis, they also find themselves
struggling with the negative perceptions of disability conveyed by medical professionals
during and after their child’s diagnosis. For many of these mothers, describing their
diagnosis stories was quite difficult. However, some actually portrayed learning of the
diagnosis as a relief. These mothers finally had concrete answers, which explained the
difficult behaviors and medical issues exhibited by their children.

Many of the mothers in this study struggle to make sense of their child’s diagnosis
and accept the disability. They work hard to construct the meaning of disability as it
pertains to their child and their family. In the following section, mothers begin to accept
the diagnosis of their child and ponder the implications of motherhood. This notion of
motherhood begins to permeate their lives as they define and redefine the meaning of
motherhood and search for their identities as mothers.

**The Meaning of Motherhood**

Mothers who raise children with disabilities have many more responsibilities and
demands when compared to mothers of typically developing children. Their mothering
role requires an increased amount of time, caregiving, patience, and compassion, as these
mothers must navigate their child’s decreased cognitive functioning, physical limitations,
challenging behaviors, and limited social skills. This particular theme portrays how these
mothers navigate their daily lives and come to terms with their realities of mothering a
child with disabilities.

This section is further divided into eight sub-sections. The first sub-section
describes these mother’s images of motherhood. A majority of the mothers in this study
insist that their current lives are nothing like they had originally pictured for themselves.
They share their ideal images of motherhood and compare them to their realities today.
The second sub-section deals with some of the mothers’ perceptions of motherhood based
on their own mothers. These women share how their mothers became their role models and instilled in them ideas about what perfect parenting should look like. The third sub-section, guilt, focuses on the mothers who describe the overwhelming feelings of guilt that pervade their lives. This guilt is directly related to their experiences of mothering typical and nontypical children. Loneliness and social isolation is the fourth sub-section, which depicts these women’s feelings of seclusion and solitude as they interact with the outside world. They share feeling desperately alone when spending time with friends and family who do not understand the daily struggles of raising a child with disabilities. The fifth sub-section dealing with sadness and depression comes next. Here, mothers describe strong feelings of sadness and disappointment that arise from the unmet expectations of having a “perfect” baby, images of what life “should” have been like, and the constant struggles to accept their children and their disabilities. These mothers work tirelessly to battle depression and heartache, rediscover themselves, and regain joy and enthusiasm in their lives. Battling anxiety is the next sub-section. Here, mothers associate their feelings of anxiety with several factors, such as being out in public with their child with disabilities, constantly worrying about the safety and well-being of their child with disabilities, and their inability to come to terms with their child’s diagnosis. The seventh sub-section focuses on how some mothers consider their children with disabilities to be gifts. While many of the mothers in this study discuss intense feelings of sadness, loneliness, guilt, depression, and anxiety, some also share strong feelings of unconditional love for their child. These mothers focus on acceptance and optimism. The last sub-section centers on these mothers’ vacillating emotions. Some commonly
experience emotional ambivalence with uncontrollable waves of sadness and happiness. At times, they are enormously proud of their children with disabilities, while at other times, they are embarrassed and despondent.

**Powerful Images**

A majority of the mothers in this study maintain that motherhood is nothing like they imagined and their lives are not the ones they assumed they would live. They had imagined falling in love, getting married, having adorable babies, and living happily ever after behind a white, picket fence. Numerous mothers share stories of growing up in a happy, healthy family with three, four, or five kids running around the house and expecting their own lives to look the same. Some reveal that, as young girls, they envisioned themselves as joyful, content mothers, and it never entered their minds that life might be other than idyllic. Or if they expected a few parenting challenges, they never expected to become experts in autism, cerebral palsy, or Down syndrome. Looking back, they realize their dreams of motherhood were quite unrealistic, naïve, and idealistic. One mother even depicted her image as insane.

For example, Barbara reminisces about envisioning motherhood as fun picnics and reading the newspaper in bed with her baby cuddled next to her. In her narrative, she says she had no realistic notion of motherhood: “I didn’t have any friends with children who lived nearby. I couldn’t see any other mothers in action. I was totally surprised by reality.” Like Barbara, Emma recalls thinking that motherhood was just about sitting and playing with your child. She explains: “I thought it was all happy, fun, and loving with lots of hugs and kisses. These were just dreams in my head, maybe from watching TV
and seeing the diaper ads. But life is not how I envisioned it to be.” In Tiffany’s narrative below, she describes yearning to be a mom since she was a little girl, but never realizing how difficult it could be:

I was sad that I was the youngest because I wanted my mom to have more kids. But it’s way harder than I ever imagined. The challenge has been eye opening. I imagined it would be all fun and games, just go and play. But I am a chauffeur, always running someone somewhere. The house is always a mess, dishes are on the table, and we are always late. I can never relax and enjoy. There’s so much responsibility . . . always making sure Abby is safe, getting fed, not freaking out, and trying to keep her happy.

Similar to Tiffany, Maureen’s life is far different from what she expected. She admits that she never pictured herself as a stay-at-home mother. However, she says she did not have a choice with her oldest child, Joseph, because he needed so much time, attention, and effort. Below, Maureen reflects on her present situation:

Staying at home just wasn’t my thing. I am not this warm, fuzzy person who likes to make cookies and play games and sing songs. It’s a stretch for me. I am not playing on my strengths. It’s so different being in the professional world one day and cleaning poop another day. You feel your mind turning to mush. But there’s so much value in me being here for my kids, and I didn’t really have a choice with Joseph. I wanted to be home to help with therapy and be in tune with what is going on. It had to be like this.

When Madeline discusses her ideal images of motherhood, she insists that she always knew she wanted to be a mother and pictured herself taking care of little kids who could do everything. Here, she describes growing up in a family of four typical kids and expecting her own family to look the same: “It never ever enters your mind that it might not be this way. You can’t conceptualize the amount of self-sacrifice that it demands of you. It doesn’t even cross your mind.” In Gabrielle’s narrative below, she describes
having distinct ideas about what motherhood would be like, but these ideas were far more
“naïve and pastoral” than what she now experiences in her life:

If someone had told me that when I grew up, I was going to have three boys, one
with special needs, I would have been like, no, not so much, I don’t think so. Sometimes I wonder why I wanted this so much. Like, what’s the upside? It’s
much better when I don’t think in terms of this is what I expected, and this is what
I actually got. Or in terms of what other people got seems so much easier than
what I got, or more desirable in all sorts of ways. It’s much better when I don’t
think about these things. It’s when I take a step back and look at it from a long-
term reflection angle that it’s problematic. Or when I think about not having a
daughter or having a special needs kid in the long term. Then I can be overcome
with feelings of this is not what I expected motherhood to be.

As a college professor, Shelley says she had always thought about
motherhood in terms of the books she would read with her children and the in-
depth conversations they would have. However, after her daughter’s diagnosis,
she came to realize she would never have any of these exchanges with her
daughter. As a result, Shelley maintains she did not know how to relate to her
daughter or be her mother. She explains below:

What I had never realized before was how much I had constituted parenthood as
an intellectual relationship. But my counselor told me that you can relate to
people on four different levels: intellectually, physically, emotionally, and
spiritually. She told me—and I will never forget this—that there was no reason I
couldn’t relate to Caroline on the other three levels. I could still connect with her
physically, emotionally, and spiritually, which made sense. It was just that the
intellectual piece had been so important to me that I couldn’t get past it, so I
couldn’t process it. I wasn’t equipped to think of our relationship without the
intellectual piece, but I had to find a way. I needed to focus on the other three
levels if I were going to be able to mother her. I needed to change the perspective
that I had on what it means to mother. I was forced to recognize that there was
more to me than just a brain, that I have more to offer people than my intellect.
Role Models

For many women, their perceptions of motherhood are formed during their own childhoods, specifically from their mothers. In this section, these women share how their own mothers acted as role models for them, instilling in them ideas about “perfect parenting.” However, these idyllic visions did not actually become their reality. For example, Yvonne explains that she desperately wanted to be like her own mother, who was so loving and patient, but life did not turn out the way she had expected. Instead, life “is so much more of a hardship.” Like Yvonne, Mary Beth’s images of motherhood also come from her own mother. In the excerpt below, she describes her fond memories of her own mother, a stay-at-home mother raising four kids, and compares these recollections with her own life today:

She was my role model. She was always calm, cool, and collected. Everything was under control. She had time to sit down and play games with me. She never seemed distracted or rushed. My ideas of parenting came from her. But if I sit down and play with the kids, I’m always thinking about something else. What else I should be doing? This is not what I had in mind about motherhood. I work full time, and Ben has a busy schedule with appointments and therapy. We are always go go go. There’s no time for games.

Sharon also talks about the difficulties of motherhood, admitting it is a great deal harder than she ever imagined. Here, she asserts she always believed she would be more like her own mother: “I thought I would be much more fun and creative as a mother. I was that way as a teacher, and when I babysat, I’d do all sorts of fun things. But you get so tired. I feel disappointed in myself that I’m not more creative and energetic.”

In Alexandra’s narrative, she explains that, because her mother stayed at home, she always figured that she, too, would stay at home with her own kids. She says she
planned to bake them cookies and do all the fun things her own mother did, but life did
not turn out this way:

This is not what I thought it would be like. I don’t think our culture has prepared
us well for motherhood. Everything that you see on television is smiling, happy
babies, and sunshine. But that’s not reality. That’s a lie. It’s actually crying,
grumpy babies at 2 a.m. You build expectations on what you think you’ve got.
Luke was born, Patrick was born, and we’ve got two sons. You immediately get
an image of typical brothers, and the kinds of experiences that they will share.
And when you find out that one of them isn’t going to hold up his end of the
typical bargain, then it shifts. You find out instead of going where you thought
you were going, you’re going somewhere else.

Guilt

Many of these mothers possess overwhelming feelings of guilt related to their
children. Some experience guilt because they cannot provide a perfect world for all of
their children, or some actually blame themselves for their child’s disability. Others fear
that, because they must focus most of their attention and energy on their child with
disabilities, they are neglecting their other children. They wonder whether sufficient
parental attention is being paid to other family members’ activities and development of
their own identities beyond the disability. This perpetual guilt is experienced by mothers
who worry that their typical children are being denied a normal childhood.

For example, Madeline struggles with intense feelings of guilt from not being able
to provide a perfect world for her two kids. Here, she explains that her husband always
reminds her that their daughters, Olivia and Abby, do not need to have the same
childhood as Madeline, but she struggles with this notion: “I always think my childhood
was the right one. That’s the way it was supposed to be. I always feel like as a mom, I
should be doing more. I put this on myself. I know that.” Madeline elaborates on her
constant feelings of guilt. In her narrative below, she describes her endless guilt related to helping her daughter perform her daily exercises. She explains how each day Olivia must do several therapeutic exercises for gluteus and leg strength, while also trying to build standing endurance. Olivia requires continuous help from her mother to perform these specific exercises, which is difficult for Madeline, and causes her to feel constant guilt. Below, she describes these feelings:

It’s really hard because I am working full time, trying to keep up with housework, planning my lessons, grading papers, getting in my own exercising, and helping Olivia shower every night. It is so tough to fit everything into our schedule. The exercises are so important, I know, but they often require more energy than I can muster.

Like Madeline, Jill considers her daughter’s therapy an endless source of guilt and stress. Instead of playing with her daughter, Sarah, and just enjoying her time as a mom, Jill feels she should constantly be “working” with her. She explains these emotions: “I feel so guilty if I don’t help her complete all of her therapy homework, but her to-do list is four pages long. I feel a great sense of responsibility in Sarah’s accomplishments. I link her failures to me.”

In Tiffany’s narrative, she also describes feelings of guilt when she doesn’t force her daughter to do her therapy exercises at home: “I hate ‘therapizing’ my child all the time. I want to love her and play with her in my own way. I try to tell myself that just because I don’t always work with her, it doesn’t mean she won’t be happy.”

In the two excerpts below, both Kelsey and Tiffany describe experiencing persistent feelings of guilt and inadequacy concerning all of their children. For Kelsey, she reveals feeling guilty that she was unable to give her two daughters a healthy little
brother, and for not giving her daughters a perfect childhood, free from the stress and anguish of disability. While she battles these persistent feelings, she insists that these emotions are completely self-inflicted:

I have a lot of guilt that the girls didn’t get their perfect childhood. This guilt stems from my “mother” perception of the things a mom is supposed to do. But the girls never put this on me. It’s me. It also stems from watching my mom friends raising typical kids and all they do. Ever since Dillon was born, it has been the girls’ faith and acceptance that has kept me going. I felt such guilt when Dillon was born. I was unable to give them a healthy, “normal” brother. But they loved him exactly as he was.

For Tiffany, guilt is a never-ending part of her life. This is articulated in her narrative below as she tries to balance the diverse needs of her two daughters, muster the energy to mother her typical daughter, and also find joy in her life:

Guilt is the story of my life. I always feel guilty about something because balancing the different needs of my two daughters is very challenging. I wish I had more energy to give to Rebecca. I feel like I focus too much on Abby and her disability. The balancing is hard. It makes me feel sad that sometimes I do not get to enjoy Rebecca because I have to mess with Abby. I am sure it bothers Rebecca, but she can’t seem to express it.

Jill describes constantly blaming herself for her daughter’s disability. She and her husband planned to start a family after five years of marriage, but when the time came, she maintains she was not ready. Jill was afraid of not being a good mother and of the sacrifices motherhood requires. She did not want to give up her personal goals and actually feared having a child with disabilities. Here, she insists the biggest mistake of her life was waiting so long to have children and feels guilt for her daughter’s disability:

“It turned out that I was a carrier for Sarah’s translocation. Maybe having her at an older age increased the risks. The guilt is overwhelming. I blame myself for Sarah’s disability.”
Loneliness and Social Isolation

When the mothers in this study interact with the world outside of their immediate families, they describe recurring feelings of loneliness and seclusion. These feelings stem from being with friends, family members, and other mothers who do not understand the daily struggles of raising a child with disabilities. Many mothers also describe feeling envious and jealous of the normal lives of others. At the same time, they understand why their friends do not understand the daily challenges of raising a child with disabilities. In her story, Yvonne explains how hard it is to spend time with family members who do not understand her son and his severe behavior issues. She describes a recent family camping trip where her son, Robbie, had several major breakdowns. Already embarrassed and uncomfortable with her son’s autistic behaviors, Yvonne describes being confronted by her niece who repeatedly questioned Robbie’s inappropriate behavior and queried whether he would ever get better: “I yelled at her and told her that he has autism, and I can’t do anything about it. I explained that he was not like her own kids, and she couldn’t compare them.” After the argument, Yvonne insists she felt embarrassed and sad that nobody understands what her life is like. In her narrative below, Yvonne expands on these feelings of isolation due to her son’s disability:

I lost a lot of friends because they just didn’t understand my situation. When my son is having behavioral problems, they think it is just him being a bad kid. He can say some pretty mean things. I don’t like going to social events because I never know what to expect from him. It makes me mad because I feel like we can’t participate in things and be around other people. Other moms don’t know how easy they have it.

Rachel also elaborates on her intense feelings of loneliness when spending time with friends in the narrative below. While she maintains that she has good friends who
are definitely interested in her daughter, Chloe, and Chloe’s disability, Rachel claims that her friends do not completely understand her daily struggles raising a daughter with a disability. This lack of understanding produces feeling of loneliness for Rachel, which she shares below:

Sometimes, it feels extremely lonely out here. I know that I’m not alone. I have great friends who have taken the time to learn about Chloe. But they still don’t fully get it. They don’t get the moments that break my heart. They don’t get the moments when I am reminded of my child’s disability. It’s the instant flashes, like when Chloe accidentally walks into a table or door jam. I have to keep it together. Friends tell me how great she is doing, learning to use all of her other senses in ways we don’t understand. I want to tell them to take those wonderful words of encouragement and put them somewhere. I just want my baby to not have these challenges. But then I get over it and know they only meant well. It’s just the reminder of my little girl’s limitations that breaks my heart. I know they just don’t get it.

Like Rachel, Barbara describes mothering a child with special needs as an extremely lonely experience. Below, she explains that it is difficult to bond with other moms who do not accept her son, do not understand disability, and lack the interest to learn:

Mothering a child with special needs has been the loneliest experience of my life. I have never felt so lost. We were kicked out of Tyler’s playgroup because he was different. The typical families we meet can be uncomfortable and unwilling to accommodate. It is hard to connect with other moms who do not have a clue. I seem to keep many women at an arm’s distance because they don’t understand my situation. And they don’t seem interested in getting it, and they are unable to get it.

In Jessica’s narrative, she explains that she does not keep in touch with many friends from childhood because it is extremely hard to connect with them. As a result, those friendships have been reduced to random emails and phone calls. Below, she
laments her inability to experience normal parent events and explains the difficulty in connecting with others who do not understand her life:

I don’t get to sit and chitchat with other parents. I feel like people don’t even know how to relate to me because our worlds are so different. A lot of times I feel like people shy away from asking anything about Grace because nobody knows what to say. And nobody wants to be rude, which is totally understandable. But I guess I’d feel better if people did ask because then maybe they wouldn’t stare. I don’t even look at people’s faces anymore. I try not to think about it. I’m closed off.

When Anita spends time at the playground with her two children, she admits to feeling removed from everyone around her. Here, she explains these feelings: “I’m just wheeling Daniel around the perimeter of the playground [in his wheelchair] and keeping an eye on Seth. Or I park Daniel near the swings, so I can push Seth. And usually the other moms don’t interact too much with me.” In her narrative, Tiffany imagines a life without disability and admits to envying other parents. Here, she describes a recent play date at McDonald’s and compares her difficult life to the easy life of mothers raising only typical kids:

All of the kids ate for five minutes and then ran to the playground. But Abby takes an hour to eat. So, the other moms chatted while I had to focus on Abby’s feeding. I had to concentrate on her not choking. The other moms are lucky that they do not have to constantly worry. They can get their kids up, dress them, feed them, and get them off to school. They don’t have to worry about them falling down the stairs or running into the road or taking over an hour to finish one meal. They go to the park and can sit in the shade, chill, and talk to their friends while their kids play on their own. Instead, I have to constantly chase after Abby and be on guard. I cannot relax for a second. It is hard.

Like Tiffany and Anita, Mary Beth acknowledges that many of her friends simply have no idea what it’s like to raise a child with disabilities. Here, she explains that while some women try to be understanding and sympathetic, most do not understand: “Unless
you’ve walked in our shoes, you don’t really know or get it. I have a friend with two
typical kids who can’t handle them. I just have to laugh because she has no idea.”

Catherine also maintains that most people in her life do not know half of what it is like to
have a son with autism, even her closest friends or her own mother. She explains these
feelings below:

I mean they have an idea, but I don’t think they really get it, so I don’t pretend. There’s no way I could handle the burden of trying to pretend and act on top of it. Owen will be part of society, whatever that looks like, so we better get used to it now. If you want to know why my son is doing this or that, you can just ask. And if you care to ask and understand, you’ll know it’s not because I’m a bad parent, but it’s because my son is autistic and this is what it looks like. I don’t blame my friends for being clueless. It’s not hurtful. They don’t live our daily life. My sister is an OT, but she doesn’t have kids of her own. While she has an intellectual understanding, she does not go home with this kid or worry about his future. And my mom is extremely interested, but sometimes it’s too much to handle. I constantly tell her that I don’t know why he does what he does. Sometimes, I can’t overanalyze him or his behaviors.

In the narratives described above, numerous mothers wrestle with friends and
family members who do not understand their daily struggles. As a result, it is no wonder
that several mothers in this study expressed feeling joy and relief in something as simple
as meeting someone who understands—even just a little—what they go through on a
consistent basis. For example, in her narrative, Jessica describes the thrill of meeting and
connecting with other mothers in her same situation: “It could be another mom raising a
kid with a completely different disability, but there’s a connection there. She gets it and
that goes a long way.” Like Jessica, Rachel enjoys meeting other mothers raising a child
with a disability because of the strong connection they share with one another. She
elaborates here: “I know they [my friends] just don’t get it. That’s why it’s nice to
connect with other mommies like me. Their child’s disability may not be similar to my child’s, but we understand that mommies heart. That’s encouraging.”

**Sadness and Depression**

In addition to feeling guilt and loneliness, the mothers in this study also describe strong feelings of sadness and despair that arise from the unmet expectations of having a “perfect” baby, images of what life “should” have been like, and the constant struggles to accept their children and their disabilities. These mothers work tirelessly to battle depression and heartache, rediscover themselves, and regain joy and enthusiasm in their lives. In Tiffany’s narrative below, she insists that before her daughter’s diagnosis, she was a very positive person who enjoyed life. However, she consistently finds herself feeling overwhelmed and frustrated, and wonders what her life would be like without her daughter’s disability:

> I have always been a positive person, but I am no longer as optimistic about things. I am frustrated a lot. I am tired constantly. I never get a break. Sometimes, I wonder what things would be like if Abby were normal. Things are just not as enjoyable as they could be. If Abby did not have a disability, I would still be working. That would make things better for me because I never wanted to be a stay-at-home mother.

Like Tiffany, Cindy feels overwhelmed and sad about her family situation, and she struggles to find happiness for herself. In the excerpt below, she shares feeling as if she has lost control of her life and wonders how she can rediscover herself and her personal goals:

> I feel as if I have lost control of my life. I don’t feel like I deal with my life well. I don’t cope with Evan well. I often feel overwhelmed, discombobulated, and sad. I never thought motherhood would be 24/7. Where is the joy inside of me? I constantly feel like I am not doing enough for each child. I feel depressed and crazed, constantly seeking an escape from all of my feelings. And what about
me? For too many years, I have tried to be everything to everyone in the family and outside. My personal journey has been put on the back burner for so long. I struggle to rediscover what I want for myself. I used to plan on going back into teaching, but that has yet to happen.

Sadness also permeates Jill’s story as she describes how she struggles to cope and accept her daughter, Sarah, for who she is. Seeing pregnant women and adorable baby girls is still difficult for Jill, crushing her with painful thoughts of what Sarah could have been. While these deep feelings of sorrow are slowly abating as her daughter gets older, Jill admits that the old feelings of extreme sadness still hit her at unexpected times. For Denise, accepting her daughter’s disability also has been a difficult process, but she has recently concluded that she must practice acceptance and stop complaining about her situation. Below, she describes her challenging life and her realization that finding happiness is extremely important:

I rarely get sleep, and then I get mad and grumpy. I’d say my quality of life averages a five out of ten. It all depends on Samantha’s mood, my sleep, and my husband. The most important thing to me is being happy. Am I? The answer is no. But it’s not going to get better, so why make my life miserable and complain about not sleeping? I do not want to spend the rest of my life complaining.

Other mothers share feelings of sorrow that come from not being able to participate as a family in activities, and watching their child with disabilities miss out on friendships, adventures, parties, and play dates. Below, Mary Beth describes the heartbreak that she feels when her son, Ben, is not invited to participate in family events with his two, younger, typical siblings:

This past weekend, Rachel and Max went away to a farm with extended family. Nobody asked if Ben wanted to go. I don’t think they feel comfortable taking him for a weekend. I know he doesn’t understand and doesn’t care. But I do. I just wish he were a normal 9-year-old, who could join his siblings on all of their cool adventures.
Heartbreak is also a persistent emotion for Donna. In her narrative, she paints an idyllic picture of tranquil, summer nights, with neighborhood kids playing and running in the streets and parents chatting nearby. However, Donna’s son, Jack, is unable to participate in these types of experiences, which breaks her heart. Below, she shares how his lack of friendships is a source of intense pain and sadness for her:

There are so many things about having a child with special needs that hurt. It’s like a million little paper cuts. Each one stings but you have to keep moving on and try to forget. Jack had field day recently. There’s nothing like seeing your kid totally isolated without a single friend in front of the entire second and third grade. That sucked.

A constant source of sadness for both Tessa and Kelsey also stems from a lack of family unity and togetherness. In the excerpt below, Tessa shares her worry that as her son, Jett, gets older and falls more behind developmentally, her family will not be able to do many activities together because Jett will be unable to sit through events, such as movies or ballet performances:

Already, my husband and I split up. One of us takes the girls to a movie or ballet and the other takes Jett. Even though I would not take a typically developing 4-year-old to these events, it is so disappointing for me to think this could happen even more in the future. Sometimes, we get a sitter so we can both the girls. This is our reality. It makes me sad.

Like Tessa, Kelsey describes similar feelings of yearning for family togetherness, but is unable to achieve this unity due to her son, Dillon’s disability. In the excerpt below, she sadly describes a recent family trip to a museum that was cut short due to her son’s behavior:

A while back, we all went to a museum together. On the way, my daughter warned Dillon not to have any fits and ruin it for the family. But he did just that, so I had to bring him home. The others stayed and enjoyed the museum together. It would have been great if it had worked but it didn’t. It made me sad that we
couldn’t enjoy an outing as a normal family. I felt so defeated. I was almost mad at Dillon because he ruined the experience.

Depression and sadness are something that Cindy fights on a regular basis. She says her depression stems from thoughts of the future and what will happen to her son, Evan. Below, she expresses her fear that nobody will be able to take care of Evan, and he will not make any developmental progress as time goes on. Additionally, she reveals that her depression grows with each new year:

It is really hard to think about the future. I am not sure where Evan will be, and I’m just afraid to think what would happen if something bad happened to me or Peter. I am sure the other boys would be willing to take him, but I don’t want to change their life in that way. It is hard to wonder what will happen each year. And if Evan will make any progress. Each new year creates a little slope of depression for me. I have no control.

Anxiety

Similar to feelings of sadness and depression, some of these mothers experience extreme anxiety in their lives. They associate this anxiety with several factors, such as being out in public with their child with disabilities, constantly worrying about the safety and well-being of their child with disabilities, and the inability to come to terms with their child’s diagnosis. In Tessa’s narrative, she shares her apprehension with taking her son, Jett, out in public. Because he tends to make loud noises, Tessa feels anxious and wishes he would talk softly and follow the societal expectations of a normal child. Here, she elaborates: “Being out in public with Jett causes anxiety for me. We do not go out to eat a lot. We avoid quiet places because I am very uncomfortable with his noises. I just want him to be calm and follow social norms.”
While Tessa worries about what other people think of her son’s behavior, Marcia feels extremely anxious about her son’s safety. She experiences angst over Daniel choking, falling, or wandering away. In the excerpt below, she describes these fears and maintains the need to erase these worries from her mind:

Some days, I must put my emotions and worry as far from me as I can. On any given day, I may have anxiety about Daniel choking in the lunchroom; falling off the high slide; running and tripping; or wandering away and getting lost. If you allow yourself to have any of these thoughts, you almost have to drive to school and make sure everything is okay. I have to harden my brain and heart to those fears and emotions, or I feel crazy with worry. I need to put them far away in a separate place, so I can get on with my day.

Unlike Tessa and Marcia’s anxiety and worry, Gabrielle’s nervousness stems from an inability to come to terms with her son, David’s diagnosis. While Gabrielle’s husband insists that David is just an ordinary child with some delays, Gabrielle believes his disability is far more devastating and life altering. She cannot seem to come to terms with his diagnosis and considers herself to be an anxious and unhappy mother. In the excerpt below, she brings to light these feelings of anxiousness and describes how she focuses on her job as a means of avoidance:

I think as a person and a mother, I’m more anxious. I’m probably more unhappy. And a little more obsessive. My husband keeps telling me to relax . . . that David is just a kid with delays. Some days, I can actually live with that. Just give him tons of love, therapy, and support, and things will be fine. Other days, it feels completely life altering and debilitating. A devastating fact in my life that I can’t seem to get over or beyond. I am currently writing a book. I’m really into it. It’s quite satisfying, but I’m also aware that it is a huge escape for me. It wards off depression and anxiety, mostly about David. If I let myself think about the disability too long, I get really sad. So, I don’t. I work instead.
**A Blessing and a Gift**

In this study, mothers share powerful feelings of sadness, loneliness, guilt, depression, and anxiety. However, at the same time, numerous mothers also speak about acceptance, optimism, learning the meaning of unconditional love, and considering their child to be a blessing and a gift. While they would not wish disability on anyone, they maintain they would never give up what they have learned and the ways they have grown as women and mothers. In the excerpt below, Tessa explains that, while she would not have chosen this complex life for her son, Jett, and would remove his disability if she could, she must consider her loving son to be a gift:

> I believe Jett’s life has value. Even if he stays a 2-year-old cognitively for the rest of his life. He adds so much love and laughter to our lives. I would never choose this life for him. I would change this in a second. But—for self-preservation—I must see the positives in his disability. I must see him as a gift.

Reminiscent of Tessa’s narrative, Cindy believes that motherhood has involved so much more heartache than she ever expected, but she still finds her life rewarding. Here, she explains these feelings: “While raising Evan can be a struggle, it has also been a gift to me personally. He certainly changed my perspective on life. This has forced me to slow down and experience life.” In Ellen’s narrative, she shares the same positive sentiment regarding her child: “I just feel blessed to have Henry. He has grown into an amazing boy and has touched my life in an indescribable way. He is my bright star.”

While Rebecca acknowledges that her son’s diagnosis of Prader-Willi syndrome will never go away, she tries to be positive and enjoy her life. In the excerpt below, she explains how she attempts to get pleasure out of life and look at things in an optimistic way:
Colin is going to be a lifelong responsibility in ways that typical children are not. But life can still be really great, even though you have these hard things happening. I feel more optimistic today. Colin is a wonderful person, and having a child with special needs is not all bad. He has great joys in his life, and he brings us immense pleasure. I couldn’t have necessarily said that when I first got the diagnosis, but now I know it’s true. And I feel like if I can handle this, I can pretty much handle anything. Life with Colin is hard, but much of it is quite joyful and wonderful. We’re all healthy. I know Colin is not dying of his illness. I try to get as much pleasure out of life as possible. One thing I’ve learned from all of this is that life is short. Bad things can happen at any time. You need to see as many friends as possible and take as many opportunities for joy as you can.

Optimism is something that Anita focuses on as well. A frequent visitor to Children’s Hospital with her son, she constantly looks around the hospital at the other kids and genuinely considers herself lucky. Here, she describes feeling blessed that her son, Daniel, is not suffering from a terminal illness like many others kids at Children’s Hospital:

Even though we deal with a lot, there are others who are worse. Daniel is not on oxygen, and we don’t have a terminal diagnosis. Daniel is holding his own. When Daniel goes in for surgery, he will be out of the hospital in three days. Some kids are dealing with cancer and will never get to leave.

Like the others mothers described in this sub-section, Shelley believes that her daughter, Caroline, is a gift. She has faith that Caroline is on this earth to teach us all what it means to be human. In addition, she asserts that while her daughter’s life is very different, it is still quite meaningful and worthwhile, and she tries to experience it as a gift rather than a burden. Below, Shelley elaborates on how her daughter has significantly changed her life for the better. She insists that Caroline has taught her a great deal about life and made her a better person:

Having a child with disabilities definitely rocks your world, but it shouldn’t be the hub that everything feeds off of. Caroline is my gift; she’s taught me so much. But it’s important not to let the disability control you. It should not define your
life or what you enjoy. There’s a nakedness and authenticity to her experience. This has changed me. The repertoire of who I am has been expanded. I am a better mom, teacher, and wife.

**Conflicting Emotions**

This last sub-section centers on these mothers’ vacillating emotions. As seen throughout this section on motherhood, many mothers commonly experience emotional ambivalence with uncontrollable waves of sadness and happiness. At times, they are enormously proud of their children with disabilities, while at other times, they are embarrassed and despondent. Their emotions run the gamut from guilt, loneliness, and anxiety, to acceptance, optimism, and unconditional love. Understanding these contradictory feelings can be confusing and challenging for the mothers in this study as they navigate the causes for their emotional inconsistencies.

For example, Jill acknowledges her continually vacillating emotions and struggles to come to terms with them. At times, she loves her daughter, Sarah, more than life itself and feels enormously proud of Sarah’s accomplishments. Other times, she is embarrassed by her and wishes she had never been born. While her narrative reflects extreme feelings of conflict, Jill insists that she prays for strength and courage, not for escapes. She strives to enjoy the present moments with her daughter instead of worrying about the future. When Gabrielle considers her conflicting emotions regarding her son, she admits she frequently has good and bad days. There are days when she accepts her son and his disability, and other days when her life feels hopeless and dark. Below, she describes being fraught over her emotional ambivalence and questioning why her feelings vacillate on a daily basis:
Some days are good when I think David is going to be okay. He may never go to college, he may never even finish high school, and he may never be able to live on his own. And even so, it’s all okay. Then there are other days when all of this just feels like the tip of the big, toppling iceberg. Where it’s dark and depressing and vaguely hopeless. Where I’m really resentful and sad and angry. I am angry at David; at my doctors who told me my babies in utero were fine; at my husband; at everyone I see with typical kids; and at my stinking bad luck. I can’t always account for why I feel a certain way.

Experiencing conflicting emotions are difficult for both Anita and Mary Beth. Anita explains that her reactions to her son’s disability are completely based on how she is feeling on a particular day. She explains here: “Depending on how strong I am that day, it can hit me, bounce off me, and I can be fine. Or it could hit me and burrow deep inside. And then I could be a mess for the entire day.” In the following excerpt, Mary Beth describes becoming depressed at random periods, but typically overcoming her depression by the following day: “I get down at times, it’s not even predictable. It can be one little thing that makes me feel sad or down. But the next day, I’m usually over it.”

In an attempt to understand and cope with her vacillating emotions, Madeline shares her experience visiting a genetic counselor. She recounts that some of the most helpful advice she received from this counselor was being told that she would never “get over” her daughter’s disability. In the following excerpt, Madeline describes the useful guidance she received: “She [my counselor] said I wouldn’t get over it tomorrow or the next day or in a year or two. Rather, it will come up at different times throughout my life. And it’s so very true.” This same concept of grief as a cycle was also an important part of Tracey’s healing process and her understanding of her emotions. In her narrative below, she admits to being obsessed with her loss until she learned to perceive grief as a process:
I’d cry for hours because my kids’ lives were not what I wanted them to be. This was not the life I wanted for them. I remember cleaning closets all day because it was the only way I could feel in control of my life. I had some great-looking closets. But I learned that grief was a cycle and it would hit at different times. In order to function, I couldn’t let myself cry all day. I could not let it take over my life. Today, I bounce back faster. I have more experience and more hope. I know setbacks are just temporary. I do not let myself feel depressed for more than one day.

Similar to Tracey and Madeline, Barbara explains her conflicting emotions regarding raising a child with special needs as a never-ending grief process. In her narrative, she compares her life to living on the seven stages of grief Ferris wheel “where you never ever leave; rather, you just cycle through it over and over again.” She believes that while living with a disability definitely changes in certain ways over time, things do not actually get any better.

**Summary**

This section elaborates on the ways in which mothers experience motherhood. They share their personal images of motherhood and compare these images to their actual reality. These notions are further influenced by the examples set forth by their own mothers who serve as their role models. The mothers in this study go on to describe experiencing a number of different emotions, such as guilt, loneliness, social isolation, sadness, depression, and anxiety, specifically related to mothering a child with and without disabilities. While these powerful feelings are described by some mothers, others shared strong sentiments of acceptance, optimism, unconditional love, and deeming their child to be a blessing and a gift. These vacillating emotions were difficult for some women who tried to make sense of their uncontrollable waves of sadness and happiness, and strived to come to terms with their confusing and inconsistent feelings.
In the following section, mothers take their singular mothering experience and attempt to blend it with the experience of their spouses and the bond of marriage. This section on marriage and divorce sheds light on how these mothers view their marriages, co-parent, seek support from their spouses, foster teamwork, balance responsibility, and navigate the intense stress of childhood disability on a marriage.

**Still Married and Recently Divorced**

The participants in this study are made up of 29 married mothers, two divorced mothers, and one single mother. This section explores how these women navigate the impact of disability on their relationships. The section is divided into five sub-sections. The first sub-section describes how some of these mothers feel lucky to be married and strongly believe their child’s disability strengthens their marriage and contributes to feelings of teamwork and friendship with their spouses. The second sub-section deals with the topic of divorce. While some mothers insist that the disability has taken a toll on their marriage and has added a layer of stress to everything in their lives, these mothers are adamant that divorce is just not an option for their families. As a result, they share their consistent efforts to reconnect and remain together as a couple. The next sub-section, unfair balance of responsibility, describes how some of the mothers feel the responsibility of childcare disproportionately falls on their shoulders, which puts added pressure on their marriages. Struggling to connect is the next sub-section. Here, mothers explain feeling extremely disconnected to their spouses. They attribute these feelings to a disparity in the way each spouse views and copes with the disability, constant conflict between partners, and a lack of energy for each other. In the last sub-section, the reality
of divorce is discussed by the two mothers in this study who are divorced. While one mother insists that she works hard not to blame her divorce on her daughter’s disability, the other mother openly admits that her son’s disability ultimately led to the demise of her 17-year relationship.

**Making it Work**

Of the 32 participants, 29 were married to the father of their children. In discussing their marriages, some of these mothers feel lucky to be married to their spouses and strongly believe their child’s disability strengthens their marriage and contributes to feelings of teamwork and friendship with their spouses. They describe leaning on each other and giving support to one another when life becomes stressful and unmanageable. Enduring difficult times and coming together as a team are very important to these mothers. For example, Gabrielle portrays her marriage as very strong and is aware that, without such a solid marriage, she and her husband “would be in trouble.” Tracey also insists that her son’s disability has been good for her marriage, bringing her and her husband closer. She explains: “We are in this together and must take care of each other. Stick together or you will fail. We try to nurture each other and make it grow, not just work.”

Like Gabrielle and Tracey, Shelley considers her marriage to be strong and solid. Here, she compares her 15-year marriage to a winding road: “While it has been a road with many twists and turns, we never have to worry about the other one veering off. Our confidence in each other is huge.” She asserts that she and her husband are more patient with each other’s weaknesses because of their daughter, Caroline, and are much gentler
with each other and with other people than they were 15 years earlier. In the excerpt below, Shelley emphasizes that Caroline’s disability has helped her marriage by forcing her and her husband, Jay, to focus on what’s important in life:

I wouldn’t wish this on anybody, but I think the diagnosis forced us to have a certain focus and intentionality about what we need our life to look like. Every marriage could use something that really makes people focus on what’s important. We have been forced to figure out our top priority. And forced to do it in a context where we really had to think clearly about it. Our reality would not have allowed our priority to be our golf game.

Gail also considers her son’s disability to have sharpened her focus and her husband’s focus on what is important in life, what is real, and what is necessary. Here, Gail describes how the couple works hard to consistently connect with each other: “We don’t have a lot of time to talk with each other, which is a disadvantage, but we try hard to make time for that. We carve out time for dates as much as possible, usually every two weeks. They are snatches of time.” In Sharon’s narrative, she insists that she has a great marriage because she and her husband make a strong team. Below, she explains how they constantly work on their marriage by making time to be together and enjoy each other’s company as much as possible:

Greg loves to do research, as well as all kinds of stuff with the kids. And we love to go to the inclusion conference together. We stay overnight in a hotel and it’s like our date night. I know for some people, it can be extremely hard, but just having kids in general is hard. We constantly work on our marriage. We go on a date once a week, take at least one trip, and have weekends away.

For Susan, communication and friendship are keys to her strong marriage. While things are not perfect, she maintains that being able to communicate about their son, Henry, has tremendously improved their bond. They work together to resolve issues and remain supportive of one another. While Jill also insists that her marriage is actually
stronger because of her daughter, Sarah’s disability, she openly admits to experiencing deep sorrow in her marriage. Below, she describes the friendship she shares with her husband, as well as the sadness she encounters in their relationship:

In the long run, the disability has brought us closer. I strongly believe that our friendship got us through Sarah’s diagnosis. We have a bond because of the caretaking and advocacy for our daughter and her needs. We are stronger because of Sarah, but there’s a certain sadness in our relationship that I don’t think will ever go away. It is hard for me to look at our wedding pictures or pictures from happy times before Sarah. It’s like we had so much potential for a great life and look what happened.

Madeline firmly believes the effect of disability on a marriage depends on the person who you ultimately marry. She explains that when you marry a person and plan on having kids together, you have no idea how that person will handle having a child with a disability. Madeline goes on to describes meeting another mother also raising a child with Osteogenesis imperfecta, who disclosed that when her son was diagnosed with OI, her husband could not cope with the disability and left the family. In the excerpt below, Madeline reflects on this story and describes herself as being very fortunate to have a supportive, loving husband in her life:

I think if your marriage is going to survive the disability, you need to be with a person who not only loves you, but believes in marriage enough to work through the difficult times. I consider myself very lucky to have Kent. What a happy surprise. It was something that I did not know I would need in a husband, but it is very, very important.

**Divorce is Not an Option**

While some of the mothers feel their child’s disability has strengthened their marriage and increased feelings of mutual support and togetherness, others believe the disability has taken a toll on their marriage and added a layer of stress to everything in
their lives. However, these mothers are adamant that divorce is just not a choice. They assert that raising a child with disabilities is hard enough with two parents and would be impossible as a single parent. As a result, they speak about working tirelessly to reconnect as couples, and about “sticking it out” through the extremely tough times. For example, Mary Beth asserts that her son’s disability has been both good and bad for her marriage. Although enduring a major struggle together has brought them closer, she says working through the long grieving process has been very difficult. In the excerpt below, she insists divorce is not an option for her family and questions what actually destroys a marriage:

I think for better or for worse, we know we could never divorce. Life would never work that way. I often wonder what destroys these marriages. Is it lack of agreement on how to treat the child? Feelings of inequality in the responsibility of raising the child? It seems that mothers do 95 percent of the parenting of these kids. I see it in my own family.

Like Mary Beth, Donna believes that divorce is not the answer to her problems because raising her son with disabilities alone would be too difficult. In the narrative below, she openly acknowledges this fact, while at the same time, describing the difficulty in staying connected, enjoying fun activities, and spending time together as a couple:

We are both very solid in the sense that no matter what happens, we will not divorce. Knock on wood! This is not something we feel we could do alone. We just couldn’t do it. There’s already enough crap in our lives. We could not add to it. But it is definitely harder. We don’t do all of the fun stuff we used to do. We have a boat, but it has been in storage for six years. We used to ski, rollerblade, hike, bike, and mountain backpack. Life is much more limiting now. We do not have a lot of time together because we work and then do kid stuff. It is really hard to keep connected and loving toward each other. There is so much guilt and pain. Some days, I don’t know how it doesn’t crush us or our marriage. Guilt
stemming from thoughts about how easy and mindless life could be if we weren’t in this situation. Pain about all of the little things.

Divorce is never far from Sandra’s mind. When her son was very young, she and her husband discussed how the stress from their son’s disability could tear them apart if they weren’t careful. They were very conscious of the fact that his disability could be a “deal breaker” for their marriage. In the excerpt below, Sandra insists that raising a child with disabilities seems hard when you have two parents and almost impossible when you have only one. As a result, she describes her quest for consistent communication with her husband:

The stress could end up splitting us up if we aren’t careful. And Bill’s job is stressful and has a high rate of divorce anyway. So we have really tried to communicate constantly. We know that Nate will be with us forever and there’s already a high rate of divorce with disabled kids. We talk it out. This communication is extremely important. If I am angry all of the time or he’s angry, pretty soon the marriage will fail. And do you think it is going to be any easier when you are by yourself? It seems hard when you have two parents and almost impossible when you have only one.

For Kate, divorce is not an option because she insists the parent who leaves the marriage must take responsibility for the kids. With two, twin teenage boys with disabilities, nobody has yet to leave the marriage. When Kate considers what makes a successful marriage, she maintains having a strong sense of self is imperative. Below, she explains how marriages can crumble due to a lack of time together, anger, and daily stress:

My mother has always said it takes two people to enter into a marriage and each must give 80 percent. And so you have to have a sense of self to bring to the marriage. And there’s no time, which is probably the hardest thing on the marriage. Lack of time together makes things even harder. The wear and tear is so destructive. There’s also a lot of anger on my part. Over the years, there have been many hurtful words said back and forth that neither Greg nor I is proud of. I
always figured this was okay because he wasn’t going to walk out on me and eventually would forgive me. We might have gotten divorced, but I have always insisted that the person who walks out, gets the kids. So, we are still together.

Unfair Balance of Responsibility

Some of the mothers in this study feel that the responsibility of childcare disproportionately falls on them, which adds to the stress in their lives. For example, Sandra explains that her husband actually believes her job is taking care of their son, Nate, while her husband is only “back-up.” Sandra insists that her husband’s back-up role needs to be a lot stronger. Donna shares similar frustrations because all of her son’s therapies, schooling, research, networking, and goals fall on her shoulders. She explains that her husband “has never cracked a book on cerebral palsy, low vision, or special education. All work and no play definitely make for some grumpy marital moments.” In the excerpt below, Kate expresses a dire need for more help with primary care. She explains that her husband considers his sole job to pay the bills and put food on the table. As a result, Kate is left feeling completely responsible for caring for their twin sons. Here, she elaborates on her feelings of frustration: “Greg didn’t learn how to G-tube the twins until they were 6 years old. For 4 years, 12 times a day, he was deliberately stupid, leaving it all to me.”

Like the mothers above, Barbara maintains that her son’s disability has exposed the couple’s “absolutely unfair” allocation of responsibility. Here, she describes the unfair balance of responsibility in her home and admits that this imbalance can certainly lead to divorce:

It’s the principle of physics: There’s a void and I am filling it. But if I didn’t do it, my husband still wouldn’t do it. I believe that if I am not on top of things, they
will not get done well enough, if at all. And I just can’t allow this to happen. My husband has definitely easily accepted this. He is not involved on any level with any of Tyler’s therapies. Or setting up activities for Sam. These jobs are all mine. I am basically raising these children on my own. I have read that there is a higher divorce rate in special families, and I can see why.

**Struggling to Connect**

Mothers describe feeling extremely disconnected to their spouses. They attribute these feelings to a disparity in the way each spouse views and copes with the disability, constant conflict between partners, and a lack of energy for each other. For example, despite feeling that she has an incredibly strong marriage, Gabrielle admits that at times, it can be difficult to discuss her son’s disability with her husband because sharing her feelings with him seems to make his burden even heavier. As a result, she tends to turn to others for support. In her narrative below, she sheds light on these difficulties:

The biggest thing with my son, David, is that at times, I can get really depressed about him. And I don’t always feel like I can talk to my husband about how upset I am. It’s not that he won’t understand. It’s more that it is not very functional for our family to have us both in a state of despondency. It’s not productive for me to talk to him. It just feels too burdensome. He’s also exhausted by work and parenting. I think he feels that when we have free time, we should be spending it in a positive way. We still have deep conversations, but the depressive aspect of it makes him feel like he needs to take care of me, in addition to the kids. It’s hard on him emotionally, too, so when I feel depressed in relation to David, I have learned to turn to friends and family.

For Catherine, marital stress also stems from differences in the couple’s approaches and views of their son’s disability. In her narrative below, she claims her husband has a difficult time understanding their son and his autism, which causes friction and tension for the couple:

I honestly think my husband has a harder time having a son with autism. Not for the macho reasons or anything like that, but I don’t think my husband really enjoys Owen that much. I think it’s hard for him to know how to “be” with his
son. And it’s hard for me to see that. Also, there is a huge amount of stress regarding juggling Owen. Who is going to do what and how much time is it going to take? Never mind that you have two other children. It’s just a lot of extra stress in that sense. My husband has a harder time understanding Owen’s behavior. Disciplining an autistic kid is a lot different than disciplining a typical kid. It is frequently a sore point between us.

Constant conflict and anxiety are also the cause of Denise’s troubled marriage. She says there have been only 4 good years in their 15-year-marriage. According to Denise’s narrative below, she has nothing left to give to her marriage because they disagree on most aspects of their daughter’s care. Additionally, her husband harbors a great deal of guilt, jealousy, and insecurity. As a result, divorce looms as an ever-present possibility for the couple:

We are struggling to keep our heads above water. Every single day, it shows its ugly head. My husband believes that working toward Samantha’s independence is ridiculous. He feels everyone should just do everything for her. We completely disagree. And there has been no sex for a long time. If you combine 11 years of sleep deprivation with stress, you have nothing left. I walk around like a sleep-deprived zombie, and sex is on the bottom of my to-do list. There’s nothing to give. I think most of our problems stem from Samantha. Jim seems to have a lot of guilt because even though it wasn’t his fault, he thinks it somehow was. Jim is also jealous and insecure about how involved and outspoken I am in the TS Alliance. I organize a walk, a conference, and do lots of activities. He sits back and watches television. Sometimes, I think that the only thing that connects us is Samantha. We rarely go out alone because he doesn’t trust anyone to take care of Samantha. He thinks I should be the only one who takes care of her. And he thinks it is silly that we need alone time.

A lack of energy also negatively affects Kelsey’s marriage. Below, she explains that taking care of her son, Dillon, consumes all of her energy, with little left over for her marriage. While this worn-out and frazzled mother is quite aware of the necessity of spending time alone with her husband, he unfortunately ends up at the “bottom of her list” after the rest of her family:
We have seen a marriage counselor. He once commented that Larry and I don’t communicate about mundane marriage issues that cause conflict. This is because our threshold is so high. And when Dillon is doing well, we don’t want to rock the boat and upset one another with “normal” problems. Until the next Dillon crisis, and then all of our issues leak. I just feel so sapped. I am constantly exhausted and stressed. My husband ends up at the bottom of the list.

The Reality of Divorce

Two of the mothers in this study are divorced, both for less than 5 years. When Brenda and Ellen discuss their ex-husbands and their divorces, both say they regret the divorce but feel they had no other choice. Brenda’s narrative reflects feelings of sadness and regret about her divorce. She admits that, in some ways, her life would be much easier if she were still married and living with her husband. At the same time, she candidly describes being in “survival mode for way too long,” where each partner had no idea how to communicate and nurture the other. She explains: “Our divorce is my one regret, but we couldn’t continue living like we were. It wasn’t fair to us—or to the girls.”

In the excerpt below, Brenda insists that she tries hard not to blame her divorce on her daughter’s disability:

Sure, Bridget’s numerous medical and sleep problems were stressful and put a strain on our marriage. They definitely contributed to the divorce, but they were not the one and only cause. Would we have divorced if we did not have Bridget and her disability? I don’t know. Who knows?

Unlike Brenda, Ellen openly admits that her son, Henry’s disability put pressure on her marriage, which ultimately led to its demise. She maintains that while she wishes she had not given up on her 17-year relationship, she knows things were not improving for the couple. Here, she elaborates: “Instead of coming together as a family, the strain of Henry’s disability seemed to tear us apart. I’m not sure I would have ever left had this
disability not happened to our family.” However, Ellen maintains that she and her ex-husband are still close and remain supportive of each other and their children. Below, she describes working hard to come together as a team to make their two kids a priority:

We were able to grow up and come together on a different level and in a healthier way. We now have a more hopeful perspective on life. While it is hard at times to be on the same page, we both make our kids a priority. I feel that it has been essential to maintain a good relationship with my ex-husband and continue to work on our communication. It so important that he is part of our children’s lives, but especially for Henry.

**Summary**

This section on marriage and divorce contains a distinct variation in experiences. Some mothers describe feeling lucky to be married to their spouses and strongly believe their child’s disability has strengthened their marriage and increased feelings of mutual support and togetherness. At the same time, other mothers feel their child’s disability has taken a toll on their marriage and added a layer of stress to everything in their lives. However, these mothers are very adamant that divorce is just not an option for their families. They assert that raising a child with disabilities is hard enough with two parents and would be impossible as a single parent. As a result, they speak about working tirelessly to reconnect as couples, and about “sticking it out” through the extremely tough times. Mothers also express frustration in being the sole caregiver and describe how the responsibility of childcare disproportionately falls on their shoulders, while other mothers speak about feeling extremely disconnected to their spouses. They attribute these feelings to a disparity in the way each spouse views and copes with the disability, constant conflict between partners, and a lack of energy for each other. The final focus of this section highlights the reality of divorce. Here, the two divorced mothers in this study
shed light on what contributed to their particular divorces and how they navigate the effects of divorce on their families.

In the following section, we move from these mother’s thoughts and experiences concerning marriage and divorce to ideas regarding family life. Here, mothers open up about how their child’s disability affects their family life, specifically their relationship with their typical and nontypical children.

**Encountering Family Life**

In this section, mothers share how their child’s disability affects the entire family dynamic, which includes their typically developing children, as well as their children with disabilities. This section is divided into eight sub-sections.

Birth order is the first sub-section, which describes these mothers’ thoughts and opinions on the particular birth order of their child with disabilities and how this birth order affects the entire family. While some mothers emphasize the positives in raising a youngest child with disabilities, others insist that having a first-born child with disabilities is actually easier on their lives. The second sub-section deals with mothers who feel cheated by their child’s disability, resent their situation, and wish their family life could be different. The third sub-section, a balancing act, focuses on the mothers who struggle to find balance in their lives. These mothers work tirelessly to split their attention and energies evenly among all of their children and carve out alone time with their typical children to better meet their needs. Appreciating the typical world is the next sub-section, which depicts these women’s feelings of happiness and joy in being able to raise children who are typically developing. They feel lucky to have normal
family experiences and put great importance on feeling close to their typically developing children. The fifth sub-section, which deals with the creation of a normal childhood, comes next. Here, mothers describe the need to establish and maintain a normal childhood for their typical children so these children can develop into strong, self-sufficient, and compassionate individuals. Worrying about typical siblings is the next sub-section, which portrays how these mothers worry incessantly about their typically developing children. They fear that their typical children experience resentment and frustration, feel shortchanged and forgotten, and believe they must be overachievers and perfectionists. The next sub-section deals with some of the mothers’ fears and heartbreak regarding the social exclusion of their child with disabilities. These mothers describe their sorrow in watching the social isolation of their children as they struggle to be accepted into society. Teaching responsibility and acceptance is the last sub-section. Here, mothers share the importance of teaching responsibility, resilience, and acceptance to all of their children. They also discuss the ways in which they encourage their typical children to speak openly about their fears, frustrations, and disappointments, while at the same time, teaching them about compassion, understanding, and patience.

**Birth Order**

When the mothers in this study reflect on their family life, some use birth order as a starting point. While a number of mothers express happiness and relief with the birth order of their child with disabilities, others wish their child had been born in a different order. For example, when the child with disabilities was the youngest child, a majority of the mothers were thankful for this. Reasons stemmed from the difficulty in watching
younger typical children developmentally eclipse their sibling with disabilities, having older typical siblings to model, and possessing more time to care for a youngest child with disabilities.

In her narrative, Shelley shares her happiness that her daughter with special needs is her youngest child because she will never have to watch her older child be surpassed developmentally by a younger sibling. In the following excerpt, she describes that having an older son who is typically developing means her younger daughter with disabilities will never eclipse her son: “It would be so hard to have younger kids who would eventually pass their sibling developmentally. You would have that constant comparison thrown in your face.” While Shelley does not have to endure this type of pain in her life, Denise does have an older child with disabilities and attests to the immense difficulty. In her narrative, she insists that watching Hannah, her younger, typical child, pass her older daughter with disabilities, has been heartbreaking for her: “I can still see the day when that happened. We were getting in the bath, and I asked Hannah not to do something. She did it anyway. That day is forever in my memory.” In Gabrielle’s narrative, she describes how her youngest child (Brody) is typical and has not yet eclipsed his older brother (David) with special needs; however, Gabrielle is bracing herself for this day. She insists that her family life would be less problematic and complicated if David were actually the youngest of her three children, so she would not have to endure the pain of watching Brody surpass David developmentally. Here, she explains this pain: “At this point, Ben is still behind David in development, but there will come a point where he will surpass him, and it will be very difficult. There’s something
painful in seeing a kid who is older than his sibling but less capable of doing the same things.”

Having older typical siblings to model is very important to Marcia, who asserts that her son with disabilities (Daniel) has gained a great deal by having older siblings to model. She elaborates this point in her narrative: “Daniel has benefited so much from having older siblings. Even though they are a lot older, they have always been his role models, showing him how and when and where. It was definitely easier for me to have older typical siblings.”

While some mothers emphasize the difficulty in watching younger typical children developmentally eclipse their sibling with disabilities and feeling happy to have older typical siblings to model, other mothers are thankful to have a younger child with disabilities because this affords them the time to care for their child with disabilities. In the narrative below, Gail reveals being happy that her youngest child is the child born with disabilities because this allowed her the time to care for him, while her older children were in school. Furthermore, she is pleased that her older children can spend time with her son and learn about difference:

It’s good that Wyatt was the youngest. Because he was the baby, I felt like I could invest the time I needed in his care and therapy. If he had been the oldest, I would have struggled to care for him, as well as an infant. Having the older ones in school freed me to concentrate on Wyatt. I think it’s good for Wyatt to have older siblings because he loves them and gets to spend time with them. He is part of their normal world, their baseball and soccer games, recitals, concerts, and church activities. But it is also good for the older kids to see him and understand that not everybody is the same. They need to learn compassion for others who are different.
Like Gail, Barbara shares feelings of pleasure that her youngest child ended up being the child with disabilities so that she was able to focus on his specific needs. With an older, independent child, Barbara was able to successfully meet the needs of both of her sons, which she describes below:

I am glad that I had Sam, my typical son, first. It has made it easier for me to meet both boys’ needs. Sam was 2 when Tyler was born. He was walking and talking, and telling us everything he needed. It was easier to tend to Tyler’s colicky needs when my older child could be more independent.

Some mothers in the study insist that if their child with disabilities had been the oldest, instead of the youngest, they may have decided not to have any more kids due to their negative experiences. Here, Gail explains her fear and panic in possibly giving birth to another child with disabilities after already having one child with disabilities: “I can’t imagine the bravery it takes to go and have another baby. You know so much about everything that could go wrong.” Brenda claims that if her youngest daughter with disabilities had actually been her first child, she would not have had a second child due to the intense time and work involved in raising her daughter with disabilities: “If Bridget had been the oldest, I don’t think I could have had another child. She was just too difficult. It was overwhelming. The horrible reflux, the failure to thrive, and the respiratory problems.” For Sandra, the mother of a 16-year-old typical daughter and an 11-year-old nontypical son, having more kids after her son’s birth would have been good for her family. In her narrative below, she wishes she could have given her daughter a typical sibling; however, life was way too intense after her son, Nate’s birth: “We look back now and say that we should have had one more. I do think it would have been great for all of us, but I do not know if we could have handled it because Nate was so fragile.”
Several mothers whose first-born children have disabilities describe longing for a different birth order. These mothers believe their lives would be much less complicated if their child with disabilities were the youngest, rather than the oldest. They cite never being able to experience a normal family life and being overly aware of what can go wrong during development or childbirth as reasons for wishing for a different birth order. For example, Denise believes her life would have been easier if the birth order of her two daughters was reversed and her youngest (Hannah) had disabilities instead of her oldest child (Samantha). This way, her family would have been able to experience a normal existence before experiencing her daughter’s life-altering disability. She elaborates on this experience: “It would have been easier if Hannah had been the oldest. We would have had a normal life where we were not afraid to go out and do things. I think we would have just continued in the same direction if Samantha had been born second.” Reflecting on the birth order of her two children, Jill believes that she, too, would have been able to enjoy the early years of her youngest son, Toby, if he had born before, rather than after, her daughter with disabilities. Here, she insists that knowing too much about childhood development and what can go wrong made her life overly difficult: “Before Toby, I didn’t really know what typical development looked like. I would have enjoyed him more if he were the oldest. But I knew too much about childhood development and all the things that can go wrong.”

While a majority of the mothers in this study maintain it is favorable for the younger child to have disabilities, instead of the oldest, several mothers disagree with this point. Some express feeling incredibly grateful that their child with disabilities is
actually the oldest. Reasons ranged from knowing no other way of life and having no idea what a normal life is actually supposed to look like, and being able to appreciate every aspect of their typical child’s development. Here, Jill insists that she is grateful to have an oldest child with a disability because her daughter’s disability makes her value nearly every interaction with her younger, typical son, Toby, and take nothing for granted:

I think that some parents who have only typical kids take their relationships with them for granted. Toby and I have wonderful conversations, and I cherish that time with him. I don’t think I would appreciate these the same way if not for my experiences with Sarah. The other day, I was strapping him into his car seat. I gave him a kiss on the forehead and he said, “Mommy, thank you for taking care of me.” I was blown away.

When Anita considers the birth order of her two sons, she is glad that her typical child, Seth, is the youngest because he was born into a family with an existing disability and knows no other way of life. She elaborates in her narrative: “Seth has always had a brother in a wheelchair; he’s always had a brother with a set schedule. I think it would be harder on Seth if he were the oldest, and we had to stop doing things because of Daniel.” In Maureen’s narrative below, she shares her happiness that her son with disabilities is the oldest child because her younger daughter has never known a life without disability, which has made their lives considerably easier: “I’m glad Joseph came first. If not, Nicole’s world would have been totally rocked. She would have taken on the role of spoiled little kid.”

**Feeling Cheated**

In the previous sub-section, some mothers spoke about feeling grateful for their child’s birth order, while other mothers described wishing their child with disabilities had
been born in a different order. Despite the particular birth order of their children, some mothers in this study regard their lives as difficult and heartbreaking. When they reflect on raising typical and nontypical children, these mothers speak of feeling cheated, resenting their child’s disability, and wishing family life could be different. For example, in the narrative below, Gabrielle expresses feeling cheated by her son’s disability and constantly worrying about how his disability negatively affects her relationship with her other two sons, Charlie and Ben. She fears the disability compromises her ability to parent her other sons:

I worry that I’m a more anxious and depressed mother than I would be without David. And that has an impact on parenting my other kids. That doesn’t feel like a good thing. And I feel cheated on some level. I also feel like my other kids get cheated. Mothering typical kids is hard, but the disability adds an extra layer of frustration and sadness.

Like Gabrielle, Denise struggles with feelings of frustration and concern over missing out on mothering her typical child. Describing a recent Mother’s Day in her narrative below, she expresses intense sadness about the holiday, which celebrates motherhood: “I felt very upset thinking about all of the other moms out there having such a wonderful Mother’s Day. I was wishing it was me. We wanted to go out to dinner, but it is just too hard with Samantha.” She adds that while she tries not to react to these missed events with anger or sadness, life would be so much easier if her family did not have to live with Samantha’s disease. Below, Denise goes on to explain how she has always dreamed of having two girls. In fact, that’s all she ever wanted. However, raising her two girls is nothing like what she had hoped and dreamed because she feels as if she misses out on mothering her typical daughter, Hannah:
I spend so much time being an advocate for Samantha and managing all of her behavioral and health issues, I feel like I neglect Hannah. We don’t do the things that I had dreamed about doing together. We never play with dolls. Maybe it’s because I am so exhausted all of the time. I feel like I am missing out on so much with her. I don’t spend a lot of quality time with her. I get upset and angry quickly. It is a very hard balance. This summer when Samantha was home, Hannah told me that she misses our time together.

With sorrow and regret, Bonnie describes feeling cheated because her typical teenage daughter, Addie, constantly avoids being at home due to the frustrating behaviors of her younger brother, Joshua, diagnosed with autism. In her narrative below, Bonnie says she has been forced to adjust to this kind of separate life where her daughter avoids being near her younger son:

Addie avoids Joshua as much as possible. She has never wanted to invite her friends over to our house because of Joshua. Even today, when she’s home from college, she prefers spending time at her friends’ houses instead of here, where Joshua is. For her, it is easier to avoid him than get into their fighting matches. It makes me upset that Addie would be home more if Joshua didn’t have autism. She explains that Joshua is just too challenging to be around at times. We almost never do things as a family. I have come to terms with the fact that it’s not doable.

A Balancing Act

In addition to feeling cheated by their child’s disability, some mothers experience difficulty in managing their stressful lives. They describe their lives as one enormous balancing act. For example, in her story, Mary Beth describes her struggle to create balance in her life. While her two youngest kids are extremely verbal and demanding of attention, her nontypical son, Ben, also requires a great deal of assistance doing almost everything. She feels very guilty about not being able to split her attention and energies more evenly among all three kids. Here, Mary Beth describes the difficulty in achieving
a more equitable balance between two typically developing kids and one with special needs:

The two typical ones are so demanding. And I work full time. How do I get it all done? While I only let the younger ones be in one activity, Ben is in a million activities to keep him stimulated and growing. How can I be fair? It’s not fair that Ben was born with a disability. How do I help them understand that? I can hardly understand it.

Similar to Mary Beth, Donna labors to successfully balance the care of her son with special needs with the care of her typical daughter. In the excerpt below, she admits that when she is having fun with her daughter, Emma, she constantly feels guilty that her son, Jack, is unable to share in the fun. And when Jack is home, she feels as if she is ignoring Emma:

I’m exhausted when I get home, but I want and need to play with the kids. Inevitably, I end up helping Jack and focusing on him. I feel so bad because it’s not fair to Emma to be penalized because she’s able bodied and independent. At times, Jack becomes all consuming. I realize that I haven’t seen Emma in a while. I feel like I miss large gaps of her life and that life has flown by so quickly already. Jack does get a lot of attention.

Kelsey and Ellen also feel the burden of trying to balance the worlds of their children. In her narrative, Ellen says her son with disabilities has always demanded more attention than her daughter, which makes it challenging for her to give both children equal focus: “I try to give both kids the attention they need. I am realizing that Julia’s needs are just as important. I need to find time to be with her and make her feel as important as her brother.” Kelsey agrees and insists that since the birth of her son with disabilities, it has been quite difficult to balance the needs of both children because there is only so much time in the day for everybody. She explains that for the first 7 years of her son’s life, about 95 percent of her time was focused on Dillon and his health issues.
As a way to cope with the difficulties of balancing the needs of each child, some of the mothers believe it is beneficial and necessary to carve out alone time with their typical children. This special time helps these mothers ensure they are meeting the needs of their typical children and staying connected with them. For example, in Sandra’s narrative, she explains the importance of setting aside alone time exclusively for her typical daughter, Audrey: “When Audrey comes home from school, I try to spend time with her. Listening to her, hearing about her day, asking what’s going on, and staying connected.” Tiffany also describes carving out alone time for her typical daughter, Rebecca. Here, she shares chaperoning her typical daughter’s class trip to the circus and explains her decision not to take Abby, her younger daughter with disabilities: “Abby didn’t have school, but I opted not to take her. I feel so guilty leaving her out, but I also think it is important to have special time with Rebecca. I need to focus on Rebecca without always being concerned with Abby.”

In Marcia’s narrative, she describes life before her nontypical son, Daniel, as being easier because Daniel and his disability have always required a “disproportionate amount of time and energy.” As a result, she insists it is very important to make special time for her oldest daughter, Sophia, who typically gets the “short end of the stick” when it comes to parental time and attention:

We try to balance things out with the other kids, but it’s not very effective. Early on, it was Daniel’s medical issues. Now, it is things like helping him cut his meat and learning to spell. Because Sophia is self-sufficient, she ends up getting very little time and attention. This gives me so much guilt. When she comes out of her room and walks downstairs, most of the focus ends up on the boys, and their behaviors, discipline, and homework. She turns around and walks back upstairs. It makes me feel terrible. I think she feels like this has gone on her entire life. She can’t remember life any other way, where the focus wasn’t always on Daniel
and Luke. I try to make special time for Sophia where we shop, have lunch, or see movies. This is important to me.

Carving out alone time is also important to Cindy who claims that ensuring her children have positive feelings about their family life is essential. She wants them to enjoy a variety of experiences and not feel as if they have lost out on anything due to their younger brother’s disabilities. Here, she describes recently taking her two typical sons, Drew and Paul, on a trip to New York City for this exact reason:

I wanted to have a vacation with Drew and Paul in which we did not have to focus on Evan’s needs. I felt so much guilt about going and leaving Evan with family, but I knew we really needed it. Evan would have struggled in a busy place like New York City, and I wanted to concentrate on the other boys. It is very important for the boys to have their parents’ undivided attention. It is especially important for Paul [middle son], who needs to be reminded that he is a significant member of our family.

Appreciating the Typical World

While balancing the varying needs of their children can be quite difficult for some mothers, setting aside alone time with typical children tends to ease some of their pain and heartbreak. This time helps mothers feel as if the needs of their typical children are being met. Out of this special alone time stems feelings of happiness and joy in raising a child who is typically developing. The mothers in this study describe feeling thankful and lucky to have normal family experiences and put great importance on identifying with and feeling close to their typical children. Some mothers of first-born children with disabilities express happiness with their decision to have more children because they believe their typical children have helped connect them to the mainstream world, decrease feelings of social isolation and normalize their family situation. The mothers in this study view their lives as a little simpler and easier when they spend alone time with
their typical children, which enables them to feel like normal mothers for a short interval.

For example, in the narrative below, Tiffany describes taking her typical daughter, Rebecca, to her class picnic. With a tremendous amount of guilt, Tiffany admits enjoying the time away from Abby, her younger child with disabilities, because time without Abby is relaxing and enjoyable:

My dad spent the morning with Abby and planned to drop her at the picnic late. I couldn’t stop thinking that I had one hour to enjoy the picnic before Abby arrived. That’s terrible, I know. But I had a small window to relax and enjoy my time before Abby showed up. Then the work began.

Like Tiffany, Brenda also confesses to enjoying the world of her typical daughter, Elizabeth, and celebrating her normal world. In the following excerpt, she describes the joy in attending her daughter’s volleyball banquet: “Elizabeth had a volleyball banquet last week. I got a sitter for Bridget. It was nice to be in the typical world. I celebrated having another world. It’s such a different world from Bridget’s world.” For Kelsey, having two other typical children in her family has made her son’s disability easier to handle because it has required her to remain in the typical world and not completely focus her life on the disability. Here, she describes feeling grateful to have her typical daughters: “The girls are always a great support. They have given me physical and emotional support. They helped with Dillon and forced me to stay in the typical world, so I can’t focus only on the disability.” Like Brenda and Kelsey, Yvonne also enjoys spending time in the typical world. In the excerpt below, she explains that when Robbie, her older son with disabilities, is at school, she feels normal and content with her typical son, Brandon:
I look forward to the times when it is just us. I feel lucky to have Brandon. We get to go to the park or the store, and we don’t have to deal with somebody screaming. It’s so easy, and we don’t stand out in a crowd. Since Robbie was born, he has felt like work. But Brandon is undemanding and fun to be with.

When Georgia thinks about her two children, she expresses gratitude for her typical daughter, Phoebe. Here, she explains that Phoebe gives her the opportunity to parent in a conventional way: “We would have felt robbed without having typical experiences, such as school plays, concerts, and sports.” With sadness, she adds: “Phoebe got robbed by not having a real playmate, and Mason got robbed by not being able to be a playmate.”

In Mary Beth’s narrative below, she explains that she is thankful she had more children after her oldest son, Ben, was diagnosed with Down syndrome and autism. She believes that raising two typically developing children, who are very active in school activities and sports, has helped connect her to other parents, diminishing her feelings of social isolation that often accompany raising a child with disabilities:

I’ve gone through tough periods from time to time. But Rachel and Max help me. They help me to stay connected. Because if I only had Ben, you know, he doesn’t have friends and he doesn’t get invited to things. Ben has a lot of therapies at home, so I’m connected to therapists, but not to parents. Rachel and Max are so involved and interact with so many kids. They have friends, play dates, birthday party invites, school events, and sports. It feels like what my childhood was like, whereas Ben’s childhood is so different.

Getting a taste of the typical world is equally important to Rebecca. Here, she shares feeling grateful for her typical daughter, Laura, because she considers their time together to be a welcome break from her life: “I feel like I get a little bit of a break, and I get a little taste of the other world. I wonder what it must be like to not have children
with special needs. I can’t even imagine what it’s like. It makes me a little jealous sometimes, too.”

For Gabrielle, being able to identify with and feel close to her typically developing son, Charlie, is very important. In her narrative, she describes her feelings of joy when connecting with Charlie: “It feels so easy to identify with Charlie. He feels so incredibly familiar to me, down to his interest in movies and his disinterest in sweets.” In her narrative, Gabrielle shares her excitement in taking Charlie to his first movie in a theatre. However, her excitement is tempered by guilt and sadness because David, her son with disabilities, is not able to join in the fun. She elaborates here: “He [David] probably would not last through a feature film. He’d be confused by the darkness, unnerved by the seats, and scared of the noise.”

Like Gabrielle, Shelly also describes the pleasure in going to the movies with her typical developing son, Zachary. She considers this time with her son as a high point in her life and a much-needed break from reality:

I like to spend alone time with Zachary because it feels like I’m taking a break from my real life. This time together feels natural. We love to go to the movies, just the two of us. What that means is you leave at a certain time and no disaster happens so you can’t get out the door. And you get there on time and buy the tickets. And you don’t have to worry that anything is going to call attention to us that will make us embarrassed or mad. It’s easy and uninterrupted. And I think it’s really important for us to interact in ways that Caroline is not directly impacting because so much of the time she is.

Creating a Normal Childhood

In the previous sub-section, mothers described feeling gratitude and joy in having a typically developing child and appreciating the typical world. Accordingly, these mothers also strive to establish and maintain a normal childhood for their typical
children. They believe this childhood is essential for raising strong, self-sufficient, and compassionate siblings who do not feel resentment or anger about growing up with a brother or sister with special needs. They hope their typical children will become independent and will not feel overly responsible for their siblings. At the same time, they believe in teaching their children about the realities of disability, the importance of teamwork, and the sacrifices everyone must make. Throughout Rebecca’s story, she worries about her typical daughter, Laura, who does not have a normal home life or a predictable sibling. Because food is a serious issue for her son, Rebecca cannot keep unplanned treats at home. The refrigerator is always locked, the pantry doors closed, the countertops are bare, and there are no late-night snacks or spur-of-the-moment ice cream runs. In the excerpt below, Rebecca describes the need to provide her typical daughter with freedom and normality, as well as love and support:

Some of the spontaneity that some families have, such as going to the movies or staying up late, can’t happen in our family. And often, if we are going to a family event, we go in two cars so one of us can take Colin home earlier. That way, Laura can have the benefit of staying. Part of my concern is what we need to do this so Laura can be as normal as possible. So that she doesn’t feel undue resentment from having a brother with special needs. I want her to feel that she has as much freedom and normality as possible, as well as love and support. We try to be careful about keeping her life normal.

Rebecca’s narrative goes on to describe how Laura spent a few weeks with Rebecca’s brother and his family in New Jersey last summer. Here, Rebecca recalls feeling extremely happy that Laura could experience a slice of life with a family not raising a special needs child: “I was glad that she could spend time with cousins and receive some respite from her day-to-day life with us. It is more relaxing and easier than our life.” Creating a normal childhood for her daughter, Elizabeth, is also important to
Brenda, who works hard to keep the lives of her two daughters separate. In her narrative below, Brenda shares sending her two daughters to different schools to ensure this healthy separation:

I never sent the girls to the same school because I wanted Elizabeth to have her own life. I didn’t want her to be responsible for Bridget in any way. Being separate and building her own life took pressure off Elizabeth. At school, she is not Bridget’s sister. Instead, she is celebrated because of who she is. This is very important to me.

In Jessica’s narrative, she wishes her typical son, Max, had a normal childhood. She describes his many sacrifices due to his older sister’s disability and explains how it constantly breaks her heart knowing that he is suffering because Grace’s severe disability dictates what the family is able to do. Here, Jessica describes how she has “drowned” herself in the world of autism and Grace’s needs, forcing Max to miss out on a normal family life:

Grace takes so much time and energy, and Max gets what’s left over. And by then, I have nothing left. We may have just arrived somewhere, but if Grace can’t handle it, we leave immediately. Max has been raised to accept it. He understands the need to be second to his sister. I know he wishes that we could stay, but he never pushes because he knows it is what it is. Max makes so many sacrifices for Grace. He is having behavior problems, and I worry it’s because of all of this. I wish more than anything that I could give him normalcy, but it’s impossible. There are so many sacrifices. I save all of my days off from work to attend Grace’s IEP meetings and therapies. So when it comes to Max’s fieldtrips and games, I can’t be there. I wish things could be different. It breaks my heart that he is missing out on a normal childhood.

**Worrying About Typical Siblings**

Although numerous mothers in this study describe feeling grateful to have typical children and working tirelessly to establish normal life experiences for them, many constantly worry about their typically developing child. This concern involves how the
disability ultimately affects their typical children. These mothers fear that some of the ongoing stress of the disability falls on the typical siblings. They also worry that increased responsibility for their disabled sibling—along with decreased parental support and attention—may cause psychological problems for their typical children. They are concerned that their family is overly focused on the disability and their typical child is the “forgotten” one. These mothers fret that their typical children experience resentment and frustration, feel shortchanged, and believe they must be overachievers and perfectionists to compensate for their disabled sibling.

Some mothers in this study describe concern that their typical child feels resentment due to their sibling’s disability. For example, in her narrative, Emma shares her fear that her typical daughter, Holly, will develop feelings of resentment toward her older brother with Down syndrome due to the increased attention he constantly demands and receives:

Simon ends up getting a lot of attention because he has extra needs. It is a challenge for us to make Holly feel like she is number one without spoiling her. I am concerned that Holly sees all of the attention that Simon gets. I worry that she may end up resenting him, resenting us, or doing negative things for attention when she gets older.

Resentment is also a cause of concern for Jill. She insists that she never wants her typical son to feel like his parents devote more of their time to his sister with disabilities. In her narrative below, she worries about how he will feel having a sister with disabilities down the road: “Will he resent the extra attention that she demands? Will he be embarrassed by her? Will he resort to drugs and alcohol to cope? I hope that he will take our lead on accepting Sarah.” Denise also admits to constantly worrying about her
typical daughter, Hannah, and her feelings of resentment toward her older sister with disabilities:

She’s only 6, but her resentment is already starting to show. She acts out in different ways to get attention however she can. I don’t want Hannah to feel responsible for her sister, but she already helps take care of Samantha. She will tell us when her sister is having a seizure or will wipe her face. It’s already part of her life.

In addition to worrying about feelings of resentment from the typical child, some mothers share their fear of the typical child becoming the “forgotten” child. In this section, mothers describe their family life as constantly revolving around the disability. As a result, they worry that their typical children receive less attention than their siblings with special needs, and are often concerned that a double standard exists in their family. For example, Madeline admits that life often revolves around the considerable needs of her daughter, Olivia. Consequently, her typical daughter, Abby, does not get as much attention as she should. Anxiety about paying insufficient attention to her typical son, Connor, is also reflected in Susan’s narrative. Here, she admits to being overprotective of her son with special needs and fears how this lack of attention will affect Connor: “I worry that Connor is suffering because he is not getting enough attention. He tries to get our attention by acting out or doing something he knows is wrong. I probably don’t help by being overprotective of Henry.”

Like Madeline and Susan, Emma spends a great deal of time worrying and feeling guilty about her typical daughter, Holly, who she says is just “tagging along” behind Simon, her older brother with disabilities. She elaborates: “Simon was our first child, and we built our world around him and his needs. We continue to do that. Our life with
Simon is therapy, therapy, therapy, and Holly comes along for the ride. I feel a lot of guilt about it.” In the passage below, Maureen explains that as the youngest child, her typical daughter, Nicole, grew up having to scream for attention and claiming it however she could. She considers Nicole to be the forgotten one because Joseph, Maureen’s son with disabilities, is consistently her first priority. Here, she wonders how this will affect her daughter in the future:

Nicole has adapted to life by screaming for attention or simply getting in my face. But she is never my first priority unless she is bleeding or throwing up. How will that affect her emotional well-being? She is being given the message to fend for herself. If I didn’t have a child with disabilities, I’d be more ecstatic about her abilities. She deserves to be encouraged and praised. But how do you do that without putting down Joseph? Is it fair for us to have different expectations for each child? Will Nicole rebel one day? Will she resent us or resent Joseph?

Some of the mothers in this study worry about feelings of resentment from the typical child, while others reveal a fear of the typical child becoming the “forgotten” child. Other mothers share their distress and concern about the psychological well-being of their typical children. They worry about their typical children being frustrated by their sibling with special needs, feeling pressured to act like parents to their siblings, and believing they must be perfect and overachieve. For example, Shelley worries about the pressure that her typical son, Zachary, seems to put upon himself to achieve in school. In the excerpt below, she describes her son’s view of grades and his sister’s limited abilities: “He stresses a lot about achievement. A while back, he got so upset about getting a B. I asked him why a B was so awful. He told me he felt like he had to get perfect grades because Caroline wasn’t going to be able to.”
Like Shelley, Rebecca also makes it a priority to help her typical daughter, Laura, understand that she doesn’t have to be perfect. This is very important to Rebecca, who believes this behavior is unhealthy. Additionally, in her narrative, Rebecca shares the difficulty in teaching her daughter the differences between helping to take care of her younger brother, Colin, and being an actual parent to him:

Laura does have to help us. We all have to take care of Colin. But we try not to put too much of a burden on her at this point. It’s a fine line because sometimes she acts like a sister, and sometimes she tries to be a third parent. But I don’t want her to be his mother now. I want her to be free. At this age, she should have the typical responsibilities for a sibling, not any extraordinary responsibilities.

Catherine also worries that her oldest daughter, Emily, is unable to enjoy a carefree childhood because she feels burdened by her brother with autism. She struggles with teaching Emily the difference between being a sister who helps her brother and actually being responsible for him:

Emily worries a lot. If Owen is in the room, she can’t relax. At Sunday school, they are in the same class together. She told me she can’t have fun there because she sees Owen just sitting in the corner and feels like she has to take care of him. She is worried about him, but she is 8, and should be able to have fun and have a stress-free childhood. I work hard at giving her this whenever possible. She goes to a different school, and she gets her own play dates. When we’re at home, she has her tasks and one of them is helping Owen. It’s a big responsibility for her. I think a lot of oldest children start taking on a parenting role. She tells Owen and Molly what to do. She inserts herself in anything I’m trying to say to them. I have to remind her that I’m the parent. I tell her that I just want her to be a kid. It’s a fine line because you want her to understand that her brother needs help, and she is responsible for him. However, at this point in time, she is a sister only and not a parent.

Like the mothers in this sub-section, Marcia is constantly anxious about her middle child, Luke, and the scars he bears from having a younger brother with Down syndrome. When Daniel was born, her daughter, Sophia, was eight and her middle son,
Luke, was five. While Sophia immediately embraced Daniel and became his big sister, protector, and playmate, Luke had a tough time accepting Daniel into the family. Below, she describes the difficult adjustment Luke has had to make concerning his younger brother with Down syndrome:

Luke went from being daddy’s only boy to sharing daddy with Daniel. When Luke was 8 years old, he started pretending he had Down syndrome because his brother was getting a lot of attention. Luke loves his little brother and constantly defends him. He has been involved in fights with other kids who have made fun of Daniel or used the word retarded. He’s definitely adjusted to Daniel and his disability, but I think there are scars there that we don’t really understand.

**Social Exclusion**

Worrying about the feelings and well-being of their typical children is extremely significant to many of the mothers in this study. At the same time, these mothers also spend a great deal of energy agonizing over their child with disabilities. In this sub-section, mothers share their sorrow in watching the social exclusion of their child with disabilities. This isolation, which causes intense heartache for many mothers, is described in several different contexts. Mothers express wishing their child with disabilities could fit in and participate in the same activities as their typical child, while others long for their disabled children to have friends and be invited to parties and play dates. Furthermore, some mothers insist their child cognitively understand his or her own social rejection, which exacerbates the heartache experienced by these mothers. For example, in Maureen’s narrative below, she describes the difficulty in managing neighborhood play for her son. While other kids on the street play and run from yard to yard, her son, Joseph, cannot participate in these activities due to his physical disability, which causes Maureen extreme sadness:
Sometimes, I think parents put their kids up to asking Joseph to come over and play. He usually says no because he knows he will need help. If I don’t offer to go and help, he won’t want to go. And sometimes, even if I offer to help, he won’t go because he knows it is kind of a drag. I so wish it didn’t have to be like this. There’s no way to feel good about the situation. It makes me sad that Joseph can’t enjoy these activities.

Similar to Maureen’s story, Donna experiences the same exclusion with her son, Jack, who is unable to play with other kids due to his physical and cognitive disability.

Below, she shares the awkwardness of taking her son to dinner at another family’s home:

Jack’s disability creates a lot of isolation. The older Jack gets, the harder it is. When he was little and in a baby carrier, you could blend in and it was not so noticeable. But as they get older, there’s complete and absolute isolation. We will go to other families’ houses for dinner, and the kids play while the parents talk. But it feels awkward because Jack can’t go off on his own to play with the other kids. So you either keep him with you while you talk to the other adults, or you stay with him and the other kids. However, the kids don’t want you there. It’s not a good situation because it becomes a weird scenario.

Because Tessa’s son is not able to take part in many activities due to his developmental disability, it is difficult to include him in family events. In the excerpt below, Tessa describes her heartache in watching her son miss out on the fun with his older sisters at a local carnival. As her two typical daughters ran around together having fun, her son was forced to stay with Tessa and just watch:

The girls were running around together having fun. Jett stayed with me and watched. It made me so sad that he couldn’t join in with his sisters. It is very difficult to include him. Every activity is just so hard for him. It seems like everyone is moving on and we are still stuck in time in the baby phase. He’s a 2-year-old boy living in a 4-year-old body. It’s like we are living in a different world from everyone else. A parallel universe.

Parties and play dates are perpetual areas of pain and heartbreak for some mothers. In this study, mothers wish their child with special needs could be more involved in social events and have the same opportunities as their typical children. For
example, in Sandra’s narrative below, she describes longing for the day that her son, Nate, will have the same social opportunities as her typical daughter, Audrey: “I wish Nate was able to go fun places and meet new people. I wish he could go to a party and have fun with other kids. To have a good friend base and have more in his life than just two parents and a sister.”

Like Sandra, Catherine insists she would love nothing more than for her son, Owen, to have a little friend or buddy. However, Owen doesn’t usually get invited to birthday parties because of his disability, and if he does attend a party, it is only because he was invited by one of his sisters or a family friend:

I understand why he does not get invitations. In all honesty, it’s a burden to go to a party. He has fun because he loves cake, swimming, and parks, but he does not interact well. I think right now he doesn’t notice the lack of invitations. Maybe Owen will get there someday, but I don’t know. I end up feeling bad because I force my girls onto him. Since nobody else plays with him and he has no other friends, I make sure the girls spend time with him. Is this fair?

When Alexandra reflects on her son’s exclusion, she recalls a few years ago when her son, Patrick, was in kindergarten. She was volunteering in his classroom when a girl in his class told the other kids that Patrick was not invited to her birthday party. Below, Alexandra shares her pain in experiencing her son’s rejection and social isolation:

It was hard to hear, even though I knew it would have been difficult for Patrick to go to the party. I would have had to be right next to him the entire time. And he probably wouldn’t have enjoyed it anyway. But it was still really painful because it was very obvious, and it wasn’t something I had thought about yet. Wow, he’s not going to get invited to people’s birthday parties. Bummer. It just hurts.

Social isolation is also a painful issue for Emma. After organizing a recent birthday party for her son with disabilities, Emma found herself wondering whether anyone would actually attend and what the other parents thought. Would they send their
kids to the party to be kind to the child with the disability, or would the kids come because they like Simon? Do kids invite Simon to their parties because they actually like him or because parents do not want to exclude the boy with Down syndrome? Here, with sadness, she describes the stark social differences between her two children: “While Holly names all of her buddies, Simon only names Holly as his buddy. I don’t think this would bother me if Simon were a typical kid.”

When Bonnie reflects on her son’s life, she says that birthdays are very difficult because Joshua’s birthday experiences are quite different from her typical daughter’s experiences. In all of his 16 years, Joshua has only been invited to three parties. While he has hosted several of his own parties, reciprocal invitations have been rare. Bonnie explains: “When I think of all the parties that Addie has been to, it makes me so sad for Joshua. I wish I could snap my fingers and make everything normal for him, but I can’t. I need to resign myself to our reality.” Bonnie adds that she is hopeful that eventually her son will have a friend or two to do things with: “I want him to have this experience. It’s part of growing up.”

Cognitive aptitude seems to have a direct effect on these mothers’ descriptions of social exclusion. Several mothers note that their children with disabilities have the cognitive aptitude to understand exactly what they are missing regarding social experiences. These kids know that they are being left out, ignored, and teased by others. On the other hand, some mothers describe children who lack this cognitive ability to recognize their own exclusion, which tends to create feelings of relief and gratitude for these mothers. For example, Tiffany shares her experiences growing up with a sister with
mild cerebral palsy. She recalls how tough it was for her sister and their entire family as her sister endured the misery of social rejection. As a result, Tiffany harbors feelings of thankfulness about her own daughter’s limited cognitive functioning and social exclusion. She elaborates on these feelings below:

This sounds terrible, but I am almost relieved that Abby is so severe. This way, she does not have the cognitive ability to really understand the cruelty or the things other kids might be saying to her. It is one less thing I need to deal with and worry about.

While Rebecca is grateful that her son, Colin, is highly functional and understands a great deal, she also believes his high functioning level is a definite curse regarding his social awareness. Here, she explains: “He is so functional, which is great, but the fact that he kind of knows what’s happening and missing, makes it harder as well. Colin sees his older sister doing typical teenage stuff. And he can rebel. It makes it hard.”

**Teaching Responsibility and Acceptance**

It is evident from the previous sub-section that these mothers wrestle to cope with their child’s social isolation. These mothers insist it can be quite difficult to raise children with disabilities and this exclusion and lack of acceptance exacerbates an already challenging situation. As a result, many mothers maintain the importance of teaching acceptance, responsibility, and resilience to their children and describe how they instill these qualities in their family. At the same time, they also encourage all family members to appreciate how the child with disabilities has helping them to enjoy a richer family experience and added so much love and laughter to their lives. In the excerpt below, Catherine explains how her son, Owen, diagnosed with autism, has given his siblings the
unique gift of responsibility and acceptance. She describes these priceless traits as gifts that Owen has given to his siblings:

I think there’s a blessing that comes with having a brother with a disability. It’s a sense of responsibility for other people who are different. Being more inclusive and accommodating of people who are different. They get to learn about people in a way that others will never learn because they are not experiencing what we’re experiencing. Others won’t know the hardship of not being able to put your clothes on in the morning or being scared of a haircut.

In Kelsey’s narrative, she also describes how her older daughters have experienced a wonderful childhood—specifically because of their younger brother with disabilities—and the resilience he has taught their entire family:

I don’t know what it would have been like without him. The girls would have been very spoiled. I’d have been bored, not sure what to do with my life. Sure, I didn’t make it to school events. We had vacations filled with stress. The girls spent birthdays in their brother’s hospital room. They make their own meals and plan their own birthday parties. But they are confident, independent, secure in love, and don’t drink or smoke. They talk to me and are ready for the world. They are very aware of the world around them and their ability to make a difference.

Acceptance is an important notion to these mothers. Many believe that being a family and spending time together is crucial, so they encourage all family members to help take care of the child with disabilities. For example, in Gail’s narrative below, she describes the importance of teaching her three typical children the realities of life and the fact that everybody has “something” in their family: “We are a family and there are things we have to do—or not do—because we are a family. While we want them to lead normal lives, Wyatt is their brother and part of this family for the rest of their lives.” She insists that it is crucial to accept the limits of what you can do as a family, while focusing on what is still possible.
A small number of mothers in this study describe the love and acceptance their typical children exhibit toward their sibling with disabilities. They explain that this acceptance has made raising a child with disabilities much easier and has made their family considerably stronger. For example, in the excerpt below, Tiffany expresses how she cherishes the strong bond between her two daughters. This bond has made raising a child with disabilities easier for Tiffany:

What has made this experience much better is the fact that Rebecca is so amazing with her little sister. I think she is going to be a more sympathetic and caring person because she has a sibling with a disability. Abby loves Rebecca. She loves to be carried around by her. She loves to nibble on her head. It is so cute. Rebecca constantly tells her that she loves her and wants to cuddle. We are so happy for that because we don’t want Rebecca to feel jealous because of the attention that Abby gets.

Similar to Tiffany, Sharon explains how her two typical children consider their brother Zachary just another kid in the family. Below, she describes how her typical daughter, Amanda, is completely accepting of Zachary and his differences and does not think of him as a boy with disabilities:

Zachary is in a fully inclusive classroom, but the school also has a center program for kids with behavioral disabilities. Amanda refers to these kids as the “special ed kids.” One day, I told her that Zachary is considered a special ed kid, even though he is in a typical classroom. She couldn’t believe it. She knows what Down syndrome is, and she knows it takes him longer to learn. But she just sees him as another kid. I remember being on the playground during Girl Scouts and a little girl came up to Amanda and asked her why Zachary looked funny. Amanda just looked at her and said, “He has Down syndrome.” Like, are you stupid? He has Down syndrome and that’s how he looks. It was so great because she didn’t feel embarrassed, rather that’s just the way it is.

In discussing their hopes for complete acceptance, these mothers insist that they encourage their typical children to speak openly about their frustrations, fears, and disappointment. At the same time, they also struggle to teach them about compassion,
patience, and understanding. For example, Gail believes it is beneficial for her typically
developing kids to learn compassion and tolerance for others who are different and
understand that not everybody is the same. In Rebecca’s narrative, she explains the need
to educate her typical daughter about her son’s disability and the sacrifices they all must
make, while at the same time, teaching her how to manage her frustrations:

There are times when she wants to express her frustration with her little brother
like anybody else. But I try to give her some avenues to deal with her feelings so
that her frustrations are dealt with properly without spurring Colin into a tantrum.
She has no desire to attend any sibling support groups. I think part of her doesn’t
want to admit that there’s a problem with Colin, although she knows that there is.
When she was 10 or 11, I sat her down to explain mental retardation. She said
that Colin was not mentally retarded. I said, yes he is, and asked if she knew what
it meant. She realized she didn’t know. I told her that it means less than normal
cognition. So, in fact, Colin is mentally retarded even though that is not a
common terms these days. I explained that we use the term, developmentally
delayed. But when she has friends who use the term, retard, that’s what they are
saying. It was an “ah ha” moment for her.

Sandra’s hope is that her typical daughter, Audrey, will be considerably more
patient and understanding of people. She is optimistic that her son’s disability will be a
character-builder for his sister. When Audrey expresses negative feelings toward Nate,
Sandra encourages open and honest communication, believing it is the best course of
action. Below, she describes using these particular experiences as valuable opportunities
to troubleshoot with her daughter:

We try to make it a frank discussion and try to problem solve. We don’t say just
live with it; rather, we try to figure out how to make the situation better for her.
We try to be open and troubleshoot. Knowing Nate’s limitations, we do what we can.
Summary

In this section, mothers paint a portrait of life within their families. They begin by examining the varying effects of birth order on the entire family dynamic. A majority of mothers insist that having a youngest child with disabilities is ideal for a variety of reasons, while others assert that having a first-born child with disabilities is actually easier on their families. Despite the particular birth order of their children, some mothers regard their lives as very challenging. These mothers discuss feeling cheated by their child’s disability, resenting their situation, wishing family life could be different, and struggling to find balance in their lives. Out of these feelings stem an appreciation for the typical world in which mothers feel happiness and gratitude in being able to raise children who are typically developing and spend time in a normal world. While these mothers place great importance on establishing and maintaining a normal childhood for their typical children, they also worry incessantly about their children experiencing feelings of resentment, frustration, a lack of attention, and the need to compensate for their disabled sibling. Lastly, the mothers share their intense fears and heartbreak regarding the social exclusion of their child with disabilities and describe their sorrow in watching the social isolation of their child as they struggle to be accepted into society. This lack of acceptance motivates mothers to instill a sense of responsibility, resilience, and acceptance in all of their children.

Whereas the mothers in this section have openly shared their family lives, the next section depicts their public lives. In this section, mothers talk about navigating public spaces with their children, where they tend to feel the need to protect themselves and
their children from any kind of public scrutiny. They must cope with stares and expressions of pity and sympathy, feelings of embarrassment by siblings, and unfitting labels of sainthood applied by others. These experiences highlight the need for increased education and societal acceptance regarding disability and difference.

**In the Public Eye**

The mothers in this study discuss navigating public spaces with their children. They describe feeling awkward and apprehensive about being out in public with their child with disabilities, especially when people stare, ogle, and comment. This makes them feel stress, anxiety, and embarrassment. Their narratives suggest that, when out in public, these mothers are extremely conscious of their children being marginalized by society. Their public experiences underscore the importance of education and the need to spread the word about disability and difference to minimize fear of the unknown and increase acceptance within society.

Divided into six sub-sections, the first sub-section focuses on mothers who must manage the stares of others. In describing stressful public situations, these mothers insist that blending in is their most important goal. As a way to cope with these stares, mothers describe putting up their guard and creating a safe barrier for themselves in the second sub-section. The next sub-section, sibling embarrassment, focuses on the pain of seeing their typical children’s embarrassment and shame, and how some of these mothers manage this embarrassment. In the fourth sub-section, mothers describe their intense dislike of expressions of pity and sympathy, as well as being deemed saints and superheroes by others. Recognizing intolerance is the next sub-section, in which mothers
come to terms with society’s negative views on difference and disability. In their narratives, these mothers articulate their dawning recognition that the world we live in is not accepting of difference of any kind. In the last sub-section, spreading the word, mothers share the significance of education and acceptance in today’s society.

Managing the Stares

Navigating public spaces is a constant struggle for some of the mothers in this study. They share feelings of frustration, anxiousness, and embarrassment when visiting public areas with their child with disabilities and describe the difficulty in coping with the stares of others. For example, in the following excerpt, Emma depicts a recent dinner out with her family when she notices a pregnant woman at the next table staring at her son, Simon. She goes on to share how her mind works to make sense of these stares: “I caught her looking at Simon and wondered if she was thinking about her own baby. Was she praying her baby didn’t have Down syndrome? Did she feel happy that she dodged a bullet? Did she feel sorry for me?” For Anita, going out as a family also can be stressful as her son’s wheelchair seems to constantly cause a disturbance. Here, she describes how she longs to blend in and be treated like everybody else: “It’s always a question of where Daniel’s chair will fit in a restaurant. And it always causes some commotion to make room for his chair. I hate the moments when I feel like everyone is looking at us. We try and play things down as much as possible.” Because being out in public with her son, Jett, causes anxiety for Tessa, she and her family choose not go out to eat often. In her narrative, she describes his loud vocalizations as unnerving and distressing: “We avoid quiet places because I am very uncomfortable with his noises. I just want him to be calm
and follow social norms.” Like these mothers, Jill experiences anxiety when she ventures out in public. She struggles with tube feeding her daughter in the public domain as this makes her extremely uncomfortable and obvious to others. Here, she describes “blowing her cover” as she tube-feeds her daughter at a recent potluck lunch:

We might pass as normal at first glance, but as soon as we pull out her feeding supplies, the jig is up. I try hard not to care what others think. Sometimes, I’m strong. Other times, not so much. Recently, Toby had an end-of-the-session potluck for his French class. Sarah’s preschool was closed, so I brought her to the lunch. When I pulled out her G-tube stuff, some of the kids began to stare. I began to feel very self-conscious and immediately wondered why I thought this was a good idea. I just wanted to run. I was no longer a member of the “healthy kid” club. I had so enjoyed taking Toby to class alone, being a normal mom, but now everyone knew about Sarah. My typical mom cover was blown.

In her narrative, Cindy admits that she tends to focus too much on trying to be a normal family and feels overly sensitive about what others think. Here, she describes constantly fearing public scrutiny about her son, Evan:

I think I hold myself hostage because I am so afraid to put Evan out in public. I am constantly trying to normalize my family. I probably stand out as being phony. Sometimes, I find myself wishing that Evan could stay a baby. Then it would seem okay that he is not acting like a typical 7-year-old boy. Nobody would question why he doesn’t talk or walk, like a typical kid. I am just too sensitive.

Like Cindy, Ellen also expresses frustration and anxiety about going out in public with her son, Henry, because of his difficult behaviors: “It’s tough if your child behaves in a way that makes others feel uncomfortable. At times, I still feel anxious because I am so oversensitive about Henry and his sensory issues. I don’t deal well with my own anxiety.” In Tiffany’s narrative, she describes how her daughter, Abby, doesn’t communicate, but rather squeaks and squeals with delight. Because she doesn’t understand the need to be quiet in certain public settings, it can be difficult to get Abby to
settle down. Here, Tiffany describes an emotionally painful trip to the local public library:

The library is a tough place to go for us. A while back, we were at the library and Abby was squealing loudly. Because her disability is invisible, you can’t tell she has any issues by just looking at her. The librarian approached me and told me we would have to leave if Abby didn’t quiet down. “This is a library and it needs to be quiet,” she told me. I was so offended. I told her Abby had a disability and did not understand how to be quiet. We stormed out. It was the first time I really felt different in society. I felt so sad and angry.

Similar to Tiffany, Mary Beth explains her struggles to keep her son quiet and within socially acceptable norms when he is out in public: “Ben yells and spits. If we are at a baseball game, it doesn’t go over too well when he tries to spit on the people sitting in front of us. So there’s a lot of time spent just trying to do crowd control. And being normal in that sense.”

**Keeping Their Guard Up**

As a coping mechanism to the stares they receive in public, some mothers describe building a wall to protect themselves and their children. For example, going out in public with her 11-year-old son with disabilities still gives Kelsey pause. Here, she describes her stress and the thoughts that flow through her head: “There is always that initial hesitation. Is this going to be awkward? My kid is in a wheelchair. Are you going to be uncomfortable, are you going to be patronizing, or will you be overly nice?” For Donna, going out in public with her family is challenging because it is impossible for them to blend in. Here, she shares her efforts to ignore all of the stares and persistent questions:

It’s a kind of Teflon coating when we go out with Jack. I ignore everyone because parents will stare, and the kids will ask their parents about Jack. I try to
ignore all of it. Sometimes it hurts if you hear a particular comment about Jack. But he looks typical, so kids can get confused. I try to portray a positive picture that it is not overwhelming our life and that we have our act together.

Like Donna, Maureen describes the challenges of being out in public. Here, she talks about putting on blinders as a way to protect herself from the stares and comments that she receives because of her son’s disability:

I feel like I must keep my guard up because people are watching, looking, asking, and commenting. I put on my blinders. It’s like we are going out there into the big, bad world, and I have to put on my thick skin. My shield is up. I am ready for you people. I must protect my soft interior. Sometimes, when your guard is down, you can get blindsided.

Going out in the community is also difficult for Bonnie, whose son does not understand social norms. As a result, she frequently finds herself on edge when out in public with her son. In her narrative below, she maintains that being with her typical daughter is much easier and more enjoyable:

Social norms are different for Joshua. He just doesn’t understand these expectations. I used to be absolutely mortified by his frequent meltdowns. But I got used to them. Today, Joshua is better, and he doesn’t have as many of these public outbursts. However, I am still always on edge when we are out in public. Spending time with Addie is much easier because it is not as emotionally intense. I do not need to watch what I say.

In the narrative below, Denise recalls feeling ashamed and embarrassed of her daughter. She describes building a wall around her family as a way to keep them safe from the stares and questions from outsiders:

I used to feel like I had to put up a wall anytime I left the house. The wall kept us safe. It was like, don’t talk to us, we won’t talk to you, and we will just do our thing. However, if people ask me questions or stare at Samantha, I am ready to tell them anything they want to know about her disability. It took me a long time to deal with the staring, but I am better now. I used to not want to go anywhere. I was ashamed and embarrassed. I did not know how to explain Samantha to people. I didn’t know what to do with the stares.
A common thread among many of these mothers’ narratives is the notion of working diligently to feel better about their situation and making life as normal as possible for their families. Some mothers describe learning to accept the disability as part of their child’s identity, and feeling comfortable out in public together. In her narrative, Jill says she no longer feels the need to explain everything about her daughter’s disability. Instead of hiding her daughter from the world, she asserts the need to be proud of her and “expose her to everything that another child her age would be doing.” Like Jill, Denise shares below how her public experiences have improved steadily over the last several years. She claims that lobbying on behalf of her daughter’s disability has helped her come to terms with the disability:

I go to Washington, D.C., every year to lobby for TS funding. This has helped me be more outspoken and assertive. It has helped me out of my shell. Lobbying and talking to senators from different states about TS forces your wall to come down. This has also helped me to grow personally, to just accept the disability and move on.

While going out in public with her daughter used to fluster Jessica, she insists she has become assertive over time and has learned to accept her daughter’s disability and what it means for her family. She elaborates below:

If Grace had a meltdown in a store, I’d notice lots of people staring. They would say rude things. I would go out to the car and just cry. We would try to be normal, but the reality was that we couldn’t be normal. I had to learn to suck it up and put blinders on. It has taken a long time to be okay with everything.

Although people tend to stare when Rachel’s daughter, Chloe, uses her walking cane, Rachel insists the cane makes her daughter who she is. In her narrative, she says she believes Chloe’s disability is not a weakness, but rather an opportunity to educate society about difference:
Most kids want to ask what the cane is for. Their parents act embarrassed and try to guide the kid away. The adults stare more than the kids. I just smile back at them. I won’t try to hide who Chloe is because this is who she is. Even my mother-in-law gets embarrassed when Chloe brings her walking cane out to dinner. She’s from a very small town and always tries to get her to leave her cane. I think this is what makes Chloe who she is. I don’t see it as a weakness. It’s an opportunity to educate others. Understanding differences has to start when they are young.

As a young mother, Alexandra used to worry about being in public with her son and felt anxious about him throwing a tantrum. However, she no longer harbors these fears and claims she had given up on this worry. She says she “doesn’t know if it’s maturity or if it’s a realization.” Brenda also insists she never worries or cares about what people think of her or her family. In fact, in the following narrative, she says she takes great pride and joy in breaking free from societal expectations: “I don’t pretend we are normal, and I don’t care if people think Bridget is weird. If she wants to wear her snow boots in July, that’s okay. My kids’ happiness and health is my number one concern. I want them to be themselves.”

**Sibling Embarrassment**

While some of the mothers describe feeling uncomfortable and anxious in public with their children with disabilities, others also share the pain of watching their typical children experience embarrassment and shame. For example, in Tessa’s narrative, she asserts that because her son, Jett, makes loud noises and does not always follow social norms, her typically developing, 9-year-old daughter, Ellie, doesn’t enjoy going to the library with him. Tessa recalls Ellie justifying her embarrassment and actually pretending that Jett is not her brother. While this is quite difficult for Tessa to hear, she admits to being happy that Ellie can verbalize these feelings about Jett. In fact, she is not
surprised by her daughter’s embarrassment and insists that she, too, feels the same way at times. Similar to Tessa, Shelley also reveals her typical son’s discomfort when he is out in public with his extremely vocal disabled sister. Shelley believes it is vital to talk to him about his feelings, while also sharing her own discomfort so that he does not feel alone. Here, Shelley describes how she manages Zachary’s feelings:

When we are out in public, Caroline will sometimes start yelling with pleasure. Zachary gets uncomfortable and says it’s just too loud. I try to tell him that it’s also hard for me when she’s loud, so he knows that it makes me a little bit uncomfortable. But we have to put up with it, and we won’t stay in the situation any longer than we need to. I don’t want him to feel guilty because it’s a real feeling, and I don’t want it to turn into resentment. I want to acknowledge that it makes me feel really uncomfortable, too. I always try to affirm in some way that I do get it, that she does embarrassing things at times. I remember telling him once about how people shoot me looks like can’t you control your kid? And even though I know it is their problem, it is still really hard. He was like, wow, you feel that way? It was important to share that with him. It makes him feel less alone in his feelings and lets him know it is okay to talk to me about difficult feelings.

Cindy’s son, Evan, also draws attention from strangers. He has a very high-pitched voice, which often embarrasses her typical son, Drew. Observing these incidents are devastating for Cindy. Below, she describes how she manages these particular occurrences:

Drew will immediately shush Evan and try to quiet him down. He doesn’t like the fact that Evan draws attention to us. It’s a tough situation because I am embarrassed, too. I don’t like feeling on display when we are out. But Evan has every right to be out in public. It crushes me to see Drew embarrassed by his own brother. I worry about him and his feelings about Evan. Will he develop into a confident human being?

Georgia admits that on some days, her daughter, Phoebe, acts as her brother’s protector. But on other days, she feels extremely embarrassed by him. In the narrative
below, Georgia explains navigating her daughter’s discomfort and trying to teach compassion and acceptance:

I tell her that the disability is not his fault, and we need to be compassionate. We need to just love him and accept him the way he is. This is hard for her. Other kids stare at him because he makes noises in quiet places, like church. She gets embarrassed, so sometimes we split up or get a sitter for Mason. We hardly ever go out to eat because he hates restaurants. He can’t eat and the stimulation can be overwhelming.

In Mary Beth’s narrative, she describes the difficulty of handling her son’s public behavior, and the concern and anxiety she feels for her typical children, Rachel and Max, during these challenging episodes:

I worry a lot about Rachel and Max. Rachel says she doesn’t want Ben to come places with us. She wishes we could leave Ben at home because he’s so slow. And everything takes longer, and it’s always harder. Going to the library is not enjoyable. We rush through because Ben is so loud and disruptive. I am so stressed to be there. Rachel is well aware of this stress. Last summer, we were at the pool. Ben was vocalizing loudly in the water. And another boy began screaming, telling Ben to shut up, over and over again. I didn’t know how to deal with it. It was so awkward for everyone.

Rejecting Pity

In the previous section, some mothers described the intense pain associated with watching their typical children experience embarrassment and shame. While several mothers admit to also experiencing these same feelings of embarrassment, they are adamant about rejecting expressions of pity and sympathy, and insist they do not want anyone to feel sorry for them or their children. For example, in the following excerpt, Maureen confesses to hating “that look” she constantly sees on people’s faces when they meet her son with disabilities: “It’s the look of, ‘Oh, poor, poor kid.’ It’s as if nobody is exposed to ‘these’ kids.” When Georgia attends church with her son in a wheelchair, she
also describes seeing perpetual pity on people’s faces: “I am sure they are saying a prayer for Mason, specifically for healing, while they are on their knees praying. I can’t help but think that many people do this.” Like these mothers, Donna insists she doesn’t want any pity. She believes there is no reason to feel pity because “one in five people are disabled” and her son, Jack, just happens to be “a little worse than the other people.”

Additionally, these mothers feel as if their child with disabilities is held to a different standard than typical children. As a result of this different standard and distorted perception, several mothers admit to consistently dressing their children with disabilities in extremely nice clothes to counter these stereotypes of disabilities. For Sharon, feeling like her son with Down syndrome should always be perfectly behaved and well dressed is essential. She describes dressing him nicely and feeling as if he needs to behave perfectly at all times:

I feel like I am held to a different standard with Zachary. If Megan were throwing a fit, I wouldn’t be embarrassed. But it’s different for Zachary because of his disability. I feel that he should be perfect all the time because otherwise, people will look at me like, oh, that kid has Down syndrome. I always try to make sure he is well dressed in clean, matching clothes. Because I often see kids with disabilities in terrible clothes. I don’t want that to be Zachary. I do worry about people’s perceptions because I want them to think that Zachary is great and cute, even though he has Down syndrome.

Similar to Sharon, Emma believes she needs to dress her son in nice, expensive clothes to ensure that he is never teased, picked on, or stigmatized by others. She elaborates below:

Simon gets brand new, nice clothes because I don’t want him walking around in ratty, old t-shirts. I don’t want people saying, oh, look at that poor child with Down syndrome. His mother can’t even dress him nicely. But then I dress Holly in hand-me-downs from my sister and sister-in-law. Maybe by focusing on Simon’s clothes, I am also making sure people don’t pick on him. I want to be
sure nobody is ever making fun of him about his clothes. He’s got enough of his own delays. I don’t need to make him a bad dresser, too. I can give him a step up on that.

Rejecting the pity of others and fighting against the different standard held to their child with disabilities are important to many mothers. Others describe their aversion to being deemed a supermom, saint, or superhero by others. In fact, they have a strong dislike for these labels and find them frustrating. For example, Denise maintains that many people think of her as a supermom; however, she insists she is not that amazing at all. In her narrative below, she believes she was not given a choice in the matter of raising a child with disabilities and is just doing the best that she can:

They think I’m like a superhero, a sliced bread kind of thing. Because of what I do, how I deal with this situation. Everyone says, I could never do what you do. Yeah, yeah, yeah. Whatever. I didn’t think I could do it. It wasn’t a choice I got. What am I supposed to do? Send her back? I am not that amazing. I’ll tell you it is not an easy ride. It has been the hardest, most difficult time in my life. And the most difficult job I have ever had. I take issue when people say that God gave you what you can handle. It’s just something to say when people have no idea how to respond.

In her narrative, Georgia asserts that many people admire her and wonder how she “does what she does.” But she says she is no hero; rather, just a tired mom who constantly worries about her children: “I plug along just like everyone else. Nobody would ever want to trade places with me. I don’t care what others think. I just worry about Phoebe. Is she doing okay? Is she embarrassed? Is she struggling?” Like Georgia, Bonnie says that while her family and friends might view her as a saint, others are just “glad it is me and not them.” She insists that she cannot blame them because raising a child with disabilities is quite challenging. When Cindy thinks about the way others perceive her, she, too, explains she does not want them to call her a saint. She
does not consider herself to be a saint, but rather a mother raising a child with special needs:

I hate that. After all, this is my kid. Am I a saint for not leaving him on the curb? I also hate when they say what a burden it must be or that’s your cross to bear. And they only give special needs kids to people who can handle it. That’s what people say when they have nothing else to say.

Although being put on a pedestal is common for Brenda, she insists that she is not “that” person, and she just wants to be like everybody else. For Barbara, hearing praise and accolades is not what she needs or wants. Instead, she craves the understanding and acknowledgment of others. Here, she explains what she yearns to hear:

When I explain or vent or complain, I don’t want to ever hear another platitude of, “You are a phenomenal mother!” or “You are freaking amazing!” What I long to hear is, “Wow! That does suck!” or “Holy shit, are you exhausted?!?” or “You must feel so lonely,” or “I don’t understand exactly what you’re going through, but I’m really interested in what you have to say,” or “I’m here for you.”

Recognizing Intolerance

Through these mothers’ varied public experiences, they describe coming to terms with society’s views on difference and disability. The mothers in this study share feeling sad and distressed that people focus on their child’s disability, instead of seeing them as beautiful, unique individuals. While they wish their child could be like everybody else, they find it heartbreaking that people equate disability with imperfection and abnormality, and choose to exclude and label their children. In their narratives, these mothers articulate their dawning recognition that this world is not accepting of difference of any kind. For example, in Marcia’s narrative, she describes an incident when her son, Daniel, first started playing pitch baseball at a local recreation center. In one of his early games, Daniel hit the ball to the pitcher, who threw it to first base and tagged him out.
Daniel stayed on first base, and nobody said a thing. Marcia recalls that she did not know what to do. She finally walked over to the coach of the other team, pointed to Daniel, and asked if he was out. “The coach got real close to me, screwed up his face, and whispered, ‘Well, he has Down syndrome, so we didn’t call him out.’ I couldn’t believe it,” she says. After the game, Marcia told the coach that the boy with Down syndrome was her son, and while he does have special needs, he also know the rules of the game and should be treated just like the other kids. “It made me wonder if I should start every experience with, ‘This is my kid, Daniel. He has Down syndrome, but please don’t treat him any different,’” she says. “But is it my job to train the world? Is it my job to change the way society looks at disability? That’s quite a job.” In the excerpt below, Marcia goes on to describe how she frequently struggles with the way society views Daniel and Down syndrome:

I constantly feel defensive and apologetic about having Daniel. Actually giving birth to a child who I knew might have complications or issues. Why as a mother did I do that knowingly? Was it my right or his right? Or is it an imposition on society? Why is this something a mother has to consider? Why is it a decision rather than a miracle? We were unwavering about limited prenatal testing and not terminating. But people are still judgmental today about the decision not to terminate. The other day, a physician’s assistant at a hospital saw Daniel and said, “Oh, that’s too bad. Obviously you didn’t know about the Down syndrome prenatally.” I was speechless. It is heartbreaking when people believe Daniel could be a drain on society. But society is like that and sometimes, doctors can be the worst. This world really isn’t designed for differences of any kind.

Like Marcia, Emma opens up about society’s expectations of difference. In her narrative, she describes hearing about a woman in rural Ohio with nine kids. The woman’s ninth child had Down syndrome, and the mother did not even know it until her child entered kindergarten. She thought he was a bit delayed, but always figured he
would just catch up in his own time. She elaborates here: “What a great way to go through life. To just treat people as they are and address the things they have, rather than all of the things they can’t do. How great would that be? Unfortunately, I don’t think that will happen in my lifetime. It’s sad.” In speaking about societal views of disability, Emma shares her vision of disability and the way in which society needs to be accepting of everyone. In the following excerpt, she wishes her son could be the same as everybody else:

I do not like the term, disability. I think of Simon as having some delays. But I wish we could talk about Simon as we would talk about someone who had bad vision. Bad vision is not stigmatized, like if he had only one kidney, for example. If his issues were on the inside, people wouldn’t assume that he couldn’t do certain things. Because Simon’s delays are on the outside, people look at him differently. He has to fight even harder to prove that he can do things. We also have to contend with strangers calling him a “beautiful angel” and telling him he’s doing a great job. I hate when people comment that Simon looks like he is doing so well! Who and what are they comparing him to? I know people say it with the best of intentions. It’s a compliment that drives a stake through my heart. When people say that Simon is so cute, I wonder if they are saying that only because he has Down syndrome. I just want him to be the same as everybody else. I don’t want him to be picked out for any particular reason.

**Spreading the Word**

As some of these mothers express their dawning recognition that this world is not accepting of any difference, they also strongly believe that education is the solution. In this section, several mothers assert the importance of educating the public. They want people to ask them questions about their child with disabilities, rather than gawk and point. They believe that spreading the world about disability, as well as making their child more visible in public, can minimize the fear of difference, promote tolerance, and help society become more accepting of disability. For example, Emma insists that
disability will be more readily accepted by society if it is more visible. In her narrative below, she elaborates:

I feel like the more people that see Simon out in public doing things other kids are doing, the more he will be accepted. If it’s visible, it might become part of our society. Maybe people will no longer think that people with Down syndrome should be terminated. They deserve the right to live. We need to make others aware that there is nothing to be afraid of. Simon might not be doing the same stuff at the same pace as others his age, but he doesn’t have to be considered scary or different. Simon doesn’t fit in because he has been excluded and labeled by society. It is up to me, my family, and friends to include Simon.

Like Emma, Tiffany says she enjoys educating others about her daughter’s disability because she feels it is important to spread the word about Rett syndrome:

I want people to ask, so I can spread the word about Rett. I want them to know so they are not questioning, wondering and staring. People stare because Abby constantly wrings her hands. While I am so proud of my beautiful daughter, sometimes I feel embarrassed. There are some days that I don’t care that people stare. Other days, it really hits me hard.

Throughout her story, Mary Beth touches upon the failure of many parents to talk to their children about people with disabilities. After repeatedly seeing other kids stare and make fun of her son, she wonders how parents can be so negligent in educating their children about disability. Here, Mary Beth proudly describes how her typical daughter has always been good about telling people her brother, Ben, has autism and Down syndrome: “She teaches them about Ben. Spreading the word is so important. Letting people know it is okay to have a sibling with a disability. Tolerance is a societal expectation.”

When Rachel’s daughter uses her walking cane, most kids want to ask questions about the cane, while their parents act embarrassed and try to steer them away. However, Rachel welcomes these types of conversations because she is a firm believer in education.
In the following excerpt, she explains: “I want to hear their questions because knowledge breaks down barriers. It’s an opportunity to educate others. Understanding differences has to start when they are young.” Catherine also describes how she plays the evangelist role for her son with disabilities, teaching society how to accept and live among people with autism. This is very important because she maintains below that her son might be their next-door neighbor some day: “You may have an autistic neighbor or a grocery clerk with autism. Society always tries to fit autistic square pegs into round holes. Why don’t we make the hole a little bit square? We can only do this if society helps.”

In the following two narratives, both Cindy and Jill share the importance of spreading the word about their children’s disability in hopes of making their children less invisible and more understood within society. While Cindy insists that “spreading the word” is the best form of education, Jill believes her daughter should be an “ambassador for people with disabilities” and a means to increase tolerance:

I always tell other kids to ask me anything they want. If they ever wonder why Evan has a feeding tube or why he has a high voice, they can ask me. I love spreading the word. Educate. Ask me questions instead of staring or wondering. Sometimes, when someone is being rude, I have to stop and think that I might have been that same way before Evan. I need to give them more slack because I might have been as clueless. (Cindy)

Having Sarah has made me realize how distanced the general population is from people with disabilities. People with typical kids don’t have to educate society about differences. That seems to be our job. Perhaps if I did not have Sarah, I would also feel uncomfortable around disability. I hate the fact that Sarah will be discriminated against. She’s invisible to society. It’s so sad. I feel like I need to continue taking Sarah out in public. We are out there being an ambassador for people with disabilities. Sarah has every right to be there. Maybe it will minimize the scariness of difference. (Jill)
Summary

In this section, mothers describe their public lives. They share managing the stares of others, struggling to blend in, putting up their guard, and creating a safe barrier for themselves and their families. They also share the pain of navigating sibling embarrassment and shame, as well as coping with expressions of pity and sympathy, and labels of saint, supermom, and superhero. Through these experiences, mothers describe coming to terms with intolerance, prejudice, and society’s negative views on difference and disability. In response to this narrow-mindedness, some of these mothers assert the importance of education and visibility as a means to minimize the fear of difference, promote tolerance, and help society become more accepting of disability.

In the following section, we move from mothers’ experiences concerning their public lives to their personal transformations. Here, mothers describe profound changes in self-development and self-concept based on their unique experiences raising a child with and without disabilities. Mothers open up about the positive and negative changes in their lives. They share gaining a positive outlook on life; learning the importance of acceptance, tolerance, and responsibility for others; pursuing a renewed life focus; and finding strength in their faith. At the same time, they discuss their negative transformations, which include intense feelings of unhappiness, panic, fear, anxiety, and cynicism, which now permeate their lives.

Personal Transformation

Many of the mothers in this study reflect on how their experiences raising children with and without disabilities have given them a new perspective on life and
motherhood. Their stories illustrate profound changes in self-development. They talk about being transformed spiritually and credit their children with teaching them patience and caring, as well as helping them become less judgmental and materialistic. These positive transformations include feeling more empathy, compassion, patience, open-mindedness, and understanding toward others. Mothers credit their children with disabilities with making them better people. They talk about discovering the meaning of unconditional love, learning not to take anything for granted, and feeling thankful for small blessings. They say their children have taught them a new appreciation for life, their faith, and their professional focus. While the majority of mothers experience these positive emotions, affirmative feelings are not shared by every mother in this study. Instead, some honestly describe persistent feelings of anxiety, fear, unhappiness, and jealousy. These emotions are now a constant in their lives.

This section is divided into five sub-sections. The first sub-section highlights the positive perspectives gained by some mothers due to their child with disabilities. Here, mothers share how they have become better people, gained a positive outlook on life, and learned responsibility. Mothers also discuss overcoming fears of disability and becoming tolerant and accepting of those with differences. The next sub-section, becoming assertive and resilient, focuses on mothers who have been “forced out of their shells” to become strong, outgoing advocates for their children with disabilities. The following sub-section elaborates on the new priorities of these mothers. Here, they share their renewed life focus and career transformations based on their first-hand experiences raising a child with disabilities. Learning how to depend on their faith as a means to cope
with disability is the next sub-section. Mothers emphasize their renewed faith in God and the strength they acquire from their faith. While the previous sub-sections all highlight the positive transformations shared by mothers, the last sub-section discusses the negative changes described by some mothers. Feelings of unhappiness, panic, fear, and cynicism are now part of these mother’s lives. They discuss these feelings in this section.

**New Perspectives**

Some mothers believe that mothering their child with disabilities has taught them how to be strong women who can handle anything that comes their way. They describe learning how to be hopeful and optimistic about life. These mothers also discuss how they have learned tolerance and the importance of accepting difference. For example, in the following excerpt, Anita shares her positive outlook on life and her realization that she actually has a lot to be thankful for in life. While her son, Daniel, has significant disabilities, he is still a happy little boy, which makes Anita believe that she, too, should be happy: “Look at Daniel. He’s smiling and happy through all of the challenges that he has. If he can be positive and happy, then I should be able to follow and do the same.”

Making the most out of life also has become a priority for Kate. In her narrative, she insists that living each day with a positive outlook is the only way to live. While she admits to wishing that she had three typical kids, instead of twin boys with severe disabilities, she claims she knows that this is her reality: “I have learned that you need to make the best out of everything. You can choose to look at the glass half full, or you can choose to look at it empty. And there’s no rational reason other than life is easier if you look at it half full.”
Below are several excerpts from mothers who describe their experiences raising a child with disabilities as transformational and life changing. Here, Sharon asserts the positive changes she has seen in herself as a result of her son’s disabilities: “I love the changes that I have seen in myself because of Zachary. He taught me that a person with a disability really is a person. And I think so many times in our culture, we think of them as not quite people.” In the following excerpt, Rachel describes becoming a better person because of her daughter’s disabilities and realizing the strength within herself:

I didn’t know if I could ever rise to the challenge, but I have. I have learned so much about myself and the strength within me. I enjoy who I am becoming. I know in the long run, I am a better person for these experiences. Having Chloe has changed how I see the world. My point of view was narrow, and I got easily frustrated with other people if they did not agree with me. But Chloe has helped me understand how different we all are. It took disability to show me how big the world is, and how much we really need to be here for each other.

Similar to Rachel, Tessa shares how raising her son has taught her about herself, as well as the world of disability, the struggles of others, and true acceptance. She insists that she now sees life through a completely different lens. This lens encompasses compassion and awareness, which she describes below:

Jett has taught me so much about myself. I have always thought one of the great challenges of parenting is loving and accepting your children for who they are, their uniqueness, and not trying to mold them into something different. Jett demands this in a different way. And I hope that makes me a better parent to all of my children. I think it has opened up my world to a better understanding of disabilities in general. It has created more awareness of the struggles some people go through. It has created a different lens through which to see things. When I see a man walking down the street with a limp, I think he was once a little boy with a disability. I think about his mother.
In Jill’s narrative below, she insists that raising a daughter with special needs has been an eye opener, which has put many things in perspective. She now sees herself as more caring and accepting of others:

This experience has been a huge eye opener for me. I wasted so much energy worrying about stuff that didn’t really matter. But the life-changing experience of having a child with special needs puts things in perspective. I no longer critically judge other people or their actions because I don’t have any idea of their life experiences. I am more caring toward people with disabilities and parents of people with disabilities. I didn’t know anyone with a disability before Sarah, but now I have a connection with them.

The themes of confronting stereotypes and finding value in people with disabilities repeatedly emerged throughout the narratives. For example, in the following excerpt, Madeline describes growing up fearful of people with handicaps because they were invisible in society when she was young. She recalls “gawking at them like zoo animals from behind a fence on the elementary school playground.” Despite these previously-held prejudices, she considers how her daughter’s diagnosis has actually transformed her and made her realize that acceptance is essential:

Now I can look at people with disabilities and wonder how they are doing and what they need. They are normal people, just needing some assistive devices and extra help. I have overcome my fear. Olivia has helped me realize what it really means to help a person.

Like Madeline, Maureen insists she now understands the important things in life. Here, she maintains the significance of becoming tolerant, discovering acceptance, and being responsible for helping others less fortunate:

I understand what’s important in life as opposed to money and prestige. Your sense of worth changes. I feel more responsible for helping others in the disability community. I want to fight the battles that need to be fought for those who come after. I feel a responsibility to do my part.
Becoming Assertive and Resilient

Self-development for some mothers also took the form of strength and advocacy. These mothers describe becoming an advocate for their child with disabilities as a very important life change. They happily portray being “forced out of their shell” to become resilient and confident women, and share their experiences learning to be assertive and aggressive on behalf of their child with disabilities. For example, in the excerpt below, Denise admits to growing into a strong, compassionate woman due to her daughter, Samantha’s diagnosis: “I am definitely more caring, and I am not afraid to help people. Because I have to be Samantha’s advocate and have to do everything for her, I can’t be shy. It has made me come out of my shell.” Like Denise, Anita and Barbara share their personal transformations as they have learned to become outgoing and assertive women. In the two narratives below, they describe these life changes:

I think Daniel’s disability has made me much more outgoing. I used to be very quiet. In fact, my first employer suggested assertiveness training for me and paid for it. I wonder, how did I have a special needs child, because you certainly have to be an assertive advocate. But I think he has done more for me than any class could ever do. I am more assertive and stronger. (Anita)

I used to be a “yes” person. I would put up with all kinds of bullshit. I would be taken advantage of because that’s how I was raised. I would put up with people saying unkind things. Now I am like fuck you. I believe Tyler’s disability has made me a truer version of myself. Being his mom has freed me to be the real me. I don’t need to put on different facades. It has also brought out the mama lion in me. (Barbara)

New Priorities

Mothers’ transformations also took the shape of a renewed life focus and direction, as well as new careers involving disability and advocacy work. Their newfound compassion and courage have led these mothers to strive for societal change in
the form of education, public policy, and social justice. For instance, Kelsey explains that her son, Dillon, has given her life meaning and has led her to a career as a parent educator for those coping with a disability. She says that Dillon has “carved out her life path.” In the narratives below, Bonnie explains how her son’s disability has given her a vocation as the full-time assistant director of a local early intervention organization, while Kate shares how lucky she feels to have discovered her passion and her occupation in public policy:

Before my son, I had no experiences with developmental delays. Joshua’s disability has given me my career. My life has been directed due to Joshua’s autism. I have met so many amazing people and learned so much about child development. (Bonnie)

I now work in public policy because of the twins. I am able to do things I have always wanted to do, but in a way that I never dreamed about. I can make connections for people that are life changing. Getting a family on Medicaid changes their financial status forever. I get to work with phenomenal, brilliant, and incredibly kind people that I never would have met. (Kate)

Several mothers speak of a passion being unearthed by their child’s disability. For example, in the following narrative, Gail shares how her son has given her life a new focus: “He has given me something to concentrate my life and energies on. I am not sure that I knew what my life focus was going to be before Wyatt.” Similar to Gail, Rachel happily describes discovering her new calling of helping other families affected by disability. She elaborates here: “My mission in life is to let other parents know they are not alone. Before Chloe, I would never have been able to sit and talk with anyone going through this kind of stuff. I enjoy who I am becoming.” In the narrative below, Jill also shares her new focus of helping others in need as a way to make something good come out of her own personal experiences:
I didn’t know anyone with a disability before Sarah, but now I have a connection with them. I would like to find a purpose. I’d like to help people with disabilities and their parents. I want to make something good come out of our tragedy. Having the perfect house and the perfect life is no longer important. My priorities have changed.

**Leaning on Faith**

In the previous section, some mothers describe their personal transformations taking the form of a renewed life focus and direction. In this sub-section, mothers discuss learning how to depend on their faith as a means to cope with the disability. These mothers bring to light their renewed faith in God, the strength they acquire from their faith, and the importance of faith in their lives. For example, here Gail shares how her son’s traumatic birth and his disability have tested her family’s faith and commitment. She expresses gratitude that her family did not lose their faith in God and wonders how families without faith can survive a disability:

The disability has definitely challenged our faith in that we were asking why in the world God allowed this to happen. Thankfully, we didn’t lose our faith. It was strong enough to withstand our doubts. Our faith is stronger and more real today. I am sane today because God gives me the strength and ability to live each day. I don’t know how families who do not have faith make it. We believe in working to help Wyatt reach his full potential here on earth. And we know that someday, in heaven, Wyatt will be able to stand, run, sing, talk, and have a body that is whole. This helps us with the reality of today.

Rachel holds on to her belief that God “did not do this to harm her.” Instead, she accepts that God wanted to show her a “different way and open her eyes to another world.” In her narrative, she says that in the past, she could not have accepted the world of disability because she lived in a bubble and looked at life with tunnel vision.

However, in the following excerpt, she happily maintains that her life has changed for the
better: “I’m kind of glad my bubble popped because Chloe has allowed me to not just become the best mommy I could be, but to become a better person."

When asked about her faith, Shelley speaks candidly about her daughter’s disability and her relationship with God. Similar to Rachel, she believes in her heart that God did not cause her daughter’s disability. Rather, God gave her what she needed need to cope. In the following excerpt, she explains her belief that God knew the genetic makeup of her daughter’s first cell when he called her into existence: “He loved her into being, not in spite of her differences and also not because of her differences. He just wanted her as herself.” Here, she reflects on what she believes to be her daughter’s role in life:

The disability has changed my relationship with God, and how I look at my faith. When Caroline was 4 or 5, I realized that she had a very specific vocation. She is here to teach us some very specific things about what it means to be human. That humanity isn’t something you earn. All of us should be able to respond to each other with the kind of openness and love that Caroline has. Really, in a lot of ways, it’s the rest of us who are disabled. Caroline is not participating in the “fallenness” of the world. She has a kind of purity that we all really need. The life she is living is meaningful and worthwhile, but it is very different. And the world doesn’t have a category to be able to respect that. If you could live a life free of fears, what would that look like? It would look like Caroline.

Faith is also very important to Alexandra. She reports that she no longer asks, “Why me?” about her son’s diagnosis of autism. While she admits to not understanding the universe, she takes a “biblical world view.” She says, “I feel like I can trust God no matter what. And that has made a big difference to me.”

**Negative Changes and Conflict**

Although many mothers in this study paint their transformations in a very positive light and believe their child’s disability has, in fact, made them better people, others
actually describe their experience as negative and harmful. These mothers openly portray their fear, anxiety, stress, and jealousy, and insist the disability has had a detrimental effect on their lives. For example, Georgia explains that she used to be a positive person who believed everything always worked out. However, in the excerpt below, she admits to now knowing firsthand that not everything in life works out. Additionally, she shares feeling jealous of other families who do not have to raise a child with a disability:

I was always saying things like, “It will all work out.” But now I know it doesn’t always work out. Anything can happen. I panic at what else might happen. I am overprotective of my healthy child. I need to keep her safe and healthy. I also find myself feeling jealous. I’m not jealous of others’ accomplishments or material things. Rather, I’m jealous when I see a family with healthy kids. How is that fair? Especially big families with all healthy kids. And I just have two.

Like Georgia, Gabrielle describes her negative life transformation as a result of her son’s disability. Here, she explains constant feelings of unhappiness and anxiety, as well as her inability to control her emotions:

I think as a person and a mother, I’m more anxious. I’m probably more unhappy. And a little more obsessive. I can’t help it. My husband keeps telling me to relax, that David is just a kid with delays. Some days, I can actually live with that. Other days, it feels life altering and debilitating. Sometimes, I can’t get through the week without crying.

**Summary**

When asked to reflect on their personal transformations, the mothers in this study describe their positive experiences and fundamental changes in self-development. These changes take the form of evolving into better people, gaining a positive outlook on life, and learning how to unconditionally love and care for others. These mothers also maintain the importance of learning acceptance, tolerance, and responsibility for others, as well as overcoming fears of disability and individuals with differences. Through the
experience of raising their children, they have become strong, outgoing advocates who have discovered a different life focus and direction, as well as a renewed faith in God and religion. While so many mothers emphasize positive transformations, some share transformations that are negative, framed by feelings of anxiety, fear, unhappiness, and jealousy.

In the final section, mothers share their visions for the future of their children. These visions are quite varied and range from not focusing at all on the future, to pondering it constantly and feeling depressed and anxious about it, to embracing the future and looking at their children’s prospects with acceptance and optimism. Additionally, mothers share their different future views for each of their children and insist on raising their typically developing children so they will never feel burdened or obligated to care for their sibling.

**Future**

When mothers in this study share their visions for the future of their children, these visions are quite varied. Some mothers refuse to focus on the future and instead choose to live day by day, while others mothers ponder it constantly and experience feelings of depression and anxiousness about the road ahead. Still, other mothers embrace the future and look at their child’s prospects with acceptance and optimism. When mothers contemplate the future, some also compare the countless life choices their typical children will likely have with the limited choices that exist for their child with disabilities. At the same time, they also maintain the need to diminish any feelings of caretaker burden experienced by their typical child in the present and in the future.
This section is divided into five sub-sections. The first sub-section describes how mothers live one day at a time, maintaining the need to exist day by day rather than focusing on the uncertain future ahead. The next sub-section highlights these mothers’ fears about their lifelong burden. Here, mothers share feelings of depression, anger, and anxiousness concerning the burden of caring for a child with disabilities. Hoping for the best is the next sub-section in which mothers embrace their child’s prospects and regard the future with optimism and acceptance. The following sub-section elaborates on how these mothers hold very different visions of the future for their typical and nontypical children. They share the countless life choices their typical children will likely have, while at the same time, express sadness and heartache about a limited life for their child with disabilities. The last sub-section discusses how some mothers put a strong emphasis on ensuring their typical children never feel burdened by their sibling with disabilities.

One Day at a Time

The mothers in this study talk candidly about how their child’s disability has changed their outlook on the future. Many maintain the need to live day by day rather than focusing on the future, because these women have no idea what the future will bring for their children—or their families. Many find it difficult and upsetting to think about what might lay ahead. It is far easier and more comforting for them to focus only on today. For example, Georgia insists that thinking about her son’s future is overwhelming because she cannot imagine what is to come. In the narrative below, she hopes for medical advancements and a cure, instead of dreaming about college and grandchildren:

I don’t think about the future. I just get through today. I will deal with tomorrow when tomorrow comes. Some moms spend a lot of time dreaming about college,
marriage, and grandkids. I don’t. I am hopeful for medical advancements for brain conditions. I pray that God blesses some scientist with the ability to find a cure. I hold out some hope for stem cell research. If a cure is not in the plan for Mason’s time on earth, he should certainly have a direct route to heaven when he leaves this earth. He is paying for something. I just don’t understand it all.

Like Georgia, Shelley describes her fear of not knowing the long-term implications of her daughter’s rare syndrome. To help her cope with the intense anxiety about her daughter’s uncertain future, she tries to be realistic and take each day at a time.

For Brenda, thinking about the future is a slippery slope and she tries to avoid it, albeit not always successfully. Below, she describes how she has come to realize that she lacks control in her life and that having expectations are not healthy or wise:

The future is not a healthy place to go because many things can change between now and then. I try not to think about the future for either Bridget or Elizabeth. I’d be insane to have any expectations. Bridget’s options are definitely limited, but at the same time, I never thought she would have the options that she does today. I have learned that I am not in control. It’s not about me. Living day to day is what’s best.

When both Mary Beth and Alexandra consider the future of their sons, their thoughts focus on the difficulty and uncertainty that seems inevitable. Below, Mary Beth shares how she chooses not to think about an uncertain future, while Alex describes the need to concentrate on the here and now, instead of stressing over the future:

There’s a lot of unnecessary pain that comes with thinking too much. Because you just don’t have any idea. We do what we can to plan financially by setting up a trust. But I don’t allow myself to think that far because it’s too scary. Derek [spouse] allows himself to worry about the future. And then he gets frustrated that I’m not worried. (Mary Beth)

I try not to think about the future because I don’t know what Patrick will be able to do. We need to figure out as he grows up what he’s good at and then help him do that. Right now, I can’t even visualize him driving a car. That gives me an absolute heart attack. The child is autistic. He focuses on one detail. When you drive, you cannot focus on only one detail. You have to be able to see the big
picture or you are toast. And will he mature enough to be able to drive? If not, does that mean that he will always be dependent on somebody else? I just don’t even know what it will look like at all. He’s still so little. I have to remind myself that he’s only 8. (Alexandra)

**A Life-long Burden**

While some mothers choose not to contemplate the future at all, others admit to pondering it constantly. For a number of moms, their expectations of the future are fearful and negative. Some admit to feeling depressed, anxious, and apathetic about the future. They worry about the lifelong burden of caring for a child with disabilities; the uncertainty of future medical needs, care, and expenses; and the fear that managing their child’s disability will only get more complex and burdensome over time. For example, Rebecca claims the most difficult part of her mothering journey is the fact that there is no end in sight. Because her son will never live independently, her parenting responsibilities will never change. While her friends are preparing for an empty nest, Rebecca knows this will never be her reality. Here, she describes feeling trapped by this reality and resents the fact that her burden will never ever cease: “I think about what I have given up already, and what I will have to forego in the future to help Colin. Most parents get a new lease on life after their kids go to college. But that won’t be true for us.” In the excerpt below, Kate describes her negative view of the future and acknowledges that her pessimistic vision is based on fear and anger:

I don’t have a very good view of the future. While most parents have a “before kids” and “after kids” experience, it is quite different in the disability world. There is no “after kids” experience. Medicaid funding is being cut quickly. Society does not value individuals with disabilities. I am angry, and under that anger is fear.
Similar to Kate, a cloud of fear permeates Jill’s life. When she thinks about what the future may hold, she describes her intense anxiety concerning potty training her daughter, having the freedom to travel and pursue her own personal and professional interests, and taking care of Sarah for the rest of her life. She elaborates below:

I am fearful of the future. What if Sarah never talks or is never potty trained? Will I be taking care of her for the rest of my life? Will I ever get to travel again or pursue my own interests? Will my life be a constant battle for her rights and getting her the services she needs? I suspect that taking care of Sarah will only get harder. She will get bigger and more independent. What happens when she reaches puberty? I also worry about the statistics on sexual abuse of people with disabilities. It scares the hell out of me.

Like the mothers above, Tiffany fears that her daughter, Abby, will rely on her and her husband for the rest of her life. In her narrative below, she admits to being in denial about how hard the future might be, given that Abby cannot feed herself, bathe herself, dress herself, or do anything independently. She also worries that life will get even harder as Abby gets older:

My husband says we are in the honeymoon stage now because Abby is so cute and little. But it is going to get tougher when she gets older and people start wondering more about her. And what about the teenage years? What do we do when she starts menstruating? It sounds so terrible, I know, but I’ve thought about a hysterectomy. It will be so much more challenging down the road.

For Susan and Marcia, their fears about the future focus on their children with disabilities growing older and fitting into society. In the excerpts below, Susan worries that life with her son will become more difficult as he becomes a teenager with raging hormones and is unable to talk like everyone else. For Marcia, life with her young son, Daniel, is currently manageable. However, below, she describes her fear of what may happen when her sweet, little boy becomes an adult:
I worry that things will only become harder. The communication piece with family, friends, and school will cause more problems. He will wonder why he can’t talk like everyone else. I think that as he gets older, he’s going to figure out that he is not like everybody else. This will inevitably cause challenges, especially in the teenage years. All of the hormones will make it worse. (Susan)

These days, Daniel does everything just like everybody else. We don’t ever really think about him having Down syndrome. Daniel is still in this little boy stage where he’s sweet, happy, and outgoing. People are very nice and sometimes over-accommodating. But what happens when he is 25 and does something unusual or inappropriate . . . (Marcia)

Some of the mothers’ narratives indicate they spend a great deal of time contemplating the future living arrangements of their children with disabilities. Some of them recognize that, while they would like their children to live separately from them, this is not realistic. They offered various reasons for this, including “nobody can take care of my child better than me” and there are “no decent group homes or long-term care facilities available.” For example, Anita describes how her son, Daniel, will most likely live with her and her husband as long as they are physically able to care for him. However, in the excerpt below, she describes how this option is less than optimal: “My fear is that I don’t want Daniel to be home with me all day when he’s in his 20s. There’s got to be some value to his life. His physical care worries me. As I get older, I wonder how I will be able to do as much for him.” In her narrative below, Gail also describes planning to care for her son:

Our plans are to have Wyatt with us until we die. I have seen what’s out there and there is no way anybody else can care for him like we can. Looking to the future, I see him living out his life with us. We will never be empty nesters. It makes me sad at times. I don’t really let myself think about what will happen when we are gone.
Like Gail, here Denise shares her reality of having her daughter live with her because of Samantha’s inability to live independently: “I never want to put Samantha in a home. She will always be with me. It is going to be until death do us part. I never see her living independently. Health-wise, she needs somebody with her because of the seizures, and she is a wanderer.”

**Hoping for the Best**

Rather than fearing the future or avoiding thoughts about what may lay ahead, some mothers actually embrace their child’s prospects and think about the future with feelings of acceptance, optimism, and hope. An example of this is seen in Sharon’s narrative, where she imagines that her son with disabilities may be able to attend college someday and have a fulfilling life. In the excerpt below, she shares her optimistic vision of education and family life for her son:

There are some great post-secondary programs that are beginning to evolve for kids with disabilities. We fully expect Zachary to have girlfriends, and if he wants to get married, that’s great. A lot of people with Down syndrome are getting married. The girls already talk about how he will be a great uncle. But I think he will have a great future. He constantly rises above our expectations.

Like Sharon, Maureen tries to be optimistic about the future. She maintains that, while she and her husband do not necessarily agree on how things will turn out for their son with disabilities, they are planning for the worst and hoping for the best. In the excerpt below, she describes how she considers a job at Wal-Mart as her worst-case scenario for her son, Joseph:

I’m thinking, why would this kid go to college? It’s such hard work for him, why would he go down that path? Maybe a trade would make more sense for him. When I go to Wal-mart, I get a strange sense of reassurance that Joseph will be okay. Because everyone from the shoppers to the people working at the checkout
seem to be at his level. I am encouraged by thinking that this might be the worst-case scenario for Joseph. And it is not bad by the average American standard.

Raising a son who is self-sufficient is very important to Catherine. She imagines her son, Owen, living in his own apartment one day, together with someone who understands autism and who can help him. She hopes he can lead a fulfilling life and contribute to society by working at something that is important to him. Below, Catherine explains how she hopes to help her son create a fulfilling future for himself:

This past summer, I got a plot in a community garden so that I can hopefully teach Owen a life-sustaining skill. I look at it as one thing I can do for Owen’s future. Society always tries to fit autistic square pegs into round holes. Why don’t we make the hole a little bit square?

**Different Futures**

When discussing the future of their child with disabilities, the subject of siblings came up frequently. A common thread in the narratives of these mothers pertains to having very different visions of the future for their typical and nontypical children.

Mothers share the countless life choices that their typical children will inevitably have, while at the same time, expressing their sadness and heartache about what might lie ahead for their children with disabilities. For example, in her narrative below, Rebecca describes not being able to think about her son’s future when he was a baby. However, she claims she has learned to accept his disability and can now ponder the future of both her children with more equanimity:

Our kids will have very different futures. For Laura, we have the typical dreams. She will go to high school, study hard, get good grades, go to college, find a partner, and have a life that makes her happy. I’m not hoping Colin will go to college and be a lawyer or a doctor. I just want him to find some type of sheltered work environment, so he can be stimulated and fulfilled, be interested, and have a safe place to live.
Like Rebecca, Anita imagines her typical son, Seth, going to college, getting married and having kids. But she sees a different future for her son, Daniel, who has disabilities. Below, she expresses her intense fears for Daniel’s future:

I can see through high school, but not beyond that. My biggest fear is what Daniel’s life will look like beyond high school. I think he’s bright, but what will he be able to do to contribute? Where will he find his social interaction beyond Larry and me? These are huge worries and fears with a lot of unanswered questions.

Pondering the future is an ongoing hardship in Donna’s life. Here, she describes her hopes for both Emma, her typical daughter, and Jack, her son with disabilities. While she hopes each child will experience happiness, Donna admits this happiness looks quite different for each of her children:

I think about the future a lot. I want Emma to find her passion. I want her to be happy, have good balance, and know she is loved and wanted. For Jack, I hope for the same things, but they just look different. We are working on communication right now. That is the key to Jack’s independence. I want him to be as independent and happy as possible. I really worry about his social life and his lack of friends because he is nonverbal. I hope he has a love of learning so that he can learn his entire life. Maybe he will go to college someday. I am not going to say no. Why close out the potential?

In sharing her visions of the future, Shelley describes feeling fearful and uncertain about her daughter’s future. Here, she shares her certainty that Caroline, diagnosed with a rare syndrome, will have few choices in life when compared to her typical sibling, Zachary: “I try to be realistic and take each day one at a time. The difference is that I see Zachary as having so many choices. For Caroline, it’s the opposite. She’s not going to have a whole range of choices.”

Like Shelley, Gabrielle pictures the future of her two typical sons looking quite different from the future of her son with disabilities. She describes thinking about her
three sons in very different ways and claims that she does not know how to picture a
future for her son, David, diagnosed with a rare syndrome. She explains below:

I never imagine David in quite the same position as the other boys. I always think
that there’s going to be some special circumstance surrounding him. And on the
rare occasion when I don’t think that, I generally tend to think that I am kind of
delusional. I have a vision of Ben and Charlie’s future, but I don’t know how to
picture a future for David. It’s hard. There are days when I look at David, and he
seems so very vulnerable to me. His hands and feet are impossibly small. He’s
still a bit wobbly on his feet, even after turning 5. I look at him and think, how
can he possibly make it in the big world? And then I need to remind myself to
take it one day at a time, to not think about the future.

Caution: A Caretaker Role

When mothers consider the stark differences in their children’s futures, the notion
of caretaker burden inevitably surfaces. A top priority for these mothers is ensuring their
typically developing children do not feel burdened by their siblings with disabilities.
Mothers discuss being careful not to unduly pressure typical siblings to help their
disabled siblings. They speak of striving to raise their typical children so they never feel
burdened by an overdeveloped sense of obligation. It is important to these mothers that
their typical children never feel forced into being a caretaker. Rather, they want their
contributions to arise from their own choice rather than from a sense of duty. For
example, Cindy expresses hope that her two typical sons will want to look after their
brother with disabilities. However, she fears burdening her two typical sons, which she
shares below:

It is really hard to think about the future. I am not sure where Evan will be, and
I’m just afraid to think what would happen if something bad happened to me or
Peter [spouse]. I am sure the other boys would be willing to take him, but I don’t
want to change their life in that way. Not burdening them is important to me.
Like Cindy, it is very important to Kelsey that her typical daughters never feel backed into a corner or burdened by their brother’s care. In her narrative below, Kelsey hopes her two typical daughters will plan their future independently of the needs of their brother, Dillon, but she believes this is probably unlikely: “I am sure they will always be connected to him in some way. But I just do not want them to feel burdened.” When discussing the future, Anita shares her reality that her son, Daniel, will need lifelong care. She insists that her younger typical son should never feel obligated to care for his brother and maintains that she and her husband discussed this issue exhaustively before deciding to have a second child. She elaborates below:

We didn’t have another child so there would be someone to care for Daniel when we were no longer able. I never want Seth to feel like Daniel is his responsibility. We will always involve him in Daniel’s care, so he’s aware of it. I want Seth to be connected to his brother in whatever way possible, but I don’t expect him to be a caregiver. If he wants to do hands-on care, then great. But only if that’s what’s in his heart.

While most of these mothers worry about their typical children feeling a sense of burden and obligation, several mothers also spoke of their hopes and expectations that one day, their typical children will actually want to take over the care of their sibling with disabilities. For instance, in Catherine’s narrative, she expresses her confidence that her other typical kids will want to begin stepping in to take care of their disabled brother. This may mean living in the same town as their brother, or it may mean having him live with them. Gail feels the same way. Raising a family with three typical children and one child with disabilities, she hopes that her other kids will want to care for their brother when she and her husband are no longer able. In the following excerpt, she explains feeling as if this is a family duty, instead of a burden:
I could see Wyatt’s siblings taking some kind of supervisory role over his care, if not actually doing it themselves. I don’t worry about burdening them because in my book, that’s what our family does for each other. That’s what we do. I am hoping they will feel that way down the road. We need to be talking about it more.

**Summary**

It is evident in this section that the future visions of these mothers are extremely diverse. Some of the mothers in this study choose to avoid the entire subject of the future and instead focus on living in the here and now. Of the mothers who do ponder the road ahead, some experience feelings of depression and anxiousness concerning future medical needs, care, and expense, while others embrace the future and look at their children’s prospects with acceptance and optimism. When mothers contemplate the future, they also share the countless life choices their typical children will likely have, while at the same time, expressing sadness and heartache over the limited choices that exist for their child with disabilities. These mothers also discuss the importance of reducing any feelings of caretaker burden experienced by their typical child in the present and in the future.

This chapter has presented an analysis of 32 mothers’ narratives. To examine the mother’s poetic representations as a whole, I used a form of analytic induction described by Bogdan and Biklen (2002). From this process, emerged several common themes, which I developed into categories. These categories successfully group the data, while also leaving room for each mother’s voice to be heard. In the following chapter, I discuss the findings and examine the importance of these themes in understanding these mothers’ unique journeys.
Chapter Six: Discussion: What Does It All Mean?

Overview

Parenting is one of the most significant chapters in the life of an adult (Hanessian, 2004). But how does having a child with special needs affect this experience? And how is the experience further altered by parenting both a child with special needs and one without? Previous research on childhood disability has generally ignored the actual lived experiences of parents. Additionally, studies of parents raising children with and without special needs are scarce.

This study sought to address these research gaps by focusing on the first-hand experience of families with and without children with special needs. Its importance is supported by disability studies and family communication researchers who have noted the need for additional analyses of parental experience to better understand relationships and life within families (Braithwaite et al., 2001; Canary, 2008; Parmenter, 2001).

Ferguson (2001) maintains that focusing on the first-person narrative accounts of families answers the need to comprehend how the accounts “match the conceptual developments in research” (p. 390). He contends that first-person narratives from parents and other family members can potentially capture the facets and flavor of daily life and family history, thereby imparting a fresh assessment of an individual’s life. This assessment is important, according to Marks (1998), who asserts that the duties of mothering a child with disabilities are often distorted and unclear. Given the large population with special
health care needs, he believes it is essential to understand the demanding multiple-role responsibilities of these mothers.

In this study, I explored the exceptional experiences of mothers raising children with and without disabilities. The purpose was to gain insight into how these mothers view themselves, their lives, their children, and the world around them. Understanding their evolving sense of self and their roles as mothers is fundamental to this effort. While the children in this study have been diagnosed with a variety of different disabilities, these mothers encounter similar, first-hand experiences. They are members of a club that promotes an assumption of common understanding, as well as a shared pragmatic view of the world in which parents of disabled children reside (Jenks, 2005). As the researcher, I hoped to expand the understanding of the unique voyages of these 32 women and gain insight into their exceptional lives.

As discussed in the introduction of this study, my personal experiences mothering one child with disabilities and two typically developing children places me within the study population. However, I was hesitant to focus on these experiences for fear of the potential bias that might occur within the study. While my own journey definitely increased my understanding of the participants’ experiences, it was important to be aware of the fact that not all of my participants had the same encounters as me and were in different stages of their respective journeys. I needed to be careful not to let my first-hand knowledge about the challenges and demands of raising a child with special needs have any impact on my role as researcher. I needed to make every attempt to remain
open and receptive to the stories of each mother and allow their individual stories to unfold naturally.

My aim was to use my knowledge, familiarity, and understanding of childhood disability to provide valuable insight. As a result, I chose to only share my story in the introduction as a springboard for the study and allow the stories of these 32 mothers to stand on their own. I used my knowledge solely to create the research and interview questions. The questions asked of participants in this study were designed to elicit information about the challenges that mothers raising children with and without disabilities encounter in their lives, as well as to provide increased awareness and insight into their journeys.

I hoped to answer two broad research questions regarding the maternal experience of raising children with and without disabilities. The first research question asked: What are these mothers’ revelations about their mothering journey? I asked this question as a way to uncover and bring to light these mothers’ feelings, thoughts, and experiences. I hoped to discover how mothering disabled and nondisabled children shapes a mother’s sense of self, identity, and development as a woman and a mother; how these mothers find meaning in their encounters; how they view themselves, their families, and their lifelong journey; and what their deepest feelings and thoughts are regarding their mothering experience. This research question was answered by mothers as they shared their stories of diagnosis, perceptions of motherhood, personal transformations, and future visions.
The second research question asked: What are the private and public experiences of mothers raising children with and without disabilities? By asking this two-part question, I hoped to gain insight into how these mothers described and found meaning in their private lives, as well as how they perceived their public lives and navigated public spaces with their children. I asked this particular question because of my interest in grasping how these mothers manage the public-private split. I hoped to elicit feedback on the many different issues that arise concerning the influences of social interaction, cultural norms and values, social status and role, as well as the private dynamics between families and spouses.

Because many mothers considered their personal lives to include their family encounters, as well as their marriages (and in two cases, divorces), the first part of the research question was answered by mothers as they shared stories of their family life and their experiences being married and divorced. The second part of the research question provided insight into how mothers manage being out in public with their children and the effects that these experiences have on their lives.

In addition to discussing these seven themes (diagnosis, motherhood, personal transformation, future visions, family encounters, marriage/divorce, and public life) as they related to the two research questions, I also considered how the findings linked to pertinent literature, as well as the theories of symbolic interaction and social construction. Because the theoretical framework of both symbolic interaction and social construction is embedded within the responses to both research questions, these two theories were discussed in relation to the
research questions and the themes presented in this study. This chapter concludes with a summary highlighting several important research findings from this study.

**Discussion of Findings: Research Question #1**

The first research question invited mothers to share their revelations concerning their mothering journey. In an attempt to answer this complex question, it made sense to start by looking at the theme of diagnosis, given that discovering the diagnosis of their children was the beginning point of these mothers’ compelling journeys.

**Tales of a Diagnosis**

When sharing the stories of their child’s diagnosis, many of the mothers in this study described feeling shocked and heartbroken to learn their child was not “perfect.” They asked why me and why my child, and felt like failures for not creating a healthy baby. They imagined a hopeless and depressed future. These negative perceptions were driven by a fear of the unknown since many of these women had no experience with disability. The few women who had firsthand knowledge of disability through family, friends, or employment reported mainly negative emotions framed by fear and tragedy. This is not a new finding. In fact, today’s advanced reproductive technologies, prenatal diagnosis, selective abortion options, and widespread education on ensuring healthy pregnancies have created the illusion of complete maternal control. This misconception prompts many women to believe they should be able to create a “perfect” baby. Supporting this notion is a study conducted by Nancy Press and colleagues (1998), who found that asking mothers about the implications of bearing a child with a handicap or severe medical problem elicited negative and fearful responses. Pregnant women
considered a potential disabled child as the “other”—not normal, perfect, healthy, or expected. Additionally, a study examining women who chose to terminate a fetus with a diagnosed disability found these women terminated their pregnancies because of their refusal to bring a fetus known to have an anomaly into a society which they believed stigmatizes, disables, and refuses to support individuals with impairments (McCoyd, 2008).

While our country’s legal system guarantees the equal treatment and full inclusion of people with disabilities, negative and stereotypical attitudes persist throughout the general population (Krahé & Altwasser, 2006). This devaluing of people with disabilities begin early in childhood, possibly arising from cultural and social norms maintaining the need for beauty, youth, and fitness, and media portrayals of disabled people as sick and suffering (Richardson et al., 1961; Ruffner, 1990; Ryan & Runswick-Cole, 2008). As a result, the mothers’ previously-held prejudices are not surprising. They describe their past inexperience with disability, holding stigmatizing views about people with disabilities, and being thrust into the unknown world of disability. The mothers in this study reflect on their past prejudices and on initially feeling miscast as the mother of a disabled child, a role they must begin adjusting to the minute the doctor hands down a diagnosis.

Green (2001) maintains that mothers typically have no experience with disability; it is unfamiliar and frightening. “Now, suddenly, they face the experience of disability from the perspective of an insider. What was formerly foreign is now part of their lives, homes, and hearts” (Green, 2001, p. 804). In Landsman’s (1998) study, she reports that
many mothers discuss the existence of prejudice toward people with disabilities, including their own previously-held prejudices. Their current experiences raising children with disabilities dispel these past prejudices, but nevertheless, they did exist at one time. In a later commentary, Landsman (2000) describes how mothers attach meaning and purpose to their child’s disability and reflect on their own growth. “Mothers often come to extend the status of full personhood to other people with disabilities and to other groups in society whose personhood has been diminished for other reasons, and to reconstruct for themselves an image of normal motherhood of a different but perhaps richer kind” (Landsman, 2000, p. 186).

While many mothers in this study described their grief and pain upon receiving their child’s diagnosis, a few said they felt relieved about having their suspicions validated and receiving a definitive explanation for their child’s delays, health issues, or behaviors. For these women, learning about their child’s diagnosis was liberating, finally answering their long-held questions and assumptions, and laying their initial worries to rest. Additionally, their child’s diagnosis ultimately resolved some of their uncertainty and ambiguousness, and offered the opportunity for support and information. This is backed by research that asserts parents embrace a diagnosis label for their child because this label offers parents a means of protecting themselves from being deemed inadequate or incompetent parents, as well as providing a plethora of resources, information, and support (Avdi, Griffin, & Brough, 2000; Ryan & Runswick-Cole, 2008). While some mothers in the study described grief and pain, others expressed relief, and still other
mothers described having ambivalent emotions—relief mixed with sadness, heartbreak, and devastation.

Many mothers in this study reported unsupportive interactions and negative feedback from medical professionals who originally had failed to uncover the disability. Some deemed the mothers to be overbearing and, in some cases, hypochondriacs. Several mothers described doctors whose delivery of their child’s diagnosis lacked empathy or understanding. These medical professionals exemplified the reality of negative societal attitudes toward disability, conveying their own personal biases toward raising a child with disabilities. Their attitudes encompassed tragedy and loss, reduced quality of life, and the lifelong burden of caring for a child with special needs. In addition, mothers described a lack of support and adequate information about their child’s disability and what the future may hold.

This negative feedback is supported by the literature. For example, in a study conducted by Kerr and McIntosh (2000), mothers claimed the information they received from doctors was scarce, which elevated concern and fears of the future. They also reported a lack of reassurance and emotional support required at the time of discharge. Additionally, in a 2007 U.S. Department of Health and Human Services study, parents reported their doctor did not spend enough time with their child, did not provide enough information, and did not make parents feel like a partner (USDHHS, 2007). While Graungaard and Skov (2007) maintain the importance for health professionals to communicate a diagnosis with equality and empathy as a way to facilitate parental adaptation, some of the mothers in this study did not experience this type of
communication in any way. This lack of support is problematic as encouragement and assistance during the initial days of a diagnosis has proven to be important and can affect short- and long-term coping and adjustment (Kerr & McIntosh, 1998).

According to Ferguson (2001), these unsympathetic and insensitive deliveries of such diagnoses are extremely common, and current literature is stocked with appalling examples. Parents often recall a coldly clinical depiction of their child, dictated by medical perspectives and prognoses (Engel, 1993). Rarely is mention made of the positive, encouraging aspects of raising a child with a disability. Lalvani (2008) describes the existence of stereotypical images of Down syndrome, as well as the perceptions of never-ending adversity for families of children with Down syndrome, which permeate medical discourse and practice. In her study of mothers raising children with Down syndrome, she found that mothers’ opinions of Down syndrome were strongly influenced by the viewpoints of medical professionals, as well as the language they used. Mothers in the study also expressed extremely negative feelings about interactions with their physicians following a prenatal diagnosis of Down syndrome.

Some mothers in this study also described negative experiences with genetic counselors that consistently linked disability with a diminished quality of life for all family members. Supporting studies have found many mothers experience off-putting reactions by genetic counselors that associate disability with damage and defect (Rapp, 2000). These experiences are unsurprising, given that the widespread practice of prenatal testing and selective termination of fetuses with possible disabilities reflect the idea that having a child with a disability is an extremely unfavorable outcome, freighted with

In this section, mothers described their diagnosis stories. But receiving a child’s diagnosis is only the starting point of these mother’s extensive journeys. The next stage of their voyage relates to their complex notions of motherhood, development, and identity.

The Meaning of Motherhood

As mothers contemplated their mothering journey, they openly and honestly shared their ideas and experiences concerning the meaning of motherhood, self, and identity. Here, mothers begin to accept the diagnosis of their child and ponder the implications of motherhood. This notion of motherhood involves defining and redefining their identities as mothers and their own personal meaning of motherhood.

Many women view motherhood as a calling (Blair-Loy, 2003). They believe that motherhood—the need to continuously nurture their fragile children—is the most intimate and important role in their lives (Blair-Loy, 2003; Nash, 2002; Rogers & White, 1998). In fact, most women are mothers at some point in their lives (U.S. Census Bureau, 2003). As defined by the social practices of nurturing and caring for dependent children, this role is the primary vehicle through which women form their identities and learn their place in society (Arendell, 2000). Mothers are often discussed as caregivers for their children, and the individuals through whom others’ lives are changed (Medina & Magnuson, 2009). Women’s identities as mothers are a fundamental element of their perception of female roles and responsibilities.
These concepts are supported in this study as the mothers discussed their crushed dreams and living a life they never expected. They once fantasized about enjoying happy, easy lives, never imagining they would raise a child who was not normal. These mothers admitted to possessing unrealistic ideas about motherhood, spending little time pondering the possible difficulties, and never considering that their children’s lives might not mirror their own childhoods. Their fantasies of blissful motherhood and perfect babies are consistent with research, which asserts that parents romanticize parenthood and expect to have an ideal child. Their images and expectations of their child and parenthood are developed prior to their child’s birth (Harwood, McLean, & Durkin, 2007). These ideas are further shaped by popular cultural and societal expectations (Blacher, 1984; Medina & Magnuson, 2009; Mori, 1983). Many women’s visions of motherhood originated from their own childhoods, specifically from their own mothers. In their narratives, they shared how their mothers demonstrated “perfect parenting techniques” and how they tried hard to emulate them. While they admitted their lives have not gone according to plan, some acknowledged the need to come to terms with the disability in order to “survive” and “move forward.”

According to Simonds and Rothman (1992), women form their identities through the experience of motherhood. At the same time, a transition of identity is also a fundamental aspect of motherhood (Boström, Broberg, & Hwang, 2009; McMahon, 1995). The mothers in this study were forced to shape new self-identities and seek new meanings for their realities, and extensively revise their expectations and preconceptions (Graunegaard & Skov, 2007). They had to learn how to reconstruct their maternal roles to
accommodate their experiences mothering a child with disabilities (Shu et al., 2006). In Landsman’s (1998) study, the mothers of children with disabilities suggest that, for them, parental adjustment is not about resigning themselves to the tragedy of having a disabled child. Rather, it is about being challenged by, and redefining through experience, existing cultural understandings of what constitutes normal and perfect. Landsman examined how these women struggle to define their maternal identities within the cultural definitions of mothers of children with special needs as different and devalued.

These difficult experiences can be further explained by the impact of the maternal role on mothers. It is the primary caregiver, generally the mother, who must adapt her life to her child with disabilities. The mother tends to have significant responsibility for the caring role, which is often expanded and extended over a long period of time (Cole, 2004; Read, 2000; Ryan & Runswick-Cole, 2008). This role usually takes on the additional duties of managing therapeutic services, special education requirements, medical intervention, and behavior management, in addition to the tasks mothers are typically expected to perform (Pelchat, Bisson, Ricard, Perreault, & Brouchard, 1999). These responsibilities often require a considerable amount of time to complete, can be physically demanding, can negatively affect family and social relations, and disrupt employment responsibilities (Brannen & Heflinger, 2006; Seltzer & Heller, 1997). Moreover, she must struggle with her own thoughts and reactions, including feelings of resentment, inadequacy, depression, and guilt; physical health problems; and decreased quality of life (Featherstone, 1980; Feldman, McDonald, Serbin, Stack, Secco, & Yu, 2007; Ones, Yilmaz, Cetinkaya, & Calgar, 2002).
Guilt was an overarching theme throughout this study. Mothers felt guilty for many reasons: Being unable to provide a perfect world for all their children; blaming themselves for the disability; not spending enough time with their typical children due to the care and attention required by the child with disabilities; worrying about not meeting the needs of other family members; fearing their typical kids are unable to experience a normal childhood; and not devoting more time to therapy exercises with their disabled child. The view of mothers as “little more than architects of the perfect child” (Eyer, 1996, p. 6) had significant implications for these mothers’ identities and self-concepts (Collett, 2005). Many of these women’s’ identities were tied to how well they performed the role of mother, which is fundamental to their perceptions of female roles and responsibilities.

These mothers also spoke of feeling intensely lonely. They shared the constant, heartbreaking reminders of their child’s limitations, which are often triggered by friends and family who do not understand or recognize the daily struggle of raising a child with disabilities. They elaborated on the difficulty of connecting with other mothers who do not seem to appreciate how “easy” their lives are in comparison. Supporting research by Green (2003) reports that mothers raising children with disabilities tend to withhold their birthing stories in groups of women unfamiliar with childhood disability, because their stories do not include the typical happy endings.

Mothers’ feelings of loneliness were linked to sentiments of depression and social isolation shared by many of the mothers in this study. They described wishing their child with disabilities could fit in and participate in the same activities as typical kids. They
spoke of feeling detached from their friends and family members, and being jealous and envious of the lives of others. These feelings of isolation have been documented by several researchers, who maintain the special needs of children with disabilities tend to separate parents from their extended families; natural support systems, such as friends and neighbors; and the community (Freedman & Boyer, 2000; Johnson & Kastner, 2005; Worcester, Nesman, Raffaele Mendez, & Keller, 2008). In fact, Todd and Shearn (1996), use the term, “peripherality,” to describe mothers’ position at the margins of society, a position of isolation and exclusion from peers.

In addition, these mothers expressed discomfort with being considered a supermom, saint, or superhero by others. They rejected the widespread notion that raising a child with disabilities makes a mother extraordinary, and insisted they are just ordinary women who had no choice regarding their child’s disability. They shared an aversion to these labels, explaining their frustration in hearing them because “nobody would ever want to trade places” with them. Mothers claimed that, while these statements are meant to sound supportive and sympathetic, they are typically voiced by women who clearly are “just so relieved it is me and not them.” These public reactions to mothers raising children with special needs—steeped in notions of misfortune, sadness, and burden—are socially embedded. It is clear from these mother’s experiences that society’s understanding and acceptance of disability revolves around tragedy and undesirability.

Many mothers in this study consistently asked themselves, “Where is the joy inside of me?” They conveyed their sadness and disappointment, including their unmet
expectations and daily struggles to accept their child’s disability. They described being overwhelmed, anxious, and unhappy; losing control of their lives; and feeling like a failure as a mother. They expressed sadness and despair about being unable to participate in normal, relaxing family activities, watching their child with disabilities miss out on friendships and parties, and not doing enough for all of their children. They shared feeling that their own needs are going unmet and struggling to rediscover what they want out of life. This finding is backed by Larson (2000), who maintains it is common for mothers raising children with disabilities to associate their feelings of well-being with their child’s progress and their ability to meet their day-to-day challenges. Lightfoot and Valsiner (1992) assert that a mother’s role as a caregiver is guided by her belief system, which is built on meanings acquired from her culture and communicated by other adults and society. Mothers impart cultural messages about childhood, as well as their experiences with children, to their children and to others. This interaction shapes their role as parents (Lightfoot & Valsiner, 1992). For these mothers, this culturally communicated responsibility for their children, as well as the duty of creating perfect children, created a sense of imbalance and distress in their lives (Landsman, 1998, 2003).

To combat these intense feelings, numerous mothers in this study discussed the importance of seeking social support. They explained that their support group provides them with strength and hope, and helps them feel less alone in the world. Forming important alliances and deep, lifelong friendships has enabled these women to be more accepting of their children and their challenging situations. The support group provides a
sorely needed outlet when they have difficulty communicating with and relating to their husbands, family members, friends, neighbors, and mothers of typical children.

Social support can be a lifeline for people dealing with difficult life issues. This support has proven to be a successful mediator between stressful life experiences and family adjustment and health (Beckman, 2002; Kerr & McIntosh, 2000; Resch et al., 2010). This is especially true for those coping with a disability, which bears an undeniable stigma. Social support enables these families to reclaim control over their lives and enhance their day-to-day well-being. Support groups have long provided a therapeutic and social resource for the positive construction of identity for the stigmatized and socially alienated (Ablon, 1981; Huws et al., 2001). They also serve other important functions, including sharing information and resources; discussing taboo topics; experiencing mutual support and catharsis; sharing feelings in a nonjudgmental environment; engaging in problem solving; reducing stress, alienation, loneliness, and isolation; reinforcing effective coping techniques; becoming a helper to others; developing social networks and supportive relationships; finding inspiration and hope; and validating thoughts and feelings (Braithwaite et al., 1999; Flexman et al., 1999; Fullmer & Majumder, 1991; George, 1987; Gottlieb, 1981; Huws et al., 2001).

According to Winterhalter (1992, 2001), support group sessions target the need for basic information; the unpredictability of an individual’s prognosis; feelings of anger; the need to grieve; difficulty in maintaining family functioning, including communication and task fulfillment; and the need to facilitate communication with family members and others.
While some of the mothers in this study expressed powerful feelings of sadness, isolation, loneliness, and guilt, other mothers believed they have learned the meaning of unconditional love and considered their child with disabilities to be a blessing and a gift. They worked hard to be optimistic and accept the disability. These mothers acknowledged their struggles but also believed their disabled child is a wonderful gift. They tried to focus on small improvements, find happiness in their children’s special abilities, and continuously searched for ways to cope with, and even enjoy, their lives. They focused on hope, knowing that the absence of faith and optimism can have tragic results. These mothers mostly found their lives rewarding and full of joy, and felt lucky to mother their child with disabilities. They described how he or she has given them a new perspective on life, forcing them to slow down and appreciate the simple things. They believed their children are on this earth to teach us about life and what it means to be human.

Numerous mothers spoke about experiencing conflicting and inconsistent emotions, and living an extreme human paradox. On the other side of their grief, anguish, disappointment, and helplessness lay happiness, love, and strength. These feelings were articulated by mothers who felt guilty and sad, yet also considered their child a gift. They revealed contradictory emotions and vacillating feelings. While some moms worked hard to be optimistic, accept the disability, and focus on narratives of hope and optimism, others spoke of feeling cheated by their child’s disability and wishing for a different life. These mothers described life lessons learned through a range of contradictions, such as joy and sorrow, and disappointment and satisfaction. They
described feeling happy and content one moment, and angry and upset another. On some
days, they felt proud of their child’s accomplishments, while other days, they felt
embarrassed and hopeless, wishing their child had never been born. Mothers described
these fluctuating emotions as uncontrollable and inconsistent—sometimes fleeting, other
times lasting for weeks. Some described the concept of grief as a never-ending cycle.
They understood their grief will inevitably emerge at different times throughout their
lives, and they must cycle through it again and again.

These conflicting feelings are supported by Greenspan (1998), who found that
mothering a child with disabilities is like parenting without a developmental map. There
are few guidelines, just a range of conflicting, contradictory, and more often than not,
negative points. Mothers in Greenspan’s study assert that while mothering a child with
disabilities is laborious and difficult, it is also a delight and a gift. However, the delight
does not cancel out the difficulties.

The conflicting nature of these mothers’ outlook on their lives is a noteworthy
finding. One possible explanation for this paradox is the disparity between the socially
constructed identity of the “perfect mother” of the “perfect child” and these mothers’
actual life experiences. This discrepancy in identities can create turmoil within the
personal narratives of these mothers. Because mothering an ideal child has long been
associated with images of joy and fulfillment, being the mother of a less-than-perfect
child can create a complicated dilemma. These mothers find themselves in a state of
chaos resulting from unmet socially prescribed expectations. They must disregard their
own pain and disappointment to seek the joy and contentment portrayed in societal
images of motherhood. They must overcome their own stereotypes of disability, as well as society’s prejudices, and struggle to make their child’s world a more accepting place for him or her. They must construct an identity in which they are strong women living out hope and acceptance. However, these mothers are only human, and they confessed to moments of self-pity, shame, disappointment, resentment, and regret. This dynamic makes their mothering experience a contradiction in terms. Congo (1988) documents this paradox in her definition of motherhood. She characterizes the culturally determined images of the “good mother” as always being energetic, patient, loving, and self-sacrificing. Nevertheless, she considers these to be romanticized myths, which often engender feelings of inadequacy, pain, and frustration for mothers.

Green (2007) suggests the lives of mothers raising children with disabilities may be much more emotionally complex than generally assumed. In her study, mothers reported valuing their children and noted significant benefits in raising them. While they recounted feeling emotionally rewarded, they also shared feeling tired and negatively affected by the financial stresses and time constraints. For Larson (1998), the paradox of depression, despair, joy, and acceptance can be explained as the tension between their child’s current circumstance and their hope and desire for a better future. Although this tension provided positive energy for the mothers, it could “crash” in an instant due to the many obstacles and hardships they face.

Another possible explanation for the conflicting nature of these mothers’ outlook on their lives may be related to the specific children in this study. Because the disabilities vary considerably, some of the children have mild symptoms, while others
have moderate to severe symptoms. Some symptoms are obvious to strangers and disruptive in public, while others are minor or even invisible in public. Given the heterogeneity of this population, some mothers’ daily experiences might be severely stressful, while other mothers may find their child’s disability far more manageable. For example, children on the autism spectrum often exhibit disruptive behaviors that are hard to manage, which can create extreme chaos for the family. (Myers, Mackintosh, & Goin-Kochel, 2009). As a result, some parents fear leaving their home due to public scrutiny, which creates stress and anxiety. It is clear that the severity of the child’s disability plays a role in the outlook and stress levels of mothers.

Additionally, some of the mothers in this study might portray their lives as much more hopeful and positive than their reality, possibly painting a bright, optimistic picture to drown out their actual feelings. These mothers also may be redrawing themselves and their family lives to avoid being portrayed—or viewing themselves—as unloving or unappreciative parents.

In the following section, we move from these mothers’ notions of motherhood to their personal transformations. In considering their revelations about their mothering journey, they opened up about the positive—and negative changes—in their lives as a direct result of their experiences raising a child with and without disabilities. They reflected on how their experiences have provided them with a new perspective on life and motherhood and shared their profound changes in self-development as part of their mothering journey.
Personal Transformations

Reflecting on their transformations, mothers spoke of many discoveries: the meaning of unconditional love, the importance of accepting their children for who they are, learning to be a better parent to all of their children, taking nothing for granted, remaining hopeful and optimistic about life, expanding their narrow view of themselves and the world, being more aware of difference and the struggles of others, and seeing the world through a different lens. These mothers spoke about confronting stereotypes and finding value in individuals with disabilities. They described learning tolerance and accepting difference, and feeling responsible for helping others less fortunate. They happily accepted responsibility for opening themselves up to a world full of differences and strived to promote acceptance of all humans. Becoming an advocate for their children was an important life change for some moms, who described evolving into strong, assertive, and confident women as a result of their disability experience.

Mothers described gaining a new outlook on life and becoming better people because of their children. They believed that having children with disabilities has helped them value what is truly important and given them a richer sense of life. Supporting these findings is research conducted by Kearney and Griffin (2001) and Green (2007), which found that parents of children with developmental disabilities regarded their parenting experience as positive and considered themselves to be better people, strengthened by their experiences.

In addition, studies have shown that parents gain an increase in compassion and tolerance for difference; resilience; posttraumatic growth; a greater appreciation for life; a
stronger family unit; and increased mental and emotional strength (Bayat, 2007; Donelan, Hill, Hoffman, Scoles, Hollander Feldman, Levine, & Gould, 2002; Green, 2007; Konrad, 2006; Murphy, Christian, Caplin, & Young, 2006). These mothers learn to negotiate, advocate, and mediate on behalf of their children. They evolve into warriors, crusaders, and vigilantes as they fight for the rights of their children (Blum, 2007; Ryan, 2005; Ryan & Runswick-Cole, 2008). In Landsman’s (1998) study, mothers of children with disabilities felt better off and more appreciative than the general population of parents. These mothers valued life to its fullest and believed their child with disabilities had enriched their lives. They explained how the diagnosis of their children and their mothering experiences have changed their attitudes toward disability, making them open and more accepting of others with disabilities. Many shared how their former biases enabled them to better understand and accept the negative reactions they received from others.

Whereas many mothers were happy with their enhanced perspective, others said their child’s disabilities have actually made their lives worse. They described being overwhelmed by sadness and fear, and feeling anxious, panicked, unhappy, depressed, and obsessive. They admitted to becoming overprotective of typical siblings and jealous of parents with typical children. These mothers painted a picture of disability as debilitating and life-altering.

Several mothers in the study touched upon the importance of their faith. They stressed their faith in God and insisted their child’s disability has only strengthened their trust and acceptance. This importance of faith is supported by research from Treloar
(2002), who found that people with disabilities and family members use their spiritual beliefs to establish meaning for a life with disability and to respond to their challenges. Treloar contends that spiritual healing related to disability takes place when reliance on self leads to a broken self and ultimately to a decision to rely on God rather than on the self.

These mothers’ transformations often took the form of changed priorities, new careers, and a renewed life focus. Some mothers poured their energy into effecting societal change through education, advocacy, public policy, and social justice. These passions were triggered by their unique experiences raising children with disabilities. Research suggests that women who become crusaders and extend their care work to incorporate disability-related public work find this experience enriching and rewarding (Darling, 2002; Ryan & Runswick-Cole, 2008). Scorgie and Sobsey (2000) maintain the significance of transformation for these mothers. Many parents in their research study reported becoming less self-focused and more compassionate, as well as developing greater personal strength due to the disability experience. In addition, many parents insisted that living with their child’s disability taught them to speak out on their child’s behalf, taking on new advocacy roles and making vocational changes. These parents agreed that having a child with a disability enriched their lives and enabled them to mature and acquire wisdom and courage earlier than parents who are not forced to tackle complex aspects of the human spirit until later in life.

As mothers described their revelations, they shared journeys that began with stories of their child’s diagnosis. These journeys continued with the meaning of
motherhood and their personal transformations based on their experiences raising a child with and without disabilities. This following section focuses on the end of their journeys as they look into the future. With an open mind and in some cases a heavy heart, mothers revealed their honest visions of what they believe the future will hold for themselves and for their children.

**A Look into the Future**

Many of the mothers expressed the need to live in the present. Because they have no idea what their children’s future will look like, they found it overwhelming and upsetting to think about what might lie ahead. It was easier and more comforting to remain focused on the here and now. However, other mothers admitted to constantly pondering what might lie ahead, sometimes with fear and dread. Some confessed to feeling depressed, anxious, and apathetic about the future. They worried about the lifelong burden of caring for a child with disabilities; the uncertainty of future medical needs, care, and expenses; and the fear that managing their child’s disability will only get more complex over time. Conversely, some moms embraced their child’s future and regarded it with acceptance, optimism, and even excitement. They were hopeful their children would lead independent, fulfilling lives.

Whereas some mothers spoke openly about fearing the lifelong burden of caring for their child with disabilities, others admitted they have accepted the idea of living with and taking care of their child until they are no longer able. These mothers spend a considerable amount of time contemplating the future living arrangements of their children with disabilities. Some have accepted the never-ending care giving role because
they believe no one else could take better care of their child, and there are no “decent”
group homes or long-term care facilities available. The severity of the child’s disability
and the extent to which the mother’s life was transformed seem to affect these specific
views of the future. Mothers raising children with mild disabilities were more likely to
describe an optimistic, hopeful future in which their child can live independently, hold a
fulfilling job, and even find happiness with a partner. However, mothers of children with
severe disabilities tended to consistently worry about who will care for their child when
they are no longer able, where their adult child will live, and what will happen to them.
They also harbored negative feelings about this lifelong burden of care and mourned the
idea of never being free of their parental responsibilities as they age.

A common thread woven through these narratives pertained to the mothers’
disparate visions of the future for their typical and nontypical children. Mothers shared
the countless choices their typical child will inevitably encounter, while speaking with
sadness and heartache about the limited options for their children with disabilities. In
addition, many of these mothers make it a priority to ensure their typically developing
children do not feel burdened by their siblings with disabilities as they grow older. They
are careful not to put too much pressure on typical siblings to help with their disabled
siblings and spoke about working tirelessly to raise their typical children without any
sense of burden or obligation. At the same time, several mothers spoke about feeling
hopeful that their typical children will actually want to take over the care of their sibling
with disabilities. A few mothers even considered this care giving to be a family duty.
In response to the first research question, “What are these mothers’ revelations about their mothering journey?” the 32 mothers in this study openly discussed their maternal experiences. They intimately shared their stories of diagnosis, perceptions of motherhood, personal transformations, and future visions, and how these influence their journey. The second research question is discussed in depth in the following section.

**Discussion of Findings: Research Question #2**

The second research question seeks to understand the private and public experiences of these mothers. In responding to this research question, mothers placed their perceptions of marriage and divorce and family life within the classification of “private” experiences, while they placed the concept of public life under the grouping of “public” experiences.

The first part of this research question focusing on private experiences is discussed in the following section as mothers shed light on how they view their marriages and divorces. These experiences describe spousal support, teamwork, balancing responsibility, and navigating the intense stress of childhood disability on a marriage. Mothers elaborated on what these varied experiences mean for their family and what effect they have on the family.

**Still Married and Recently Divorced**

A majority of the mothers in this study were currently married to the father of their children. In some cases, the child’s disability strengthened the marriage, fostered teamwork, and compelled mothers and fathers to lean on each other. The disability and subsequent need for caretaking and advocacy created a strong bond between parents.
They realized the necessity of making time for each other, and communicating effectively and consistently. This finding is supported by Scorgie and Sobsey (2000), who report that parents believe their marriages are stronger due to the disability. The mothers in their study stressed the need to talk openly, listen to each other’s concerns, and give one another physical and emotional support.

While some mothers in this study spoke of the sadness in their relationships, they also believed the disability has deepened their friendship and brought them closer. One mother explained that the effect of her child’s disability on her marriage is ultimately influenced by the stressors that shape her family and her family’s responses. She insisted that before her daughter’s diagnosis, there was no way she could have predicted her husband’s reaction to the disability, or how he would cope with the disability. She strongly believed the effects of disability on a marriage are quite unpredictable and can have either a positive or negative outcome. Research by Shaw et al. (2005) supports this notion. They found that numerous chronic and atypical stressors in the lives of families can disturb relationships between partners and directly influence the functioning of each member of the family.

Many mothers described how their child’s disability has taken a toll on their marriages, and some admitted their marriages have barely survived. They described how the disability adds an additional layer of stress to their lives, as well as financial and emotional strains, physical limitations, and a significant reduction in positive communication with their spouses. Many of them insisted life is considerably harder with a disability. These findings are clearly supported by research on family
communication. Beavers, Hampson, Hulgus, and Beavers (1986) maintain that, while parents might value communication within the family as a whole, some avoid it because open discussions break down a parent’s denial, causing them to feel overwhelmed by their anger, loss, guilt, fear, and sorrow. This lack of communication creates misunderstandings, intensifies loneliness, and reduces access to support. Without the sharing of feelings, concerns, and information, family members tend to feel isolated and dysfunctional. It is important for families to engage in open communication around disability; promote opportunities for all family members to voice their concerns, fears, and questions about disability; and receive support and assistance in understanding the disability and its ramifications (Marshak & Prezant, 2007). Featherstone (1980) claims a child’s disability attacks the fabric of a marriage in four ways: It excites powerful feelings and emotions in both parents; it acts as a “dispiriting symbol” of shared failure; it redesigns the order of the family; and it creates “fertile ground” for conflict. Meeting the needs of a child with disabilities, caring for other nondisabled children, fulfilling professional commitments, and maintaining satisfying marital relations, as well as the more mundane concerns of daily living, can be quite overwhelming for parents (Brannen & Heflinger, 2006; Lyon & Preis, 1983; Plant & Sanders, 2007).

Although some mothers in this study were acutely aware that the disability could destroy their marriages, they did not consider divorce an option, simply because they recognized their inability to parent alone. They were adamant that life would only be harder as a single parent. At the same time, they struggled with an unfair balance of responsibility, feeling unconnected to their spouses, taking completely different
approaches and holding different views on child rearing, and placing their spouse at the bottom of their priority list. It was evident in some of the mothers’ narratives that remaining married has proven beneficial to a number of families, while also creating acute marital stress for other couples.

Of the 32 mothers in the study, only two were divorced, and they divorced within the last 5 years. Both mothers acknowledged that while their child’s disability was difficult on their marriage, they work hard not to blame the divorce directly on the disability. While these moms harbored regrets and admitted that life would be easier as a couple, they insisted they could not remain married. In their narratives, they maintained their marriages had become quite unhappy, and they no longer had any idea how to communicate with or nurture their spouses.

To understand the phenomenon of divorce in couples raising children with disabilities, it is useful to consider the literature examining the impact of children with disabilities on marital relationships. According to some researchers, families with a disabled child tend to experience more conflict, financial burden, maternal depression, and marital stress compared with families without a disabled child (Murphy et al., 2006; Nixon & Cummins, 1999). Other researchers have found that parents of children with disabilities report lower levels of marital satisfaction than parents of typically developing children (Cummins, 2001); having a child with poor health decreases the likelihood that parents will continue to live together (married or cohabiting) and increases the likelihood that their relationship will move in the direction of less involvement (Reichman, Corman, & Noonan, 2004); children with disabilities are more likely to live apart from their
biological parents altogether (Cohen & Petrescu-Prahova, 2006); and parents are at a
greater risk of marital dissolution among couples with disabled children (Joesch & Smith,
1997). Additionally, the parents of children with chronic illnesses are at higher risk for
distress and hopelessness (Harris, 1983; Plant & Sanders, 2007; Resch et al., 2010).
According to other studies, a child’s disability typically becomes a constant source of
stress in couples’ lives, leaving little time for nurturing the marriage (Lawoko & Soares,
2002).

However, this literature is contradictory, and some studies report that many
marriages not only remain intact; they are, in fact, strengthened by the disability. These
studies have found that couples raising children with disabilities report high levels of
marital satisfaction (Green, 2002), and the quality of marriages remains stable regardless
of the child’s disability (Longo & Bond, 1984). In another study, parents describe many
positive changes in their lives, including personal growth, improved relations with others,
and changes in philosophical or spiritual values (Scorgie & Sobsey, 2000). Finally, other
researchers have found that parents believe their marriages are stronger after their child’s
diagnosis, and insist parenting a child with a disability has given them a new appreciation
for other family members, especially their nondisabled children (Scorgie et al., 1996).

The data regarding marital function and dysfunction are clearly mixed. What we
do know is that these marriages are exposed to extreme stress, and some parents are able
to cope with this stress, while others cannot. Some parents felt their marriages grew
stronger as a result of the disabled child. In other marriages, the stress associated with
the birth of a child with disabilities magnified preexisting incompatibilities and led to
separation or divorce. For parents with chronically ill or disabled children, successful coping is associated with the quality of the parents’ marital relationship, as well as openness in communication, emotional support, family income, religious beliefs, and medical care (Eisner, 1990). Studies also have found that a couple’s reaction to their child’s disability depends on the couple’s strengths and weaknesses, as well as their sources of family and community support. Additionally, family well-being is established through marital cohesion and harmony (Demarle & Le Roux, 2001; Trute, 1990). This is backed by a study conducted by Lee and Waite (2010) that found spouses who spend time together create commitment and solidarity though the exchanges of daily life, which strengthens the bond between partners. As a result, each spouse becomes more concerned with the marital relationship and the family.

Why do some families crumble while others thrive? In some cases, marital disharmony might have occurred without the presence of a disabled child. In others, dormant problems might be further aggravated by the child’s issues. Some families might be better able to cope if they received more support from family, friends, and the community (Darling & Darling, 1982). Having a child with disabilities amplifies what occurs in a more typical marriage: Divisions might be greater, closeness may be stronger, sadness deeper, parenting decisions weightier, feelings of anger intensified, and happy times more exciting (Marshak & Prezant, 2007). Successful marriages lead to successful families—mothers and fathers are capable of stronger parenting when their relationship is healthy and solid (Bradbury et al., 2000). Marital satisfaction, parental functioning, and positive communication are so important because they strongly affect the health and well-
being of each parent, their marriage, their family, and their ability to cope with the burden of caring for their child with disabilities (Seligman & Darling, 2007). The difficult challenges associated with raising a child with disabilities make the social context of these marriages different from those of parents with typically developing children. Parents of children with disabilities confront multiple hardships and stressors, and maintaining a satisfactory, functional marital relationship is among these demands.

In the following section, mothers move from their thoughts and views concerning marriage and divorce, to ideas regarding family life, which they also considered to be private in nature. Here, mothers opened up about how their child’s disability affects the entire family dynamic, which includes their typically developing children, as well as their children with disabilities.

**Encountering Family Life**

In this study, some mothers described how their child with disabilities has taught their family the importance of resilience, as well as a sense of responsibility and acceptance of those who are different. Many of these mothers worked hard to ensure the disability did not control their family and lives. They insisted on spending time together as a family and believed all family members need to understand the challenges faced by the family. Additionally, they felt family members should help take care of the child with disabilities because this teaches responsibility and the realities of life.

At the same time, other mothers considered their lives to be quite difficult and even heartbreaking. They spoke of feeling resentful of their child’s disability and longing for another life. They constantly lamented the fact that the disability causes them to miss
out on mothering their typical children. Because family outings tended to be difficult and stressful, these moms often tried to create separate special time with their typical child. The mothers in this study described their family lives as balancing acts in which finding stability and equity is a daily challenge. They constantly questioned how to allocate their attention equitably among all their children and how best to balance the worlds of their children.

Mothers reflected on the anxiety and sadness they felt about birthday parties and play dates, which they admitted were challenging events in their family. Because their child with disabilities often received very few (if any) invitations compared to their typical siblings, these mothers were continually hoping for more friendships and social opportunities for their child with disabilities. Several mothers noted that their children with disabilities are cognitively able to understand their own social exclusion and recognize being rejected, ignored, and mocked by others. These mothers described the heartbreak and pain of coping with these scenarios. Other mothers explained that their children with disabilities do not have the cognition to recognize rejection when it occurs, for which most of them expressed bittersweet gratitude.

Many mothers found the clear developmental differences between their children painful to observe, especially as the younger typical child leapfrogged the older child with disabilities. When discussing birth order, a majority of mothers were thankful that their typically developing child (or children) was older than their child with disabilities. Many thought it was better for the child with the disability to be the youngest, so the younger child did not eclipse his or her disabled sibling, the child with disabilities had
older typical siblings to model, and the parents had more time and energy for the child with disabilities. Additionally, these mothers were thankful that their older children were typical because they considered their families to be complete. After the birth of a child with disabilities, many did not want more children because they feared something might go wrong during development or birth. They firmly believed they knew “way too much about what can go wrong” during development and birth.

Some of the mothers whose firstborn children are disabled agreed that their lives would be easier if their child with disabilities had actually been last in the birth order. Their reasons included being able to experience a normal family life before encountering the intense difficulties of disability and being able to enjoy their pregnancies without worrying incessantly about what could go wrong. They also expressed guilt that their youngest child was forced to “fit into” the disability world and thus never experienced a normal childhood. At the same time, several mothers were grateful their child with disabilities was the firstborn child. Some believed their lives were easier because they were unaware of what life was “supposed to be like,” and they were able to appreciate every aspect of their younger, typical child’s development.

This impact of disability on birth order and childbearing decisions was studied by MacInnes (2008). This study found that having a firstborn child with disabilities decreased the rate of subsequent childbearing because parents wanted to be able to invest in their child with disabilities. The increased needs of their child, coupled with the parents’ decreased time, energy, and finances, led these parents to decide against having a second child or led many parents to have fewer children than they had originally planned.
In speaking of their typical child, mothers shared feelings of tremendous joy and gratitude. They described feeling lucky to have a “normal” family experience and being thankful they can identify with their typical children. Research by Scorgie and Sobsey (2000) found that parenting a child with a disability positively influences the way parents relate to their typical children by making them more supportive and open parents. The mothers of firstborn children with disabilities expressed happiness with their decision to have more children, revealing their typical children have actually helped connect them to the typical world, diminished their social isolation, and normalized their family situations. These moms viewed their time alone with their typical children as simple and effortless, and also stressed the importance of focusing on their typical children away from the time-intensive needs of their child with disabilities.

The mothers in this study strived to keep life as normal as possible for their typical children. They worked hard to raise self-sufficient, compassionate, and understanding siblings who do not feel resentment or anger toward their siblings with special needs. While these moms hoped their typical children would become strong, independent individuals, they also taught them about the realities of disability, the importance of teamwork and patience, and the sacrifices that must be made within their families. These mothers tried to manage their typical child’s frustrations and disappointments regarding their sibling with disabilities through open and honest communication. They described the importance of helping their children cope with complex feelings about their sibling and the disability.
All of the mothers in the study were concerned about the well-being of their typical children and worried about the impact of the disability on them. They feared their typical children would resent their sibling with disabilities, feel like a forgotten child, receive insufficient attention, experience pressure to overachieve and be perfect, and consider themselves to be more of a parent than a sibling. Mothers worried that the burden of family stress would fall too heavily on their nondisabled children, who often accept extra responsibility for their disabled sibling while making do with less parental support themselves. These fears are supported by studies indicating that children with a disabled sibling experience adjustment problems, greater isolation from peers, more parental conflicts, lower sociability, more guilt and confusion, and excessive worries about their sibling’s future (Fisman, Wolf, Ellison, & Freeman, 2000; Siemon, 1984). In some families, parents expect more from nondisabled siblings, thus subjecting them to additional pressure to achieve. In addition, nondisabled siblings report experiencing jealousy of the attention and extra care given to the disabled sibling, specifically when the needs of the disabled sibling take priority over the needs of the typical sibling (Crocker, 1983; Van Riper, 2000).

Additionally, several studies have found that typically developing siblings have higher levels of depression, loneliness, embarrassment, anxiety, and aggression, as well as lower perceived self-competence when compared to siblings of typically developing children (Fleitas, 2000; Rossiter & Sharpe, 2001; Van Riper, 2000). Others studies discovered that typical siblings assume extra responsibilities for the disabled sibling, mature too quickly, and worry excessively about the genetic implications of the disability.
Several negative factors affect the typical sibling’s experience: Greater competition for parental attention and resources, misconceptions about the disability, having to act as a surrogate parent, feeling obligated to compensate for the disabled child, altered family patterns, and confusion about parents’ changing reactions to the disabled child (Crocker, 1981).

While all of the mothers in this study acknowledged worries about the health and welfare of their typical children, some mothers were happy to note several positive effects of the disability on siblings, including increased compassion and patience. In some cases, where siblings were too young to display these traits, mothers spoke of their hopes and desires for their children to become more empathetic, sensitive, and accepting of others’ differences. These affirmative aspects of the sibling experience also have been documented in the literature. For example, positive effects for siblings include increased understanding; tolerance and compassion; appreciation of their own good health; and altruism and independence (Fleitas, 2000; Rossiter & Sharpe, 2001; Van Riper, 2000). Additional studies report that some typical siblings possess increased feelings of competence for having successfully coped with the disability and demonstrate extremely mature behavior and attitudes (Lobato, 1983; Simeonsson & McHale 1981). Studies of siblings of children with Down’s syndrome found greater care giving responsibilities were correlated with increased empathy and more kindness in their relationships (Cuskelley & Gunn, 2003).

To explain these contradictions, researchers point to several mediating factors that may affect the sibling relationship. These factors relate to the disabled child (place of
residence, severity of disability, sex, age, type of impairment); nondisabled sibling (age, sex, birth order); and the family (socioeconomic status, size, parental expectations). Researchers believe these different characteristics affect sibling adjustment and the risk of adverse experiences. The complexity and individuality within families makes it difficult to definitively determine whether siblings of children with disabilities are problematically different (Hannah & Midlarsky, 1985).

While the mothers in this section openly shared their private, familial experiences, the next section depicts their public lives. Here, mothers talk about encountering community spaces with their children and constantly being forced to navigate these difficult spaces. They bring to light being out in public with their child with disabilities and the effects these experiences have on their lives.

**In the Public Eye**

Some of the mothers in this study described feeling uncomfortable and apprehensive in public with their child with disabilities. They were extremely conscious of the stares and comments of strangers, and feared that society was marginalizing their children. This behavior compelled them to “build walls” and “put up blinders” to protect themselves and their children from public scrutiny. Some of these mothers described being uncomfortable when attracting attention and struggling to keep their child’s behavior within socially accepted norms. This caused extreme stress and anxiety for mothers on what would otherwise be routine outings to places such as the library, church, local mall, and sporting events.
These findings are supported by the literature on stigma, which maintains that in our society, disability diminishes personhood (Goodley & Tregaskis, 2006; Green, 2007; Landsman, 2000; McCoyd, 2008; Zola, 1993). This negative view of disability is commonly encountered in public, face-to-face interactions with strangers, which tend to stigmatize the individual with a disability (Frank, 2000). In the case of a child with a disability, these negative judgments devalue the child, and by extension, the mother (Green, 2001, 2003; Press et al., 1998). Goffman (1963) refers to these close associations with a stigmatized individual as courtesy stigma, defined as the experience of stigmatization by relatives or friends by virtue of their close relationship with stigmatized individuals. These experiences are especially significant for a parent of a child with a disability (Green, 2003, 2007; McKeever & Miller, 2004). In our society, health, beauty, and independence are highly valued, and imperfection associated with disability violates this ideal. As a result, people with disabilities are sometimes viewed as bearers of “negatively valued traits” (Barnes, 1996; Krahé & Altwasser, 2006). Others often feel awkward and apprehensive when interacting with those who bear these traits and, as a result, tend to act inappropriately (Zola, 1993). Feelings of discomfort, apprehension, and fear during interactions with disabled persons are common (Krahé & Altwasser, 2006). These negative attitudes begin early in childhood, with young children categorizing people as disabled or nondisabled, and favoring the nondisabled (McCoyd, 2008; Richardson et al., 1961). These attitudes might arise from existing cultural and social norms that emphasize beauty, youth, and fitness, as well as media portrayals of disabled people as sick, suffering, and having specialized needs. Unable to conform to
these norms, people with disabilities are therefore marginalized by society (Krahé & Altwasser, 2006; Ruffner, 1990).

Mothers of children with disabilities describe experiences of impairment that are consciously public (Kelly, 2005). They struggle with managing and maintaining their child’s social identity in a range of public settings—school, stores, and community settings. Several studies conducted by Green (2001, 2003) describe how mothers of children with disabilities face a confused world in which interactions with others can be a source of discomfort and social alienation. These mothers experience “an amazing array of peculiar public attitudes, reactions, and behaviors, which vacillate in dizzying fashion from kind to cruel to benign but awkward and back again” (Green, 2003, p. 1362).

Managing the stares and glares of people in public was problematic for some of the mothers in this study. They described feeling uneasy and awkward at the grocery store or local library. Some confessed to staying at home because it was “much easier than leaving the house.” According to their narratives, the reactions of strangers in public places have driven some of these mothers into self-imposed social isolation because they are tired of struggling to interact socially with people who do not understand the experience of disability. Conversely, over time, other mothers discussed learning to accept their child’s disability and feeling comfortable being in public with their child. They described coming out of hiding, learning how to break free from societal expectations, and striving to sustain a normal life. This is supported by a study from Ryan (2005), which found that mothers changed considerably over time in the ways in
which they approached and mediated public interactions involving their children. Moth-
ers of children with disabilities start off as worriers and eventually become warriors.

Watching their typical children experience embarrassment and shame was quite painful for some of the mothers in this study. They described typical children who avoided going to the library, playground, or store with their disabled siblings because of their loud noises and inappropriate behaviors. These typical siblings were very uncomfortable with their disabled sibling drawing attention to them. Some of the mothers sympathized with, or at least understood, their child’s feelings of embarrassment. They expressed relief that their typical child could verbalize these emotions, and they offered support by sharing their own feelings of discomfort and embarrassment, believing this helped their child feel less alone in his or her feelings.

In their narratives, some mothers described loathing public expressions of pity and sympathy from strangers. Because these mothers believed their child with disabilities was viewed through a different lens when compared to their typical children, they tended to dress them in particularly nice, matching clothes to counter some of the stereotypes of disability. Rejecting the pity of others and fighting against the different standard held to their child with disabilities was important to many of these mothers. Some described their aversion to being considered a supermom, saint, or superhero by others and described their dislike for these labels. Although these kinds of remarks were recognized by mothers as well-meaning, they also were perceived by many as suggesting a common belief that raising a child with disabilities is an undesirable experience.
The importance of promoting education and understanding disability issues was a focus for these moms. They believed that spreading the word about disability, as well as making their child more visible in public, can minimize the fear of difference and maximize societal acceptance for their children. They described welcoming questions and conversations about their child’s disability because knowledge breaks down barriers. Some moms explained that having a child with disabilities has opened their eyes to the extent of stigma in our society and the distance between the general population and people with disabilities. They believed it was their duty to help educate society about difference and foster an increased acceptance of all people. They insisted society must stop treating people with disabilities as invisible, learn to understand their differences, and accept their personhood. While society has often defined disability as a personal problem (Resch et al., 2010), the mothers in this study refute this view and insist that all of society must work together to break down the existing barriers.

In response to the second research question, “What are the private and public experiences of mothers raising children with and without disabilities?” the mothers in this study openly shared how their perceptions concerning their marriages and divorces, family life, and public life affected their journey. In the following section, I discuss the theoretical significance of symbolic interaction and social construction in this particular study. The findings of this research lend support to a theoretical framework firmly grounded in symbolic interaction and social construction, and help us comprehend the maternal and familial experience of raising a child with and without disabilities.
Discussion of Findings: Theoretical Significance

By using a symbolic interaction framework—together with social construction—one can create a new paradigm for understanding the context of family relationships and disability. These two theories are quite valuable in understanding mothers’ experiences raising a child with and without disabilities, as well as the numerous implications this can have on their self-concept and identity. This section begins with a review of symbolic interaction theory and follows with a discussion of how this particular theory applies to the themes of diagnosis, motherhood, personal transformation, marriage and divorce, and visions of the future. After examining the theory of symbolic interaction, I then move on to the theory of social construction.

Symbolic Interaction

As discussed earlier, symbolic interaction is a theory that demonstrates the link between language, meaning, and human behavior. It is a perspective concerned with individuals and their influence on each other. Central to symbolic interaction is the production of meaning. The theory of symbolic interaction stresses the importance of understanding the subjective meanings and interpretations that people ascribe to events and relationships (Mead, 1934). This is a key theoretical paradigm that brings insight into understanding the individual and society as a whole.

This theory focuses on the connection between symbols (i.e., shared meanings) and interactions (i.e., verbal and nonverbal actions and communications). It is essentially a frame of reference for understanding how humans, in concert with one another, create symbolic worlds and how these worlds, in turn, shape human behavior. (LaRossa &
Reitzes, 1993). From this perspective, society is interaction and interaction is symbolic, which indicates that interaction exists in relation to the meanings that people develop. People do not respond directly to things, but instead attach meanings (derived from interaction) to them and respond based on that meaning (Blumer, 1969). Therefore, understanding meaning is an important step to understanding behavior. This approach to society and interaction provides a perspective for studying how individuals interpret and relate to other people, as well as objects in their lives, and how this leads to behavior. In this sense, the key to understanding behavior is to identify the meanings behind it.

**Diagnosis.**

Mothers’ stories of diagnosis can be interpreted in terms of symbolic interaction by examining the ways in which mothers coped during the diagnosis process. In particular, this phenomenon can be understood using Blumer’s framework of meaning. Blumer (1969) argued that symbolic interaction rests on three premises concerned with meaning. First, people’s behavior toward all things is governed by the meaning that things hold for them. Second, the meaning of objects for each individual is not anchored and inherent in the object itself, but derived from the individual’s interactions with others. Third, people determine the meanings of things through interpretation. The creation of meaning is an ongoing process generated through interaction between or among individuals. Whether a concrete object, a person, a place, or an abstract idea, nothing has an inherent meaning; its meaning arises through people interacting.

The first part of Blumer’s framework involves how people’s behavior toward all things is governed by the meaning that those things hold for them. For the mothers in
this study, their initial reactions to their child’s diagnosis were experienced with heavy emotion and intense sadness because their children were not what they had expected. Many of these women had specific ideas—often unconscious—about how the “perfect” baby should look and act. As a result, the diagnosis of disability left many of these mothers feeling inadequate and disappointed in themselves due to their inability to create this perfect child. Additionally, some of these mothers’ feelings of shock and devastation were exacerbated by their lack of understanding and inexperience with disability. It is clear that their behavior toward the disability diagnosis was influenced by the significance of what disability actually meant for them. They described a fear of the unknown and previously-held prejudices, which intensified their distress and panic. These mothers typically had no experience with disability, which resulted in an intense fear of the unknown. The meaning of disability for these mothers dictated their behaviors toward their child and the child’s diagnosis.

The second premise asserts that the meaning of objects for each individual is not anchored and inherent in the object itself, but derived from the individual’s interactions with others. This can be seen in the mothers’ interactions with medical professionals who were unsupportive and off-putting. Several mothers described doctors and genetic counselors that acted in a negative and uncaring manner, and lacked empathy when delivering their child’s diagnosis. These interactions likely affected how these mothers coped with and managed the implications of their child’s disability.

The last tenet of Blumer’s framework maintains that people determine the meanings of things through interpretation. Nothing has an inherent meaning; its meaning
arises through people interacting. Based on this belief, the mothers in this study not only had to struggle with their own personal interpretation of disability, but also had to manage the negative interactions with medical professionals. In their narratives, some mothers described these professionals as conveying their own personal biases toward raising a child with disabilities. Their attitudes encompassed tragedy and loss, reduced quality of life, and the lifelong burden of caring for a child with special needs. As a result, mothers were forced to navigate these off-putting communications, while also coming to terms with their own reactions to the disability.

*Motherhood.*

In addition to these mothers’ stories of diagnosis, the theory of symbolic interaction also can be applied to the mothers’ perceptions concerning motherhood and identity construction. The findings in this study bring to light the ways in which these mothers created their identities as parents of a child with an unexpected disability.

Symbolic interaction theory is useful in understanding how these mothers construct their identities and build meaning in their relationships. This theory is based on the idea that people construct meaning as they interpret and negotiate experiences with one another, and they actively interact with the social world to make sense of it. People do not respond directly to things, but instead attach meanings—derived from interaction—to them and respond based on those meanings (Blumer, 1969). This theory provides a useful lens through which to understand how these mothers interpret and interact with individuals and objects in their lives, thus shaping their individual behavior
and personal identities. Symbolic interaction recognizes the role of these mothers in defining their own reality and makes sense of their conflicting and inconsistent emotions.

According to Bateson (1989), mothers of children with disabilities create a life for themselves by continually reimagining the future and reinterpreting the past to give meaning to their present. They repeatedly reinvent themselves in response to their shifting and uncertain environments. LaRossa and Reitzes (1993) maintain that people strive to make sense of the things they encounter—that they act on the basis of the meanings things have for them, and that these meanings are not inherent in the things themselves but arise from social interactions. In a world in which children with disabilities are stigmatized and considered different, it is necessary to explore the meanings of these beliefs and behavior to understand both why they occur and the larger implications. In the unique relationship between a mother and her child with disabilities, it is the mother’s expression and self-reflection that actually define the meaning of motherhood. Mothers of children with disabilities are acutely aware of the identity that has been constructed for them by others. Their interactions with therapists, teachers, physicians, and strangers constantly remind them of their child’s difference and the stigma associated with this difference. Interactions with and reactions from society and “the generalized other” (Mead, 1934) remind these mothers of the prevailing social attitudes surrounding disability. These mothers must balance the symbolically constructed identity of a “mother of a child with disabilities” with the social pressures of being the “perfect mother.” It is this intense pressure that causes the mothers in this
study to experience perpetual feelings of identity loss, guilt, loneliness, social isolation, anxiety, and depression.

While some mothers expressed these feelings of sadness and despair, others insisted on actually learning the meaning of unconditional love and considering their child with disabilities to be a blessing and a gift. They worked tirelessly to accept the disability and live a happy life. These mothers were successful in resisting dominant discourses of burden and tragedy. They rejected notions of hardship and difficulty, and instead, represented themselves as mothers who focus on small improvements, find happiness in their child’s special abilities, and search for ways to cope with and enjoy their lives.

How these mothers construct their identities and create meaning in their relationships is further explained by examining today’s advances in reproductive technologies. Prenatal genetic testing and other medical advances have significantly changed the implications of motherhood for women. Landsman (1999) stresses a cultural expectation of maternal responsibility in “attaining perfection in fetal outcome” (p. 153) and links a child deemed by society as having diminished personhood with the experience of diminished motherhood for the woman who nurtures it (p. 135). She maintains that mothers of children with disabilities are either blamed for their part in creating imperfect children or elevated to the role of special mothers chosen by God to have special children. According to Kelly (2005) and Landsman (1999), these mothers resist the devaluing of their children and struggle to develop new interpretations of
perfection and normalcy. At the same time, many of these mothers also represent themselves as the recipients of special “gifts.”

Hayes, Flannery, Brooks, Tisdell, and Hugo (2000) assert that motherhood can create divergences between what women have learned about the ideal mother and what they experience in their daily lives. This paradox is clearly a perpetual struggle for the mothers in this study. As these mothers negotiate their complex transformation, an intricate identity makeover occurs. This makeover is essential for mothers raising children with disabilities. While all mothers see their responsibility as supporting the growth and development of their children, mothers of children with disabilities have many more roles and demands than mothers of typically developing children. Raising a child with disabilities is quite challenging and requires an increased amount of energy and time (Brannen & Heflinger, 2006; Crowe, VanLeit, Berghmans, & Mann, 1997). These mothers often experience elevated stress levels due to their child’s decreased cognitive functioning, physical limitations, challenging behaviors, and limited social skills (Feldman et al., 2007; Lessenberry & Rehfeldt, 2004). They are ultimately responsible for planning medical appointments and therapies, as well as managing heavy adaptive equipment, complex daily self-care activities, and medical management tasks. Mothers raising children with disabilities consistently associate their feelings of well-being with their child’s progress and their ability to meet the daily challenges of taking care of their child with disabilities (Larson, 2000).

In addition to assuming the highest degree of responsibility for their children’s health and well-being, mothers raising children with disabilities share the stigma and
marginalization of their disabled child (Carpenter and Austin, 2007; McCoyd, 2008; McKeever and Miller, 2004). Because a mother—obligated and committed to providing superb care for her child—is the primary caregiver, she ultimately bears responsibility for how her child turns out (Ryan & Runswick-Cole, 2008). As a result of this power, she is blamed for her child’s limitations, internalizes this accountability, and experiences guilt and self-blame (Dinnerstein, 1991).

Research by Shu, Lo, Lin, Hsieh, & Wu (2006) support this notion. They found that mothers raising adolescent boys with autism form new self-identities and seek new meanings for their realities. These mothers must reconstruct their maternal roles as they experience mothering a child with disabilities. Additionally, in Landsman’s (1998) study, stories told by mothers of children with disabilities suggest that for them, parental adjustment is not about becoming resigned to the tragedy of having a disabled child, but rather about being challenged by, and redefining through experience, the existing cultural understandings of what constitutes normal and perfect. Landsman examined how these mothers struggle to define their identities of “mother” within the cultural definitions of motherhood that view women raising children with special needs as different and devalued. The mothers in this study must come to terms with all of their unmet expectations and devise a new path for themselves and their families. Following a significant life-altering event, a woman often discovers inner resources, and as she begins to listen to a voice within her, she unearths unexpected sources of strength (Belenky et al., 1997).
**Personal transformations.**

Similar to the themes of diagnosis and motherhood described previously, the personal transformations of these mothers also can be explored using the theory of symbolic interaction and the concept of meaning making and identity. Meaning making is a central focus of coping with adversity (Frankl, 1984). This search for meaning has been documented to help families cope with disability. For example, Pakenham, Sofronoff, and Samios (2004) found parents of children with Asperger syndrome reported a growth in spirituality, changes in life priorities, and increased patience. Additionally, Bayat (2007) asserted that resilient families successfully create meaning out of adversity.

Drawing from their personal experiences, the mothers in this study altered their life priorities and poured their time and energy into societal change through new roles in public work related to the disability cause. They learned how to create a positive meaning of disability. Their shift into careers dealing with advocacy, social justice, education, and public policy developed out of their own processes of meaning-making. These transitions had a significant impact on the particular meaning they gave to the definition of disability, as well as to their individual identities as mothers of children with disabilities. In addition, many mothers described becoming less self-focused and more empathetic, as well as developing greater personal strength and advocacy skills due to the disability experience. Through their personal transformations, these mothers constructed new identities for themselves and worked tirelessly to redefine the meaning of disability and motherhood.
Marriage and divorce.

The theory of symbolic interaction also can be applied in this research study when considering how one’s sense of self affects marriage and divorce. Self refers to an individual’s conception or understanding of themselves, which arises out of social interaction. As individuals become aware of how others see them, this influences how they see themselves (their self). Mead (1934) theorized that the image we have of ourselves comes from imagining how we look to others and how others seem to us. Interactionists refer to this as the “looking-glass self.” The looking-glass self refers to our perception of how we think others see and judge us. Self-feelings emerge out of these perceptions, and we begin to see ourselves as we believe others view us. Cooley (1902) maintains that one’s sense of self develops primarily through interaction with the people in our lives who are most important to us, such as a spouse.

There is no question that marriage is a private relationship between couples. It is an intimate bond involving a high level of emotional contribution and considerable obligation. Within this union, one’s functions and responsibilities come together and decisions are made with regard to how each spouse will carry out their particular roles. Because this interaction tends to contribute to the development of a clear definition of an individual’s self and worth, the union of marriage is often associated with the health, happiness, and well-being of individuals. However, these attributes also can cause unrest and anger in the marital relationship when a spouse’s needs are not being met or conflict arises. Additionally, it is well documented that raising a child with disabilities amplifies marital stress and friction. In fact, according to McCoyd (2008), most women believe
marriages become stressed and prone to divorce when a child with disabilities is born or diagnosed. This type of strain and discord is evident in the narratives of these mothers as they describe how their child’s disability has taken a toll on their marriages, as well as the intense sadness in their relationships, the unfair balance of responsibility in their homes, feelings of disconnection from spouses, and placing spouses at the bottom of their priority list. As a direct result of this conflict between spouses, the mothers in this study struggle with their relationships and their self-concept. This, in turn, creates difficulties and stressors in their marriages, which are clearly documented in their narratives.

*Visions of the future.*

Using Mead’s notion of self, the theory of symbolic interaction can be applied to the concept of looking into the future. According to Mead, an individual’s behavior in a given situation arises from his or her concept of self, gained through interaction with others. Because individuals behave according to their self-concept, this, in turn, contributes to their sense of self. They take the attitudes of others, arrange them, form a self-consciousness in the process, and then act according to this view of the self (Mead, 1934). This principle can be applied to how mothers in this study interpreted their future. Many worried about the lifelong burden of caring for a child with disabilities and feared that managing their child’s disability would only get more complex and burdensome over time. They asserted the most difficult part of their mothering journey was the fact that there was no end in sight. Because many of their children will not live independently, their parenting responsibilities will never change. With feelings of jealousy and envy, some mothers observed friends and family members currently preparing to send children
to college and enjoying an “empty nest.” However, the mothers in this study were sadly aware that this will never be their reality. They described feeling trapped and resentful that their burden will never cease. This interaction with friends and family shaped these mothers’ self-concept and created intense feelings of sadness, envy, jealously, and heartbreak in their lives.

Additionally, some mothers transferred their own concept of self to their typically developing children. This is evident when mothers discussed the future burden of care for their disabled child. For example, some of the mothers who felt depressed and anxious about the future, and worried about the lifelong burden of caring for a child with disabilities, also experienced this same anxiety for their typical child. Many of these mothers made it a priority to ensure their typically developing children did not feel burdened by their siblings with disabilities as they grew older. They were careful not to put too much pressure on typical siblings to help with their disabled siblings and spoke about trying to raise their typical children without this sense of burden or obligation. Through their own concept of self, these mothers harbored fears of never being free of their parental responsibilities. These same worries seemed to carry over to their typical children as they transferred their concept of self to their children.

There is no question that people are the best observers of their own lives (Denzin, 1992). The narratives of the mothers in this study have provided an accurate reflection of their interpretation of experience. By utilizing a symbolic interaction perspective, new insights into the meaning of childhood disability can be made in this study. This is essential given the number of mothers struggling to raise a child with disabilities and the
potential impact that disability has on today’s families. This research has clearly benefitted from the insights provided through the theory of symbolic interaction. A clearer understanding of how mothers develop meanings and what these meanings are in relation to their children with disabilities can be obtained by exploring the role of interaction. Understanding meanings can bring us closer to uncovering the link between childhood disability and behavior related to this phenomenon.

In the following section, the relevance of social construction theory on this particular research study will be discussed. This section begins with a review of the theory and follows with a discussion of how social construction applies to the specific themes of motherhood, diagnosis, and personal transformation. In this discussion of the applications of social construction, the theory of symbolic interaction is also wedded. In particular, this coupling of the two theories can be seen within the themes of motherhood and personal transformation.

**Social Construction**

Social construction theory is a useful framework for understanding how mothers of children with and without disabilities experience and understand their world, and negotiate their identities within this social world. Social constructionists assert that meaning evolves from social systems rather than from individual members of society. They maintain that humans obtain knowledge about the world from larger social discourses, which tend to support dominant belief systems.

Berger and Luckmann (1966) draw upon the tradition of the sociology of knowledge, concerned with “the relationship between human thought and the social
context within which it arises” (p. 4) and “knowledge that guides conduct in everyday life” (p. 19). How we understand the world we live in is fundamental to the framework of this theory. Loseke (2003) asserts that we categorize things and people as a way to organize and simplify our complex world. Classifying our world and attaching labels helps us distinguish types of things or people, which in turn inform us about how to act toward these things and people.

This theory supports the idea that language is essential to social processes and their implications for identity development (Allen, 2005; Leeds-Hurwitz, 1995). Identities are constituted, maintained, and negotiated through communication and interaction with others (Baxter, 2004; Tracy, 2002). Allen (2005) contends that this language allows us to make sense of the world and share experiences and meaning with each other. Language and meaning are social productions (Hall, 2000), and how disability is represented in society is important to the public understanding of disability. Mothers of children with disabilities are conscious of and sensitive to the socially constructed beliefs about disability. Public narratives of disability as imperfect and negative become familiar through the socially constructed discourses that frame them. For individuals coping with disability and stigma, interpretations of disability are socially constructed from the ideology of the society in which we live (Greil, 1991). One’s understanding of disability is based on an individual’s experiences and history from within his or her personal and cultural environment (Medina & Magnuson, 2009).

Social constructionists maintain there is not one true understanding of the world. The same can be said for disability; there is not one true understanding of disability and
there are a number of discourses available as to the meaning of disability. The different ways of thinking about disability emphasize the many discourses around disability. This concept of discourse is an assumption of social construction in that social constructionists assert that our identities are affected by our cultural understandings, as well as the discourses that are readily available to us (Burr, 1995; Medina & Magnuson, 2009; Ryan & Runswick-Cole, 2008).

*Motherhood.*

The theory of social construction also can be applied in this research study when considering the position of mothers. In their role as mothers raising children with and without disabilities, the women in this study experienced increased public scrutiny when compared to mothers parenting children without disabilities. This scrutiny develops through the socially constructed belief that these mothers need to comply with specific indicators of good mothering, including giving birth to the “perfect” baby and strict compliance with proper and accepted behavior management. When mothers do not adhere to these cultural prescriptions, they become apprehensive, uncomfortable, and socially isolated. In an effort to distract attention and manage their child’s behavior, they build walls and apply blinders to protect themselves and their children from public scrutiny.

These intrusive interactions exemplify Galvin’s (2006) model of discourse dependency, which highlights the importance of language in validating family ties. While all families engage in some type of discourse-driven family identity building, less traditional families are highly discourse dependent due to their differences.
Dissimilarities between family members seem to leave outsiders feeling they have a right to comment or question these families (Suter & Ballard, 2009). Sometimes insensitive and invasive, these outsider remarks are experienced as identity-disconfirming and challenging to family identity (Suter, 2008). These families must utilize discursive practices to manage and maintain their identity on an ongoing basis (Galvin, 2006).

Internal and external boundary management practices are used by these families to create a strong family identity. Internal boundary management refers to the communicative processes within the family that create a sense of family identity and cohesion, while external boundary management practices refer to the discourse needed to explain and legitimize the family to outsiders (Docan-Morgan, 2010).

It is clear that the public narratives of disability as imperfect and negative become familiar through the socially constructed discourses that frame them. This tenet of dominant discourse is established again within the themes of motherhood and family. For example, as these mothers described their family life and mothering accounts, their experiences can be studied in relation to social construction theory. Here, the mother’s narratives defied the dominant discourses surrounding disability as tragic. While some mothers in this study did consider their lives to be difficult and even heartbreaking, many others worked hard to ensure the disability did not control their family and lives. They insisted on spending time together as a family and believed all family members needed to understand the challenges faced by the family and should help take care of the child with disabilities. Some mothers described powerful feelings of happiness and joy in being able to raise a typically developing child. These mothers described feeling thankful and
lucky to have normal family experiences and put great importance on identifying with and feeling close to their typical children. They viewed their lives as a little simpler and easier when they spent alone time with their typical children, which enabled them to feel like normal mothers for short intervals.

These findings are indicative of the ways in which the dominant discourse of tragedy and heartbreak were resisted by many of these mothers. They rejected notions of pain and suffering as they shared their positive familial experiences. By revealing their joy and pleasure in raising their children, these mothers highlighted the fact that their lives were not full of burden and hardship. Rather, they were living fulfilling roles as mothers, regardless of how society interpreted their situation. As these mothers described their lives, they searched for ways to confront and resist the existing dominant discourses and definitions of their children as “others” and “unwanted.” Instead, they attempted to create perceptions of themselves as ordinary mothers striving to live fulfilling lives.

In an attempt to manage the intense and challenging feelings experienced by many of the mothers in this study, some maintained the importance of seeking social support. They insisted this support provided them with much-needed strength and hope, and helped them feel less alone in the world. Social construction theory is critical for understanding how these mothers interpret and narrate their experiences of disability and how they benefit from support groups. For example, Huws et al. (2001) and Lave and Wenger (1991) assert that the role of support groups for mothers raising children with disabilities is to provide a safe community in which members can learn how to convey a story about their experience and construct a narrative about themselves as mothers of
children with disabilities, whose identities are valued within society. Within the safe community of their support group, mothers of children with disabilities develop narratives to explain to themselves and to others what the lived experience of disability means (Pennebaker & Keough, 1999). The recovery movement and support groups are important in identity construction and personal empowerment because they allow individuals to make sense of themselves and their experiences (Herndon & Eastland, 1999). For individuals coping with disability and stigma, interpretations of disability are socially constructed from the ideology of the society in which we live (Green, 2007; Greil, 1991; McKeever & Miller, 2004). One’s understanding of disability is based on an individual’s experiences and history from within his or her personal and cultural environment.

The importance of support groups also can be applied to the theory of symbolic interaction and specifically, to Mead’s concept of the looking-glass self, as mentioned earlier. As individuals become aware of how others see them, this knowledge influences how they see themselves. Mead (1934) theorized that the image we have of ourselves comes from imagining how we look to others and how others seem to us. Because many mothers’ experiences are powerful and can be characterized by feelings of conflict, guilt, self-doubt, anger, and self-loathing, the mothers in this study tend to seek and value relationships with other parents who are sympathetic and compassionate, and can understand the difficulties of raising a child with disabilities. These relationships are frequently created through support groups, which offer a social and therapeutic resource for the positive reconstruction of identity for the stigmatized and socially alienated.
(Ablon, 1981; Huws et al., 2001). Support groups allow these mothers to express their feelings, construct their experience, process information, and reclaim control over their lives. Moreover, through the construction of their own narrative, as well as taking note of others’ narratives, these mothers gain perspective, create their identities, find coherence in their lives, and establish tools for communicating about and coping with disability, stigma, sorrow, and despair. As a support group member, these mothers receive and send messages of encouragement and acceptance, which assists these mothers in defining themselves according to these particular messages.

**Diagnosis.**

The concepts of discourse and meaning making, central to social construction, underscore the importance of the theory for understanding and interpreting these mothers’ diagnosis experiences. As these mothers shed light on their child’s diagnosis stories, it became clear from their narratives that their diagnosis episodes were not experienced in isolation. Rather, in accordance with social construction, the meaning of their child’s diagnosis was culturally embedded. The negative and off-putting reactions to their child’s disability from the medical community, as well as from these mothers themselves, are strongly grounded in the theory of social construction. The way in which these mothers managed and coped with the diagnosis of their child with disabilities can be understood by examining the ways in which these mothers interpreted the diagnosis, attached meaning to this life altering experience, and challenged the dominant discourses surrounding disability as undesirable.
According to Danforth and Navarro (1998), what people assume to be their objective reality is actually self-constructed through the course of their activities, thoughts, and relations. Berger and Luckmann (1966) assert that we create a social world, a means of interpreting the phenomena we experience, by identifying and externalizing specific patterns of behavior or belief. These patterns are made into objective facts, or institutions, which become legitimate through reification, making them natural creations of divine will or the products of inevitable processes. We accept and internalize these new truths, and then pass them on to others through our social interactions. The negative reactions from medical professionals, and from some of the mothers themselves, reflected culturally fixed views of disability and normalcy. The narratives of the mothers in this study highlighted these pessimistic and harmful views and notions, which are clearly embedded in our culture.

**Personal transformations.**

The theory of social construction, as well as symbolic interaction, can be applied in this study when considering the mothers’ experiences of personal transformation. As discussed previously, the tenets of social construction support the belief that identity is rooted in social contexts. This is maintained by Mead (1934), who asserts that the self arises through the joint participation of individuals in a shared, social environment. We see this phenomenon in action as some of the mothers described personal transformations in which they attempted to create meaning through their engagement in valuable and meaningful activities. For example, before their child’s diagnosis, most of these mothers were not involved in any type of disability rights. However, after their child’s diagnosis,
they took on roles of advocacy and social justice as a way to resist the common belief of
disability as tragic. This new-found commitment to civic activism and the disability
cause by mothers can be understood in terms of identity and meaning. As these women
experienced everyday life, they constructed new identities for themselves through their
interpretation of the world around them.

For mothers of children with disabilities, the disability experience challenges a
woman’s sense of herself as a mother. Becoming a mother of a child with disabilities
often sparks a complex identity transformation, as mentioned earlier. The mother’s own
future is irrevocably changed, and she must negotiate a new kind of mothering. The
mothers in this study used their life experiences to completely reevaluate their roles in
life, redefine the meaning of disability and motherhood, and recreate themselves through
advocacy work. They took on new professional roles related to disability, which
influenced the meaning they designated to disability and to their constructed identities as
mothers. Furthermore, the mothers in this study engaged in these disability-related roles
as a means of attaining social acceptance for their children and for themselves. This is
supported by the assumption of social construction, which asserts that our identities are
affected by our cultural understandings, as well as the discourses that are readily
available to us (Burr, 1995; Medina & Magnuson, 2009). In this way, mothers rejected
socially accepted views of disability as undesirable and tragic, and they supported and
promoted the need to educate society about disability, understand difference, and break
down existing barriers. They insisted upon the importance of educating others about
disability and making their child more visible to minimize the fear of difference and
maximize societal acceptance for their children. They embraced questions and conversations about their child’s disability because they asserted that knowledge is a crucial way to break down barriers. These mothers believed in the duty to help educate society about difference and foster an increased acceptance of all people. They longed for society to stop considering individuals with disabilities as invisible, learn to understand their differences, and accept their personhood.

Applying a social constructionist approach to the study of mothers of children with and without disabilities has shed light on how these mothers are able to enact and understand their identities. The philosophy of social construction theory emphasizes the importance of listening to and learning from those who are (or were formerly) marginalized, who have had their perspectives and voices submerged, or dominated by those with more social power or privilege. The constructionist paradigm seeks to learn from diverse worldviews (Hartman, 1994). This entails collaborating with individuals who are oppressed, listening to their life experiences, searching for meaning within them, and helping to end any type of oppression (Huws at al., 2001; Laird, 1993).

Summary

My research highlights several important findings. First, while some of the mothers in this study spoke about the difficulty in balancing their complicated lives and feeling cheated by their child’s disability, all of the mothers emphasized their immense pleasure and tremendous joy in having a typically developing child. They described feeling lucky to have a normal family experience and thankful to be able to identify with their typical children. Their typically developing children helped connect them to the
nondisabled world, decreased feelings of social isolation, and normalized their family situations.

Another significant finding in this study brings to light the extreme human paradox experienced by these mothers. For most mothers in this study, there exists a combination of positive and negative emotions toward the child with disabilities. It is clear that the lives of these mothers are emotionally complex (Green, 2007). Many described their children with disabilities as their greatest joy and, at the same time, as their greatest sadness. They shared their loss and heartbreak, but also considered their child to be a blessing and a gift. They explained the meaning of unconditional love, while also acknowledging their emotional, physical, spiritual, and financial exhaustion. These reactions were backed by Hastings and Taunt (2002), who found that parents raising children with disabilities display an increase in negative perceptions of their present life situation, while simultaneously describing positive perceptions.

Some mothers insisted that, while they would not have chosen this life for their children and would eliminate the disability if they could, they would never give up what they have learned and gained, and the ways they have grown as women and mothers. Some described this lived paradox as a never-ending cycle they expected to continue throughout their lives. These views are supported by Bateson’s (1989) assertion that women reinvent themselves over and over again in response to their shifting and uncertain environments. Reinventing themselves and their previously-held notions of blissful, joy-filled motherhood enables these mothers to cope with the emotionally painful, but nevertheless rewarding, job of raising a child with disabilities. Moreover,
parents’ level of acceptance varies continuously over time and involves the ability to control opposing thoughts and emotions about disability without being preoccupied with or dominated by this conflict of thoughts (Boström et al., 2009).

The mothers’ narratives also lent support to claims by many scholars (Ferguson, 2001; Graungaard & Skov, 2007; Lalvani, 2008) that negative reactions from medical professionals are quite common. Doctors and geneticists rarely emphasize the positive aspects of raising a child with disabilities, focusing instead on notions of tragedy and loss, reduced quality of life, and lifelong burden. In addition to coping with negative encounters with the medical community, these mothers also must manage off-putting expressions of pity, sadness, loss, and misfortune from family members, friends, and acquaintances. One of the most difficult struggles seems to be tackling their own personal, previously-held prejudices. These mothers describe their past inexperience with disability, holding stigmatizing views about individuals with disabilities, and being thrust into the unknown world of disability. These findings support the works of scholars who assert that mothers typically have no past experience with disability; thus, it is unfamiliar and frightening. What was once foreign is now a part of their lives (Green, 2001; Landsman, 1998, 2000). Findings of this study suggest that, while these mothers are forced to confront reactions from the medical community, their social circles, and their own notions of disability, they must also challenge a larger, overarching issue—the existing cultural definitions of disability and perfection. Through raising their kids, they must learn to reconstruct ideas of motherhood that counter society’s negative views.
These mothers must break new ground by redefining the lives of their “imperfect” children as “perfect.”

The narratives of these mothers also are indicative of significant transformations in their lives. These mothers agree that having a child with a disability has enriched their lives and created opportunities to mature and attain insight and strength. These transformations take the form of changed priorities, new careers, and a renewed life focus. The mothers described concentrating their energies on societal change through education, advocacy, public policy, and social justice. This type of transformation by parents is supported through research by Scorgie and Sobsey (2000), who maintain that many parents become less self-focused and more compassionate, and develop greater personal strength due to the disability experience. Mothers adapt, adjust, and develop new skills as they mediate and negotiate the world on behalf of their children (Green, 2001; Read, 2000). They begin as worriers and evolve into warriors (Ryan, 2005) and act as “vigilantes” as they battle the educational and medical establishments on behalf of their children (Blum, 2007).

Another interesting finding in this study is that these mothers’ views of the future are shaped by the severity of their child’s disability and the extent to which their life is transformed. The narratives suggest that mothers raising children with mild disabilities feel more positive about their children’s future. These mothers can envision their child living independently, holding a fulfilling job, and even finding happiness with a partner—scenarios fueled by optimism and hope. However, the mothers raising children with severe disabilities are unable to imagine such bright futures. Instead, these mothers
agonize about who will care for their child as they age, where he or she will live, and what their future holds. Additionally, they feel burdened by the prospect of lifelong responsibility for their child’s care and mourn the loss of freedom they will never have the opportunity to enjoy.

An additional finding builds upon the stigma literature (Darling, 2003; Frank, 2000; Goffman, 1963; Green, 2007; Landsman, 2000; McKeever & Miller, 2004; Read, 2000; Ryan, 2005; Zola, 1993) by addressing how these mothers learned to cope. Some mothers detested public expressions of pity and sympathy and did not want strangers feeling sorry for them and their children. Believing their child with disabilities is held to a higher standard than their typical children, they admitted to taking more time to dress them in attractive, matching clothes to counter stereotypes of disability. The importance of promoting education and understanding disability issues also was imperative to these moms. They believed that spreading the word and educating others about disability, as well as making their child more visible in public, can minimize the fear of difference and maximize societal acceptance of their children. They embraced questions and conversations about their child’s disability because knowledge is an important way to break down barriers. They insisted they wanted others to openly ask them questions instead of staring, gawking, or wondering. Some of the moms in this study assert that having a child with disabilities has opened their eyes to the stigma associated with disability within society and how distanced the general population is from people with disabilities. They believed it was their duty to help educate society about difference and foster an increased acceptance of all people. They yearned for society to stop considering
individuals with disabilities as invisible, learn to understand their differences, and accept their personhood.

The last finding focuses on the experiences of the mothers in this study. While some mothers share similar stories of mothering a child with and without disabilities, other stories are quite dissimilar. As Ryan and Runswick-Cole (2008) assert, there is a tendency for researchers to treat children with disabilities as a homogeneous group, yet the experiences of families raising children with different types of disabilities can be quite dissimilar. For example, the researchers maintain that the experience of parents raising children with physical impairments and health problems differs substantially from raising children on the autism spectrum. Patching and Watson (1993) support this finding in their claim that families with disabled children are so variable that they most likely have as much in common with typical families as each other.

While my study found there to be numerous differences between families raising children with different disabilities, there also exists many similarities. When examining the findings of this particular study, it is inaccurate to say that mothers raising children with and without disabilities are a homogeneous group. But at the same time, it is also incorrect to say they have completely different experiences. In some respects, their experiences are quite similar, and in other respects, they vary greatly. This variation seems to be based on many issues related to the entire family dynamic, as well as the child’s diagnosis and characteristics.
Chapter Seven: Significance, Implications, and Conclusion

Introduction

This chapter is divided into five sections. The first section reflects on the research process. Here, I discuss the methodological significance of my particular study, including the use of the collaborative narrative method, the use of the diary method, and the implications of using a research method in which the researcher is considered an insider. The second section centers on the impact on family communication, and the significance of using both social construction and symbolic interaction in this study. The third section focuses on the methodological limitations of this study and suggestions for future research. The fourth section offers several suggestions for professionals working with families of children with and without disabilities. These professionals include mental health counselors, social workers, doctors, and geneticists. In addition, this section outlines how the findings can be useful for families raising children with and without disabilities. The last section discusses the face of disability regarding awareness and acceptance within society and finishes with a conclusion.

Part One

Significance of the Collaborative Narrative Method

There were several benefits, as well as limitations, to using the collaborative narrative method in this study. The first benefit was the valuable and beneficial collaboration with participants. I deviated slightly from the degree of collaboration
proposed by Arvay (1999, 2002, 2003) due to issues of time and feasibility; however, I still spent a great deal of time collaborating with participants on their narratives. Each mother reviewed her full narrative, offered valuable input, clarified any questions I had, and worked with me to ensure her story was presented accurately. While this amount of collaboration was extremely important to my study, it was also quite time consuming. As a result, I must consider the use of collaborative research to be a limitation, as well as a benefit, because this method was extremely time intensive.

Another significant benefit of the collaborative narrative method was its focus on personal narratives. Each participant shared her emotional account in detail. Participants spent large amounts of time conversing with me during in-depth interviews, meticulously recording their heartfelt thoughts in journals, and providing detailed feedback on portions of this study. They shared their unique stories of motherhood and disability, as well as their triumphs and struggles, experiences which are rarely acknowledged and appreciated. These in-depth life stories offered a window into the world of disability, which adds to the research by allowing us to understand and learn about disability from the first-hand experiences of these 32 mothers. Through the narratives of these participants, we are able to expand our insights into the under-examined world of childhood disability. Hopefully, these narratives are a source of knowledge and insight for others to learn about family disability.

While eliciting feedback from participants was beneficial to my study, it also posed a notable limitation. A majority of the mothers were quite pleased with their narratives and enjoyed being able to read them in print. However, on several occasions,
mothers were unhappy because they felt they sounded too “pessimistic” and “off-putting.” I struggled a great deal with these situations because while I wanted the narratives to be accurate and truthful, I did not want to print a narrative that made any of the mothers uncomfortable or upset.

To assist with this dilemma, I considered the current literature on the ethics of member checking. For Lincoln and Guba (1985), member checking—playing back the interview to the participant who provided it to obtain a reaction—is a crucial method for establishing credibility. They advocate negotiating the interpretation of data with participants because the “specific working hypotheses that might apply in a given context are best verified and confirmed by the people who inhabit that context” (p. 41). This sharing of interview transcripts and/or analysis with participants guarantees an accurate story. While Lincoln and Guba advocate for this particular technique, they also describe the potential problems, such as placing participants in an “adversarial position.” They trust that participants will be able to “agree that reconstructions are fair even if they are not in total agreement with them” and expect investigators to exercise care so as not to “simply reconstruct an average or typical position” (p. 315).

Talburt (2004) asserts that while the member check allows for clarification and explanation of ideas, respect for participants becomes conflated with verification through these member checks, and the author ends up ceding authority to participants. She ponders whether the only goal of research is to represent accurately the views and perspectives of those who participate in studies. Must researchers and participants reach
interpretive consensus? Can researchers risk interpreting participants’ worlds with and against them?

I also considered the research of Morse (1999), who maintains that it is necessary to practice reliability and validity in qualitative inquiry. She considers it highly inappropriate when researchers ask participants to verify their results, and then revise their final product based on a comment or suggestion made by a single participant. According to Morse, “There is something quite wrong with this picture in which the participant has more analytic authority than the researcher” (Morse, 1999, p. 717). This idea is also supported by Kvale (1989), who asserts that the decision to discard essential and commonplace procedures, such as reliability and validity, have caused qualitative studies to be “rejected as subjective, unreliable, and invalid. In particular, when judged against the common criteria for validity, as developed for psychometric tests, the qualitative methods have been dismissed as unscientific” (p. 73).

In an attempt to take into consideration all of the recommendations put forth by these researchers, I decided not to radically change any of the text. However, I did soften some of the language in several narratives by changing a few of the words which made participants feel uncomfortable. By doing so, these particular participants felt satisfied with the wording of their narrative. At the same time, I did not consider the text or tone to be compromised or inaccurate in any way. I specifically followed the advice of Talburt (2004), who suggested that when sharing interview transcripts or interpretations with participants, researchers should ask: What interpretations do participants take comfort in and take issue with? And what do I as a researcher take comfort in and take

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issue with? She emphasizes that honoring the stories of participants while reading beyond them is a difficult task. Nevertheless, a researcher must be able to “navigate among the perspectives and contradictions represented” (p. 89).

A final limitation to the present study is the fact that while I did collaborate with each participant on her personal narrative, I chose not to collaborate with participants on the actual interpretations of these narratives. This decision was made due to time and feasibility. As a result, I do not know how each mother might react to my specific analysis of her particular story. In future research, I would like to obtain this type of feedback to ensure that participants concur with my interpretations and analysis. This additional collaboration would add even more vigor to future research findings.

**Significance of the Diary Method**

The goal of a diary in qualitative research is to capture the participant’s daily lived experience and uncover the meaning created by the individual. Diaries provide a window through which the researcher can observe the participant in a natural setting, allowing for a more holistic and contextual research approach (Sa, 2002). Diaries also provide the researcher access to settings where observation is either impractical or creates an intrusion or distraction (Alaszewski, 2006).

The inclusion of diary methods in this study enabled exploration of the participants’ perceptions of raising a child with and without disabilities. In addition, collecting diary data further explained, provided support, and enhanced interview data with longitudinal information regarding the lived experiences of these mothers. Participants were given a bound journal, but were urged to type entries if they preferred.
They received detailed instructions regarding the content of their diary entries (Appendix C) and were instructed to write about their day-to-day experiences mothering their children. They were urged to include all of the high and low points and make a minimum of three entries per week for 4 to 6 weeks. Included in these entries were general impressions, feelings, and thoughts about day-to-day interactions with their children, friends, family members, neighbors, teachers, therapists, doctors, and strangers. Additionally, several participants included their personal letters, emails, and chat room dialogues.

What were the mothers’ reactions to keeping a diary? Did they perceive this method as a positive or a negative? Was it helpful in coping with the day-to-day difficulties of raising their unique families? Or was it too time consuming? To answer these questions, I asked each participant to describe her reactions to keeping a diary at the conclusion of her in-depth interview.

Initially, several of the mothers were hesitant to commit to keeping a diary due to the required time commitment. However, after beginning to write in the diary, many of these mothers reported that while it was difficult to find the time to write, they were pleasantly surprised by the therapeutic nature of keeping a diary. Many mothers felt it was healthy to be able to “bless and release” and welcomed the opportunity to get things “off their minds.” For example, in the following excerpt, Denise explained that it was a nice change to get her feelings out instead of shoveling them under the rug where they typically fester: “I usually sweep it under the rug and then all of a sudden, it gets so big I can’t deal with it. If I could just handle things a bit at a time, everything would be
easier.” Here, Alexandra shared that the diary allowed her a place to “talk” about her feelings: “Because my husband frequently works out of town, I don’t have anybody to talk to at the end of the day. When he is on the road, we only get in a short conversation, so we can’t get into anything real deep. The diary allowed me to let it all out.”

The diary was regarded by some participants as a safe venue in which to purge their innermost feelings. In the following excerpt, Tiffany compared keeping the diary to sharing her feelings with a friend: “It was very cathartic to let it out. It was like a friend to talk to or a shoulder to lean on. It was eye opening to see where my frustrations lay.” Like Tiffany, Rachel described her experience as a positive one. In this excerpt, she explained how the diary provided her with a safe place in which to purge her innermost thoughts and feelings: “It was neat to be able to put my feelings into words. I did not have to take it out on my husband. You get the thoughts out of your head because they are swirling around up there with no place to go.”

Several mothers shared their diary entries with their husbands. Here, Sandra described this collective experience as a positive one: “My husband and I sat down, and we read a few entries together. We reminisced a bit and it was good. I felt more connected.”

These positive findings are consistent with narrative therapy, which maintains that providing people with an opportunity to tell their stories helps them come to terms with difficult life events (Weber et al., 1987). Frank (2002) maintains the importance of narratives is not so much that they convey a story, but that they instill in us a belief that the world is a place we can make sense of. “Narratability” means that because events and
lives are worth describing, they are also worth living. “Stories give lives legibility; when shaped as narratives, lives come from somewhere and are going somewhere” (Frank, 2002, p. 5). Frank (1995) writes of the benefits to the self and to others through the sharing of these narratives. In the case of children with disabilities, this storytelling focuses on the parents’ experiences of raising a child with disabilities and specifically on the parents’ “wounds.” Narrative theory offers hope through telling one’s story and reclaiming one’s identity as a person, and not a disability or illness (White & Epston, 1990).

A few mothers were concerned that their raw honesty would be construed as negativity and ungratefulness. Because their diaries included more negative experiences than positive, they felt guilty and worried about being judged. For example, in Tessa’s narrative, she explained that she wrote off-putting details in the diary simply because she needed to put these thoughts on paper since they are extremely difficult to talk about: “I write negative things only because I need to write them down. These are the issues that are harder to talk about and don’t come up in conversations with others. The diary is a place to get them out in the open.”

One mother insisted that the diary was not a useful outlet for her because she embraced denial and avoidance. She believed that “burying all feelings” instead of facing them was a good practice for her, and therefore, planned to stop writing in the diary. Another participant described how writing in the diary forced her to recall all of the dark and negative aspects of her life, and therefore, was not a constructive exercise for her. For example, in the following excerpt, Jessica shared how the diary was
unhelpful for her because it forced her to remember and relive the destructive aspects of her life: “The diary forced me to be realistic, which is not always helpful. It was hard to relive everything as I was writing it down. I already feel emotionally exhausted and find myself crying a lot. The diary made this worse for me.”

Several mothers noted that while they enjoyed the diary, they considered it to be a large time investment in an already overly hectic and demanding life. Here, Emma explained that the diary made her sit back and think about motherhood; however, it was too much work to sit down and write: “I wish I had more time. But I’m honestly on autopilot every day just trying to get to 8 p.m. every night.”

**Significance of the Researcher as an Insider**

My experiences as a mother raising a young child with special needs, as well as two typically developing children, was the beginning point for this study. The research I conducted here can be considered “insider” research, because I carried out this study with a group of which I am a member and share social and historical connections (Kanuha, 2000).

According to Kvale (1996), a researcher must possess knowledge of the research topic, but this knowledge must be used carefully so as not to reinforce the power structure often present in qualitative studies. The issue of trust and credibility was vital. Creating open and conversational questions and allowing the participants to see the person—and mother—behind the researcher helped establish a positive relationship and reduce issues of power.
Self-reflexivity enabled me to share with my participants my connection to the study, as well as the importance I place on sharing one’s life story. While my own journey strengthened my understanding of the participants’ experiences, I needed to be aware that not all of my participants had the same experiences as me and were in different stages of their respective journeys. I needed to be cognizant of placing myself “in the other’s place” (Canales & Bowers, 2001) as I reviewed the participants’ diary entries and conducted the interviews. I was careful not to let my first-hand knowledge about the challenges and demands of raising a child with special needs have any impact on my role as researcher. I made every attempt to remain open and receptive to the stories of each mother and allowed their individual stories to unfold naturally.

While a researcher’s experience and interest with this population can enhance the interview process and augment the ability to relate to and understand participants and their experiences, this also can pose threats. Bias and subjectivity may be created, which can negatively affect the interview itself, as well as interpretations of responses. Whenever we, as researchers, assist other people in sharing their stories, we inevitably become involved in “telling our stories of their stories; we present our interpretations of their interpretations” (Ferguson, Ferguson, & Taylor, 1992, p. 299). My intent in this study was to share the accounts of mothering children with and without special needs by giving voice to the mothers who participated in the study. However, it should be recognized that their voices may possibly have been shaped through my own insight and sensitivity as a mother of a child with special needs.
For these reasons, I wanted to investigate exactly how the mothers perceived their participation in a study led by a researcher who was also a mother raising a child with and without disabilities. Did they perceive this commonality as a positive or a negative? Was it beneficial to have an “insider” as a researcher? To answer these questions, I asked each participant to describe her reactions to my role as a researcher during her in-depth interview.

A large majority of participants noted the many positives in having a researcher who understood first-hand the day-to-day difficulties of raising a child with and without disabilities, and appreciated how hectic life can be with the constant juggling that occurs on a daily basis. For example, in the following excerpt, Sandra explained that any mother who has a child with special needs can relate to others in the same situation and therefore, can explain things in a better way: “A mom who doesn’t get it is just going off hindsight, kind of like me reading a book on how to build a rocket engine. I do not really know about rockets. There’s a difference there.” Here, Tessa also expressed her beliefs that you cannot understand life without actually experiencing it: “I cannot explain to a non-mom what motherhood is actually like. There’s a wide range of emotions and experiences, and the feelings are so complex. You can’t possibly comprehend unless you are in the same situation.” Madeline added that because I also had a child with disabilities, she was much more receptive to participating. She explained: “I felt less judged. I did not feel threatened. I think your situation helps your credibility. It helped because it made me more honest.”
Several mothers stated that they would not have participated in the study if I had been a mother of only typically developing children or was not a mother at all. Kelsey clearly articulated this trend by maintaining her fear of being judged by others who do not understand. She elaborated here: “I would not have participated because I fear being judged. I would be afraid of the researcher’s inability to understand me and my unique situation.” Jill explained that she would not have participated in the study because she would have wondered if I felt pity for her. However, she says that knowing the researcher “had her own similar struggles made it easier to open up” about her own insecurities. Donna concurred and asserted that she would not have participated for fear of being misunderstood. Here, she explained this fear: “I would never want to expose myself to somebody who doesn’t understand because they can’t grasp the situation if they have never lived it.” In the following narrative, Maureen elaborated on this point and claimed she felt comfortable knowing I was part of the disability community and as a result, within the circle of trust: “The fact that the researcher was part of the disability community meant that I knew I could take part in this study. I could be totally comfortable and candid, and would not have to watch my words. I could be open and free.”

Some mothers reported they would have participated in the study regardless of the background of the researcher. For example, Brenda explained if I had not been a mother raising a child with disabilities, she still would have participated; however, she would have been more descriptive in her journal entries and interview responses. She elaborated on this point: “I would have felt the need to explain my responses in more
detail for you. I would have been more cautious and a little fearful that you would think I was abnormal or needed therapy.”

Tiffany insisted that she would have participated no matter what, but if I had no experience with disability, she would have felt like she was educating, rather than sharing her story. If I did not have any kids or had only typically developing kids, Gabrielle maintained she would have felt awkward and more strained. She found it much easier and comforting to communicate and open up to someone who understands and lives the same life.

Part Two

Impact on Family Communication

Discourse processes are pertinent to the study of family communication because through interaction and language, family members construct their familial identities (Stamp, 2004). Galvin (2006) maintains that as today’s families become more diverse, their “definitional processes expand exponentially, rendering their identity highly discourse dependent” (p. 3). Therefore, family identity is based upon members’ communication methods with outsiders in addition to their communication with each other. Because a family’s identity is characterized as who and what a family is or is not, identity directly relates to how a family sees and defines itself and how outsiders see and define the family (Suter et al., 2010). This approach to family communication is congruent with current family communication research that asserts the importance of studying communication processes in nontraditional families (Harrigan, 2009), as well as
the actual definition of family, which is reliant on the communication that members employ both inside and outside the family perimeter (Turner & West, 2006).

While all families engage in some level of “discourse-driven family identity building” (p. 3), less traditional families are highly discourse dependent. These families must utilize discursive practices to manage and maintain their identity on an ongoing basis (Galvin, 2006). Families raising a child with disabilities can be considered less traditional because these families are defined by difference, whether visible or invisible difference. These differences between family members tend to generate insensitive and invasive outsider remarks, which challenge the family identity (Suter, 2008). The presence of a disability also renders the family connection more unclear to themselves, as well as to outsiders. This ambiguity is observed in external and internal boundary management practices. Stressful situations and boundary ambiguity challenge these disabled families because expectations of inclusion and support are less apparent for these families. As a result, explaining, legitimizing, narrating, defending, clarifying, and negotiating identity become everyday occurrences (Galvin, 2006).

The concept of discourse dependency provides a useful framework for studying family identity and family communication. This framework is significant for helping improve our understanding of families experiencing stressful life events. In my study, mothers shed light on this stress and trauma. Although some mothers were acutely aware that the disability could destroy their marriages, they did not consider divorce an option, simply because they recognized their inability to parent alone. They were adamant that life would only be harder as a single parent. At the same time, they struggled with an
unfair balance of responsibility, feeling unconnected to their spouses, taking completely different approaches and holding different views on child rearing, and placing their spouse at the bottom of their priority list. It is evident in some of the mothers’ narratives that remaining married proved beneficial to a number of families, while also creating acute marital stress for other couples. But what can we learn from these mothers?

Given the large number of families under stress, it is necessary to examine the struggles that exist between couples, as well as the specific environment in which they reside (Bradbury, Rogge & Lawrence, 2001). Fincham (2004) maintains that stressful family events actually predict communication, and communication, in turn, predicts marital satisfaction. He suggests that a couple’s communication processes may reflect the adequacy of a couple’s resources (personal, interpersonal, and material) and their ability to manage the unique surroundings in which they exist.

In an effort to understand the relationship between marital discord and family functioning, Story and Bradbury (2004) found that when couples in nondisabled families work together to resolve a problem and consider one another’s feelings, they are more likely to reduce their daily stress levels and report a higher degree of marital satisfaction. However, when identifying specific stressors in families raising children with disabilities, families must contend with numerous additional issues, such as a lack of secure attachment, lower socio-economic status, poor child temperament, severity of disability, and poor marital relations (Keller & Honig, 2004).

Traumatic life events, communication, and marital satisfaction are clearly related. However, a more complete understanding of marital and family communication requires
a consideration of a broader communication context, which includes environmental factors that influence individual spouses and/or the couple (Fincham, 2004). This communication context is imperative because language reflects and shapes family experience. And families living in a world of instability and crisis depend on this discourse to construct their identities (Galvin, 2006).

**Significance of Social Construction and Symbolic Interaction**

The theories of social construction and symbolic interaction overlap, as well as diverge. In both theories, we use language to create the self, as well as a sense of the world around us (Leeds-Hurwitz, 2006). What separates these two theories is that social construction focuses on how individuals make sense of the social world through language and relationships, while symbolic interaction concentrates on making sense of the self and social roles. (Leeds-Hurwitz, 2006). It is because of these similarities, as well as the differences, that researchers will find it useful and appropriate to include both theories in a single study.

Symbolic interaction examines the self and the effect that social relationships have on the self. Becoming a mother of a child with disabilities clearly results in a complex identity transformation for these women. These mothers must come to terms with the alteration of the many expectations that most parents take for granted (Wallander & Venters, 1995). A mother’s own future is irrevocably changed, and she must negotiate a new kind of mothering, significantly different from her idealized or constructed experiences (Nelson, 2002). When these women did not give birth to the perfect baby they had dreamed about, it challenged their conceptions of themselves as women and
mothers. In this study, we see how raising children with disabilities challenges a woman’s sense of herself as a mother and causes mothers to completely reevaluate themselves and their role as mother.

Social constructionists maintain there is not one true understanding of the world. The same can be said for disability; there is not one true understanding of disability and there are a number of discourses surrounding the meaning of disability. This concept of discourse is an assumption of social construction where social constructionists assert that our identities are affected by our cultural understandings, as well as the discourses that are readily available to us (Burr, 1995). For example, the mothers in this study described experiencing intense scrutiny while in public with their disabled child. This scrutiny develops through the socially constructed belief that these mothers need to comply with specific indicators of good mothering. When mothers do not adhere to these cultural prescriptions, they are subject to labels of poor mothering, selfishness, and resistance (Garcia-Coll, Surrey, & Weingarten, 1998; Read, 2000).

Berger and Luckmann (1966) define society as the largest social construction and the individual as the smallest. It is within this framework that the mothers in this study exist. On a daily basis, they must navigate the construction and reconstruction of their identities, as well as the cultural understandings and social norms that define disability and normality. They must explain the meaning of motherhood and their child’s disability to themselves and to the world around them. Through the narratives of these mothers, we are able to listen to their life experiences and search for meaning within them. This is particularly important within the tenets of social construction, which emphasizes the
importance of listening to and learning from those who are, or were formerly, marginalized; who have had their perspectives and voices submerged; or were dominated by those with more social power or privilege (Hartman, 1994). These narratives are important because we “become who we are through telling stories about our lives and living these stories; our stories are a cornerstone of our identity” (Andrews, 2002, p. 75).

There is no question that using a symbolic interaction frame coupled with social construction has allowed me to study these mothers and their unique perspectives, as well as the numerous implications this can have on their development, self-concept, identity, and view of the world. These theories were extremely useful frames for studying the recreation of self and identity, and understanding the lived experiences of mothers raising children with and without disabilities.

**Part Three**

**Limitations of the Present Study**

The current study contains several limitations worth mentioning. Specifically, this sample constituted a relatively homogenous group of mothers. While there was some diversity among the mothers in terms of ethnicity, socioeconomic status, and family structure, all of the mothers in the study lived in the same Western city and a majority of the mothers were from white, suburban, intact, middle- to upper-class families. Mothers from dissimilar cultures, races, nationalities, and regions of the country might describe different experiences. Additional characteristics that distinguish the sample from the general population, and therefore limit the generalizability of the current study, include the fact that most of the mothers had a college education, which likely influenced their
responses and interpretations. By not relying on data from other types of participants, the breadth of experiences reported was somewhat limited. An expansion of the current study should include mothers from different cultural backgrounds; mothers from other family constellations, such as same sex and foster parents; and mothers who have low socioeconomic status. These groups, largely underrepresented in research, most likely possess other perspectives not represented in the current study.

One limitation worth noting is the high number of stay-at-home mothers in this study. Of the 32 participants, 17 were homemakers. It is unclear whether my recruitment of participants yielded a majority of stay-at-home mothers or whether the demographics from this Western city led to this high percentage. Another likely possibility is the fact that many of these mothers may have quit their jobs after having children. This phenomenon is described by several of the mothers in this study who were no longer able to work after the birth of their children with disabilities due to their child’s extensive needs. This trend is also supported by the literature. For example, several studies found that childcare responsibilities can “bleed” into paid work time resulting in increased absenteeism, distraction, and exhaustion (DeRigne & Porterfield, 2010). Consequences include reduction in work hours or a cessation of paid employment (DeRigne & Porterfield, 2010). Because raising a child with disabilities is energy intensive and time consuming, many mothers often give up their roles as workers because these jobs require a large time commitment and rigid obligations, which can be difficult to maintain while concurrently meeting the needs of their child. (Crowe et al., 1997; DeRigne & Porterfield, 2010; Leiter et al., 2004).
Several studies also have demonstrated that lower maternal employment exists in families with disabled children, especially among married mothers. The severity of these children’s conditions and type of limitations has been found to influence these employment decisions (Corman et al., 2005; Gordon et al., 2006; Kuhlthau & Perrin, 2001). Mothers seem to have a decreased likelihood of working if the child has a condition requiring significant care (Leiter et al., 2004). For example, a study by Baydar et al. (2007) found that mothers of children with Down syndrome and asthma spend fewer hours in paid employment than mothers of children without these conditions. This is supported by a 2007 national survey of children with special health care needs. Administered by the U.S. Department of Health and Human Services, the study found that 24 percent of parents surveyed had to stop working or cut back because of their child’s health care needs. This change in employment status is more likely to occur in families who have a child more severely affected by his or her condition (measured by hospitalizations, activity limitations, and chronic conditions) compared to children whose daily activities are not affected by their condition (USDHHS, 2007).

Furthermore, a study conducted by Larson (2000) found that mothers often choose occupations geared toward meeting the demands of parenting children, rather than their own personal needs. Because mothering a child with special needs requires additional skills, knowledge, and organization, these mothers devote a great deal of time to care giving and household labor, which often results in restrictions on their choices of occupations. As a result, it is likely that many of the stay-at-home mothers in this study
became homemakers as a direct consequence of their extensive caretaking responsibilities and role expectations.

The differences in the mothers who chose to participate in this study and those who did not also may raise concerns about selection bias. During the recruitment process, I explained to prospective participants that this would be a study about the experiences of mothers raising children with and without disabilities, and this was an opportunity for mothers to share their unique selves and their stories from their own viewpoints. It is possible that mothers who have particular kinds of experiences associated with their child may have volunteered to participate in the study. For instance, mothers who chose to participate may have had a more positive outlook on life and more support that would give them time to keep a diary and meet for interviews. On the other hand, mothers who did not participate may have had a negative outlook on life, been more overwhelmed and distressed, and had less support and time. Since this information is unknown, self-selection as a possible limitation cannot be overlooked. For these reasons, it is difficult to generalize these findings to other mothers raising children with and without disabilities.

Another limitation to the current study is the reliance on capturing the experiences of participants at a particular point in time. In most cases, the individual interviews took place during the 4- to 6-week diary phase or directly after this time period. Because parent-child relationships are continuously changing and evolving, examining these relationships at a single point in time can possibly lead to an inaccurate picture of the dynamics of this relationship. It was not the intent of the study to conduct longitudinal
research; however, a longitudinal design may result in a more complete understanding of a mother’s exceptional journey.

The final limitation involves the actual children in this study diagnosed with a variety of disabilities. Some of these children exhibited mild symptoms, while others exhibited moderate to severe symptoms. Some symptoms were obvious and quite disruptive, while other symptoms were mild or invisible. As a result, conclusions about the entire population of mothers raising children with and without disabilities cannot be drawn due to the heterogeneity of the children included in this particular study.

**Directions for Future Research**

A discussion of the directions for future research is warranted to address the limitations in this study. One consideration for future research is designing a study examining the long-term effects of raising a child with and without disabilities on the family relationship. Because coping with the effects of a disabled child is a lifelong process, studies need to be longitudinal and should focus on how mothers learn to adapt and cope over time, and how this relates to family functioning and communication.

Family systems theory maintains that family life can best be understood by studying the relationship among its members. Because siblings help to shape each other’s identity, and the nature of the sibling relationship is one of intensity and long duration, the impact of a disability on this relationship is of significance (Crnic & Leconte, 1986; Featherstone, 1980; Fleitas, 2000; Rossiter & Sharpe, 2001; Van Riper, 2000). Most families with a disabled child also include other nondisabled children. As a result, the entire family as a system needs to be studied; the behavior and development of
the siblings of disabled children can only be understood in the context of the entire family system (Skrtic et al., 1984). To better understand the impact of childhood disability on siblings, future qualitative studies need to examine how siblings of children with disabilities describe and experience the disability, as well as the effect of a disabled sibling on nondisabled siblings. Conducting valuable research on the relationships and communication practices experienced by siblings will contribute to the creation of much-needed community support and resources. Studying siblings’ adjustment strategies and coping techniques would help practitioners develop useful intervention strategies for siblings struggling to cope with the impact of a disabled child on the family system.

In addition to the perspectives of siblings, future studies also need to examine the views of fathers. For this study, I carried out an examination of the unique experiences of mothers. The role of fathers and fathers’ points of view were discussed and presented solely through the perspectives of the mothers in the study. I specifically chose to examine mothers because it is the mother, and not the father, who is most vulnerable to criticism of their parenting skills. Typically, mothers are blamed for producing a dysfunctional child. A review of literature clearly indicates that mothers are subjects of scrutiny and surveillance, both by professionals, academics, and the public (Blum, 2007; Read, 2000; Ryan & Runswick-Cole, 2008). However, there is a recognized need for researchers to study fathers to better understand this phenomenon. In addition, a deeper understanding of the familial experience can be achieved by including the perspectives of fathers raising children with and without disabilities.
Another useful study would focus on the disability itself and investigate how the severity of a child’s disability affects family members. Depending on the disability, some children may exhibit severe symptoms, which are extremely obvious to strangers and quite disruptive in public, while others may exhibit mild to moderate symptoms, which are invisible in public. Due to these differences, some mothers may experience acute, daily stress because of the disability, while other mothers may consider their child’s disability to be more manageable. This would definitely affect the attitudes of mothers as they describe their lives in positive or negative ways. Therefore, it would be useful to better understand how the severity of the disability influences the lives of mothers.

Part Four

Suggestions for Mental Health Professionals and Social Workers

Disability can affect families in many different ways. Commonly overlooked are the sacrifices made by the mother, who is most commonly the primary caregiver in these circumstances. Golodetz, Evans, Heinritz, and Gibson (1969) describe this trend:

She is not trained to do her job, a priori. She may have little choice about doing the job. She belongs to no union or guild, works no fixed maximum of hours. She lacks formal compensation, job advancement and even the possibility of being fired. She has no job mobility. In her work situation, she bears a heavy emotional load, but has no colleagues or supervisor or education to help her handle this. Her own life and its needs compete constantly with her work requirements. She may be limited in her performance by her own ailments. (p. 390)

This passage supports the assumption that families, especially mothers, are paying a very high price for providing care. Caregivers of individuals with disabilities are at
extreme risk of being highly stressed and clinically depressed, and maintaining a subjective quality of life that is way below normal (Cummins, 2001).

The narratives in this study support this notion, making it crucial for these mothers (and families) to receive necessary resources from social workers and mental health professionals. Understanding mothers’ experiences with family disability can assist clinicians in recognizing distress and developing treatment approaches sensitive to coping styles and emotional responses. Additionally, recognizing how mothering is influenced by disability allows for a better understanding of family strengths and difficulties, and determining who would benefit from assistance. Clearly there is a need for marriage and family therapists to be well-informed about childhood disability and its impact on families. It is unknown to what extent information on disability is addressed in marriage and family certification programs because no relevant empirical studies were found. Nevertheless, the field of marriage and family therapy can benefit from extensive professional training, as well as continuing education specific to the needs of families raising children with and without disabilities. The field of marriage and family therapy requires a strong commitment to understanding the daily challenges of families managing disability.

**Suggestions for Medical Professionals**

Many of the mothers’ narratives revealed that family doctors, pediatricians, and geneticists played a prominent role in the diagnosis of their children. Because these professionals have an important part in these mothers’ diagnosis stories, and parents tend to rely on these doctors for guidance, advice, and information, it is vital for doctors to
thoroughly understand the complexities of childhood disability. Many mothers in this study admit to having little knowledge about disability before their child’s diagnosis. As a result, their early perceptions of disability are likely shaped by their doctor, who they depend on and trust. Professionals who work with these families must be familiar with the social paradigms of disability and should have first-hand experience working with individuals with disabilities and their families.

In addition, as part of their medical training, these professionals need to understand how to refrain from conveying personal biases toward raising a child with disabilities and how to reveal a child’s diagnosis to the family with sensitivity and compassion. Instilling hope in these mothers is essential. Medical professionals need to comprehend how certain facial expressions, as well as the tone and manner of their delivery, can have an impact on these mothers’ feelings of hopelessness and despair. Mothers need to be encouraged to concentrate on notions of faith and optimism concerning their children’s lives.

As described in many of the mothers’ narratives, receiving a diagnosis is often shocking and traumatic, so doctors need to be proficient in discussing a child’s diagnosis. An increased awareness and sensitivity to the family’s reactions to the diagnosis and prognosis can help doctors encourage families to explore all options and support services available. The educational curriculum of family doctors also should include current information regarding common syndromes and diseases, as well as exposure to the complexities of raising a child with disabilities, as well as the medical concerns.
Another way to help mothers cope with the diagnosis of their child is to provide psychological and social supports in all medical, genetic, and prenatal diagnosis clinics. This onsite support would be helpful in supporting mothers and families through the diagnosis process as they learn coping techniques. While these supports are occasionally offered, they are seldom part of the care team and are typically unavailable in a majority of diagnosis clinics (McCoyd 2008).

Suggestions for Families

Some of the narratives in this study explored the benefits of connecting with other families experiencing similar issues. Because we know this connection can be quite therapeutic, families who learn about their child’s diagnosis should be offered the opportunity to meet with other families of children with special needs and learn about their personal perspectives and coping strategies. This method is supported by Kerr and McIntosh (2000), who found that parent-to-parent support can be extremely successful in reducing parental stress and anxiety. They maintain that the challenge is to ensure professionals are aware of the potential benefits of parent-to-parent support and provide parents with information about available organizations and contacts as soon as a diagnosis is delivered. Additionally, it is important to refrain from introducing new parents to other parents experiencing unresolved problems or negative feelings towards disability so as not to cause any harmful effects on parents. One suggestion is a mentoring program where mothers who are struggling can connect with other mothers who have successfully created a high-quality life for themselves. This mentoring relationship can be a useful tool for both mothers as they share their life experiences.
Another suggestion is joining a support group. Several mothers in this study note that being a member of a support group has given them strength and helped them feel less alone in the world. A support group gives them a much needed outlet when they have difficulty communicating with and relating to their husbands, family members, friends, and other mothers with typical children. For example, Gabrielle explained that her support group has been extremely important to her because of the strong connection with other mothers raising children with disabilities. She elaborated: “Their experiences are distinct, but also comparable. Everyone is feeling the same feelings . . . anxiety, guilt, and sadness. It’s about knowing there are people out there like me. Realizing I am not alone has been great.”

Support groups provide a number of functions, including sharing information and resources; discussing topics considered to be taboo; experiencing mutual support and catharsis; sharing feelings in a nonjudgmental environment; engaging in problem solving; reducing stress, alienation, loneliness, and isolation; reinforcing effective coping techniques; becoming a helper to others; developing social networks and supportive relationships; finding inspiration and hope; and validating thoughts and feelings (Beckman, 2002; Braithwaite et al., 1999; Flexman et al., 1999; Fullmer & Majumder, 1991; George, 1987; Gottlieb, 1981; Huws et al., 2001; Kerr & McIntosh, 2000; Resch et al., 2010). Belonging to a support group can help these mothers cope with their emotions, feel more confident in their role as mother, and strive to be a better mother. The group can provide each woman with a sense of identity and a place to reconstruct this identity as their children grow and face new challenges. Within the dominant
culture, there are stark differences between the socially constructed views of mothering a typically developing child and mothering a child with disabilities. The women in this study are constantly aware of these differences, which create turmoil in their lives. However, by challenging the socially constructed views of motherhood, these women can create a new identity for themselves as mothers, an identity in which they successfully manage the stigma and stereotypes of disability. Belonging to a support group can provide a safe and nurturing place in which to reconstruct these identities, a place that provides them with strength, support, and hope.

Mothers also can gain control over their lives through the empowerment they receive from support groups. Empowerment is defined by Wallerstein and Bernstein (1988) as a social action that promotes the participation of people, organizations, and communities in obtaining control over their lives. Cox (1991) asserts that empowerment provides an opportunity to achieve a greater sense of self-esteem and reduces feelings of guilt and self-blame. At the same time, empowerment provides a strategy to address oppression by creating shared goals and objectives to shape public policy. Support groups that encourage the development of empowerment generate important dialogue and collaboration, education about disability issues, insight into personal difficulties, and an increased sense of hope for the future (Boehm & Staples, 2004; Kerr & McIntosh, 2000).

Part Five

Future Perspectives: The Face of Disability

One important finding in this study pertained to the face of disability. It is clear by these mothers’ initial perceptions of disability, as well as the reactions by their
physicians, genetic counselors, friends, and families, that much more needs to be achieved in the area of awareness and acceptance. Children with disabilities are clearly seen as lesser beings with limited possibilities. Damage, tragedy, and burden are still notions attached to the label of disability. By redefining what disability means and fostering acceptance and familiarity, we may be able to help positively change the face of disability for society as a whole.

For example, Sharon shared her vision of how disability awareness can be improved through employment education and opportunities: “I think that as parents of young kids, we need to be working on the issue of employment for people with disabilities today. It is about getting people to hire individuals with disabilities so it won’t be such a rare thing.” Catherine also insisted we must work together to include individuals with disabilities in the community and help them become functional members of society. Here, she described how she is working hard to pave the way for her son, Owen, to succeed in the future: “I bought a plot in a community garden so I can teach Owen a life-sustaining skill. Society tries to fit autistic square pegs into round holes, but why don’t we make the hole a little bit square? We can only do this if society helps.”

Additionally, numerous mothers spoke about the need for the creation of training programs, which would serve two purposes. One is to educate and train the employers who hire individuals with disabilities, and one is to train the actual individuals with disabilities to help them succeed in their jobs. To assist these individuals in becoming fully functioning members of society, it is clear that we all need to play a role.
Inclusive education is another means to foster the acceptance of disability within society. For example, Sharon and Catherine were both strong proponents of full inclusion in school and believed inclusion can help bridge the gap between society and individuals with disabilities. In the following narrative, Sharon shared her thoughts on inclusion: “When Joe Smith is trying to hire someone, and a person with a disability applies, he might remember my son. He might recall that while Zachary wasn’t great at everything, he was a good person who tried very hard.” Catherine also hoped that with the growing number of people in our society with autism, there will be more opportunities for mainstreaming. She explained: “You may have an autistic neighbor or a grocery clerk with autism. And I think it is an important ability to recognize that and know that it requires accommodations.”

Conclusion

This study explored the unique experience of mothering a child with and without disabilities. The need to uncover these lived experiences from a qualitative perspective, particularly one using the insights drawn from social construction and symbolic interaction, was emphasized. Using diaries compiled by participants and in-depth interviews structured by the collaborative narrative method, this study sought to address two complex research questions and capture the narratives of 32 participants. Through this study, we have acquired a better understanding of what it means to mother both typical and nontypical children by listening to the actual voices of these women. The true life accounts gathered from these mothers expands our understanding of their lives. The findings highlighted the true realities of parenting a child with and without disabilities,
including living an extreme human paradox, negotiating new meanings of motherhood, managing social alienation, battling medical scrutiny and perceptions of tragedy, learning acceptance, fostering growth, and understanding unconditional and unlimited love.

Specifically, the findings uncovered in this study reflect these mothers’ immense pleasure and tremendous joy in having a typically developing child; the extreme human paradox experienced by these mothers; and their personal transformations in the form of changed priorities, new careers, and a renewed life focus. Additionally, these mothers’ narratives revealed an intense struggle to confront the negative reactions of their community, their social circles, and their own previously-held prejudices and stigmatized notions of disability, as well as the existing cultural and social definitions of disability and perfection. Findings also suggest that these mothers’ views of the future tend to be shaped by the severity of their child’s disability and the extent to which their life is transformed. For some mothers, public expressions of pity and sympathy can be difficult to handle. Because these mothers believe their child with disabilities is held to a different standard when compared to typical children, they admit to dressing them in nice, matching clothes to counter some of the customary stereotypes of disability. The final finding highlights the importance of promoting education and understanding the issues surrounding disability. These moms believe that spreading the word and educating others about disability, as well as making their child more visible in public, can help minimize the fear of difference and maximize societal acceptance of their children. They embrace questions and conversations about their child’s disability because knowledge is a vital
way to break down barriers. They insist they want others to inquire about their child instead of staring, gawking, or wondering.

For mothers raising children with disabilities, there is no question that disability challenges a woman’s sense of herself as a mother. Her development and sense of self is reflected in the narratives presented in this study. It is clear that these mothers’ identities are affected by their cultural understandings, as well as the discourses that are readily available to them. This can be established throughout the study.

The benefit of this study was to bring about an awareness of mothers who struggle to raise both typical and nontypical children. Hopefully, the information generated from this study will bring about a new understanding of these women’s lives and encourage future research that can improve the lives of families affected by a disability. By documenting these mothers’ journeys, the findings of this study contribute to the knowledge of how these mothers negotiate their child’s disability and how disability is perceived within society.

Looking to the future, one important finding in this study pertained to the face of disability. It is clear by these mothers’ initial perceptions, as well as the reactions by their physicians, genetic counselors, friends, and families, that ignorance and intolerance is widespread. Much more needs to be achieved in the area of awareness and acceptance. Children with disabilities are clearly seen as lesser beings with limited possibilities. Damage, loss, fear, tragedy, and burden are still attached to the notion of disability. By redefining what disability means and fostering acceptance and familiarity, we may be
able to positively change the face of disability for society as a whole. Each of these mothers is helping, one step at a time.

These final words are taken from the narrative of Jessica, a 32-year-old unmarried mother of two, raising Max, age 7, a typical child, and Grace, age 8, diagnosed with both epilepsy and severe autism. Jessica works tirelessly at being optimistic and strives to view obstacles as learning experiences. “Adapt” and “overcome” are her constant mantras. She insists that while her life is extremely stressful, overwhelming, and sad, she still thinks of herself as blessed. In the following excerpt, she explains this conviction:

“Before Grace, I was immature and selfish. But Grace helped define me as a woman. She taught me strength and confidence. She taught me about priorities and selfless love. She gave me life, as hard as it is. She is my guiding light.”
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Appendix A: Narratives from 32 Mothers

This section presents readers with the opportunity to get to know each of the 32 mothers in this study. While their worlds are chaotic and overloaded, these mothers found the time to share their lives with me in in-depth interviews, journal entries, and collaborating and providing feedback on portions of this study. They laughed and cried as they explored the ups and downs of motherhood and disability. They described how disability has affected them and their families, and the meanings they have taken from their experience. In addition, mothers shared their advice and recommendations on coping as a way of helping others. The result is deeply emotional and personal stories that reflect life inside families managing and overcoming the difficulties of childhood disability.

As a way of introduction, I created a brief profile of each mother. These summaries are followed by a detailed narrative told in each mother’s voice, written in a poem-like form. The poetic representations (Richardson, 2002) are direct quotes excerpted from the mother’s interview transcripts and diaries, and arranged by headings/sections. Reading these narratives in poem-like form allows the reader to understand each mother’s world through her own words. All names have been changed to protect the confidentiality of the participants in this study and their families. Details that may have supplied clues to their identity (such as diagnoses) have been altered. However, all information included here represents the actual responses and insights of the mothers included in this study.
Alexandra

Alexandra is a teacher turned homemaker. This 36-year-old, married mother is raising Luke, age 10, and Patrick, age 8. Patrick was diagnosed with high functioning autism at the age of 6. Here, in her own words, is Alexandra’s story:

**Diagnosis**
We took Patrick to a psychologist when he was 5.
She told us that he was not autistic. But I did not believe her.
We lived with the tension of the unknown for another year before we could afford to see another psychologist.
After Patrick was evaluated, she said he was definitely on the spectrum.
She gave us a diagnosis of high functioning autism.

In some ways, hearing the diagnosis was a relief.
Because we had been thinking it was autism for so long. And we were hoping the label would help us with insurance.
But then again, I think there’s a part of you that tries to deny it to yourself when you don’t know for sure.
When we got the diagnosis, I cried. And I think my husband cried too, because it was just the two of us there together.
It was for real. And it is really, really sad.

**Family Life**
I think what makes it difficult for the family is that it feels like Patrick is always the first priority in everything that we do.
You know, we’re going to the amusement park, how’s Patrick going to handle it?
How is Patrick going to manage? What is that going look like?
There have been things we have chosen not to do because it was going be a pain in the neck and no fun for anybody.
So sometimes I feel like Luke gets shortchanged.
But it’s kind of the way it has to be. And that’s life.
The older he gets, the more he notices. He is becoming concerned about what other people think.
Just the other day, he asked me if I told the people at vacation bible school that Patrick tends to be emotional.
He also asked me if the other kids will make fun of him.
How do I answer that? Especially when it is also my fear?
Luke loves his brother dearly. I think it’s like most little brothers . . . I can make fun of him, but nobody else can . . . or you’re toast.

I think we would have had a really different experience if we had a younger child who was typical and therefore passing the older child developmentally.
I don’t know if we would have had a second child if we’d had Patrick first.
I guess I can’t say that for sure, because I never wanted to have just one child.
But Patrick was tough as a baby. Who knows . . .
Also, as the older brother, Luke will always feel protective of Patrick.
I hope he always has that sense of keeping an eye on his brother.
In some ways, that doesn’t feel fair to me. Why should he have to do that? But that’s life.

It’s just stressful. There are so many extra things that you have to pay attention to that other people don’t.
And even if you don’t think about those day to day, there is an extra weight from all of the stuff you have to think about.
Patrick started singing in a choir this summer. Everybody else drops their kids off at the door.
I can’t leave him because I don’t know how he will react. They will not know how to deal with him if he melts down.
So, I had to stay at the entire 2-hour rehearsal.
My older son brought a book, and he had to sit with me.
I just can’t send Patrick by himself. If something comes up, he will flip out.
And they won’t know what to do. It’s not fair to anybody.

Motherhood
I remember one particular experience when I was teaching school.
There was a child’s therapy center in town that hosted a big fundraiser every year.
They would send around a “poster child” to schools, so that kids got a chance to meet folks that were different.
And there was a big assembly where they showed a video of the center.
I just remember watching the video and thinking, how would I cope if I had a child born with Down’s syndrome or any of those kinds of things?
Luke had just been born, and I remember feeling so fortunate to not have to deal with that.
I didn’t know what the future was going to hold with Patrick.

There are activities where all of the other moms drop their kids off and they leave.
They meet for coffee, but I can’t go. I cannot leave Patrick.
At times, it feels constraining. Other times, it is easier to accept as part of the package deal.
I don’t think I’ve really stopped to think about it very much. It is what it is.
You just have to keep putting one foot in front of the other.
Sometimes, it feels like you’re just going through an extended grief process all of the time.
And I think that’s part of what makes it stressful. It tends to go in waves.
You’ll have times when you go along and things feel fine, and then something will happen and you will think, ugh, I hate this.
I get really angry, and then I just try to ignore it for a while.
There’s no person to blame. There’s just so much frustration that comes from it. I used to ask why me, but I don’t feel that way anymore. I don’t understand the universe, but I look at it through a biblical world view. I guess when it comes down to it, there’s a scripture that says, the clay can’t look at the potter and say why did you do this to me. I feel like I can trust God no matter what. And that has made a big difference to me.

I think I’ve been really blessed because my parents have always been the, “this is what you got, deal with it” kind of people. I remember camping as a kid. I would worry so much about forgetting something. I’d say to my dad, what if I forgot something, and he’d say, then you just won’t have it. So, I’ve always had a real down-to-earth philosophy. I’m not saying that I don’t have feelings of grief or it doesn’t hurt or it’s not hard. But this is what I have been dealt, so what can I do about it?

My mom stayed at home, so I figured that I would stay home with our kids. I planned to bake them cookies and do all the stuff that my mom did. But this is not what I thought it would be like. I don’t think our culture has prepared us well for motherhood. Everything that you see on television is smiling, happy babies, and sunshine. But that’s not reality. That’s a lie. It’s actually crying, grumpy babies at 2 a.m. You build expectations on what you think you’ve got. Luke was born, Patrick was born, and we’ve got two sons. Are they going to play football? You immediately get an image of typical brothers, and the kinds of experiences that they will share. And when you find out that one of them isn’t going to hold up his end of the typical bargain, then it shifts. It’s like the Welcome to Holland poem. You find out instead of going where you thought you were going, you’re going somewhere else.

**Transformation**
Because I’ve walked that road, I have way more empathy. I have empathy for any person I see dealing with a child who looks difficult in any situation. I think I would have been a lot more judgmental before Patrick. And I’m much less condemning of any of those sorts of things. I’ve heard horror stories about people walking up to folks and saying, you have to get control of your child. It’s like, yeah well, thanks, but he’s autistic.
Marriage
When children come along, there’s always a shift because you have to start defining your roles a little bit more traditionally. Or you have to figure out how to divide up the work. So, I think there are a lot of husbands who tend to feel a little bit left out. And with Patrick that’s never gone away. He has always been closer to me, which makes my husband feel rejected. Only now are they beginning to bond.

I would really like my marriage to be the very first thing in the family that we pay attention to. But sometimes it’s not. It gets pushed aside. Marriage is tough enough. Trying to love somebody who you have made a promise to. They do stuff that hurts you, and you do stuff that hurts them. Just because we’re people. It’s a long-term, day in and day out, added stress.

We’ve had our moments, but I have a wonderful husband. He tries really hard to be plugged into the kids and what’s going on. And he is very supportive of me.

Public Life
There used to be a time when I worried about being in public. I think that was when I was a younger mother, and I felt anxious about my kids throwing a tantrum in public. I actually gave up on that. I don’t know if it’s maturity or if it’s a realization. As a kid, normal was never an ideal for me, so I don’t have any trouble being abnormal.

When we went to Disney World, we didn’t have a diagnosis yet, but we were dealing with major sensory issues. So, we got a pass, which signified that we had a disability in the family and did not have to wait on any lines. Patrick doesn’t necessarily look autistic, so it made me feel odd using the pass. I wondered what people thought of us in the fast pass line. It felt weird, especially since we didn’t have a formal diagnosis.

Mothers who don’t have a child with special needs don’t get it. Especially the sweet, young mothers who have only one child and moan to you about how hard it is. And you just want to go, yeah, honey, you ain’t seen nothing yet. I think even a year ago, I would have had a lot more condemnation for that, but I don’t anymore. They are just clueless, and it’s not their fault that they don’t have that experience. And I wouldn’t wish it on them.
For Patrick, it’s part emotional and part sensory. You can’t talk him down off the ledge, so to speak, so once he’s gotten to a point where he is really distressed, he’s pretty much really distressed. And so we just have to prepare a lot. Prepare for his moods and for the special diet that he is on.

I remember a few years back when Patrick was in kindergarten. I was in his classroom and a girl was talking about her birthday party. We were all sitting at a table coloring, and she told everyone that Patrick was not invited. It was hard to hear, even though I knew it would have been difficult for him to go to the party. I would have had to be right next to him the whole time. And he probably wouldn’t have enjoyed it anyway. But it was still really painful because it was very obvious, and it wasn’t something I had thought about yet. Wow, he’s not going to get invited to people’s birthday parties. Bummer. It just hurts.

**Future**

I try not to think about the future because I don’t know what Patrick will be able to do. We have tried to make sure that we don’t sell him short in any way. As far as I’m concerned, we need to figure out as he grows up what he’s good at and then help him do that. Right now, I can’t even visualize him driving a car. That gives me an absolute heart attack. The child is autistic. He focuses on one detail. When you drive, you cannot focus on only one detail. You have to be able to see the big picture or you are toast. And will he mature enough to be able to drive? If not, does that mean that he will always be dependent on somebody else? I just don’t even know what it will look like at all. He’s still so little. And sometimes I have to remind myself that he’s only eight. When you talk about saving money for college, you can’t really ever start too soon, but we don’t have the money to save for college right now. We’re not even saving for Luke.

**Advice**

Be okay with grieving about the disability. Let yourself feel what you need to feel. Figure out how to feel supported. Arm yourself with all the information you can get. Don’t rely on other people to give you information about your child. You need to be the expert because you know them best.
Try and find all the positive things that you can. Because it will be really easy to find the negatives. You’ve got to hunt down the positives and hang on to them.

Recently, I had a lady tell me that Patrick is doing a great job in choir, and he’s really valuable. I was in shock. I didn’t know what to say to her. He’s never been treasured in those kinds of situations. So often, when we venture out in public, his behavior is not treasured, but merely tolerated. Perhaps that’s why this comment was hard for me to take in. It is a big shift from our usual experience. He is desired at choir, and not “put up” with. And I am afraid it will not last. But it was so nice for someone to cherish him. If you’re looking for the good stuff, you’ll find it. But I think you have to make an extra effort to hunt it down.

Anita

This 41-year-old, married, stay-at-home mother is raising sons Daniel, age 10, and Seth, age 4. Daniel is diagnosed with cerebral palsy. He is visually impaired, uses a wheelchair, and has severe scoliosis, which requires surgery every six months to expand the titanium rods supporting his spine. He is unable to sit or stand independently and requires total care. Here, in her own words, is Anita’s story:

Diagnosis
Daniel had a traumatic delivery. Seconds after he was born, he had a seizure. So, we knew there were concerns. However, the neurologist viewed his CT scan and insisted this wasn’t something that was going to affect Daniel long term. While we had a scary first 24 hours, we left the hospital after six days with high hopes. And then our hopes started to plummet when he was 2 months old. We realized that developmentally, he wasn’t able to do any of the things that a 2-month-old should do. And so that started us on the path of trying to figure out what was going on. At 6 months, Daniel started having significant seizures and his development was very delayed. We got a diagnosis of developmentally delayed at that point. The neurologist told us that whatever normal is, Daniel won’t be 100 percent normal. What an awful way to explain what the future held for us.

I was absolutely devastated.
I look back now, and I’m really not sure who drove Daniel and I home from the doctor’s office that day. My mind was not at all on the road. I just remember getting home and putting him in his crib, and then just sobbing for a couple of hours until my husband got home. I remember my husband saying that Daniel will always be our son, and we will do whatever we can to make life the best that we can for him. I was still nursing him at that time, so I had to be strong and positive for him. When he was up during the night, I would try and switch gears from being sad and try to comfort Daniel and offer him strength.

Nobody said cerebral palsy to us when he was a baby. But between six and seven months, the seizures were identified as infantile spasms. That’s when I knew that my roller coaster ride of yes, there’s a problem; no, there’s not a problem; was finally yes, there is a problem. Early on, my husband and our extended family had accepted it. But I kept saying, look at the things that he is doing. I kept thinking, he’s going to pull out of this.

We got the label of CP when Daniel was about a year old. The pediatrician said let’s call it cerebral palsy. Let’s put it on all of his records and go forward. I was absolutely devastated. It was finally clear to me that yes, this was a long-term situation for Daniel. And then I remember just crying on and off that night. Sleeping for a bit, waking up, and having that pit in my stomach, realizing what was going on. I was thinking ahead to all of the things he wouldn’t be able to do, and all of the things he may miss out on. What comforted me the most was my husband saying that the dreams we had were going to change, but there were so many things we could still do. That’s where our mindset has been ever since. In some ways, having a diagnosis at that point was a relief. We said, this is what it is, so let’s do what we can to help our son, and focus on his therapy and his progress.

**Family Life**
The decision to have another child was very difficult. At first, my husband and I both thought Daniel is our first and maybe there’s a reason for that . . . that he requires 100 percent of both of us. So, we really never thought seriously about having another child. But when Daniel was three and started preschool, he just lit up around all of the other kids.
And when we were in the classroom with him, we saw how much he giggled and how happy he was to be around other kids.

It was actually Daniel who made us think we were wrong in believing we could give him everything he needed.

Maybe a sibling could offer him more than we ever thought.

That was an eye-opening experience for us. And we decided to have another child.

While we had always been certain that Daniel’s issues were due to a traumatic birth, we were advised to pursue genetics, just in case.

We learned that Daniel’s diagnosis had nothing to do with genetics.

So, we went along the path to have a child naturally and that worked out.

I always knew it would be a challenge to have two kids, but I didn’t know how much of a challenge.

I think I had no idea about the time and energy, but it has been wonderful.

Because Daniel was our first, we didn’t know anything other than special needs. It’s good to have a foot in both worlds.

With Daniel, every development and every step has been such a challenge.

And then with Seth, it was effortless.

He started nursing immediately. I was amazed at how quickly he was sitting up and holding onto a cup.

It was magic.

My worst fear had been what if Daniel needs something and Seth is crying? Who do I go to?

But Daniel was always so good natured. As long as he could hear my voice, he was fine.

I thought, wow, he really does enjoy having a little brother.

I do worry about Seth not getting a typical childhood experience.

He’s starting to express little things.

Just today, he wanted to go swimming.

But I can’t take both boys swimming by myself because Seth is not a solid swimmer, and Daniel needs total support.

I told him there are some things we just cannot do. But I know that will probably not always work.

There will come a time when my husband and I will have to divide and conquer.

Because there will be things that are only going to work for Seth and things he really shouldn’t miss out on.

I worry because all of Seth’s friends do typical things.

But we always have to think about the timing of things, such as Daniel’s feeding schedule and where we can do his diaper changes.

I’m always thinking about what outings are going to work for us, and which ones we have to reserve for a time when Daniel is in school.

It’s a huge balancing act.

But I also think there are a lot of pluses, too.
Recently, we went to Disney World. With Daniel’s special needs, we were given a pass that allows us to enter the line and jump ahead of people. And I thought, wow, this is an experience that Seth wouldn’t have had if he did not have a brother with special needs. We got to ride on one of the rides two times in a row because nobody was waiting for the wheelchair accessible car. There are some pluses in this situation.

I haven’t had to discipline Daniel, but I’ve had to discipline Seth. Sometimes it’s just a different kind of relationship. I think Seth feels like we’re harder on him. With Seth, there must be consequences. With Daniel, it’s more or less being a caring mother all of the time. More of a teacher, a therapist, and a nurse all rolled into one.

It’s hard to say, but sometimes I am glad that Seth is the youngest. He was just born into this. He’s always had a brother in a wheelchair; he’s always had a brother with a set schedule. I always think it would be harder on Seth if he came first, and we had to stop doing things because of Daniel.

It is so difficult to watch our extended family treat Daniel and Seth differently. Recently, we visited family who we have not seen for some time. It was obvious they were nervous around Daniel. But they embraced Seth. It really hurt. I wanted to get mad at them, but it wouldn’t solve anything. I just tried to describe all of the amazing things that Daniel can do and answer their questions.

When we’re in crisis mode, we just look forward to the next positive time when we can do something as simple as a zoo trip. We appreciate that time so much more after spending time in the hospital. We have tried to slow down and enjoy the good times.

I think Daniel has opened a lot of people’s eyes. My nephew helps out in high school with the special needs physical education program. He is a caring individual, but I think it really helps that Daniel is part of his world. I’m hoping that Daniel will have a ripple effect on his brother and all of his cousins. That they will always have a softer side to them and an appreciation for somebody with a challenge.
Seth has started to become very helpful with Daniel’s care. I welcome the help and realize this will always be a part of his life. I never want to burden him with Daniel’s care, but at the same time, there are situations where it makes Seth happy to help. He feels important. I just hope we are always able to balance things and never overwhelm Seth.

While it is very difficult for Seth to truly comprehend the severity of Daniel’s disability, he is beginning to understand. He asked me why Daniel can’t climb stairs. I explained that Daniel’s legs were not strong enough.

He listened intently and said, “When Daniel goes to heaven, he will be able to do stairs.” I was speechless.

Last night, my mother-in-law used the “r” word at the dinner table. She was talking about one of the players on Daniel’s adaptive baseball team. I find that word so offensive and hurtful, even though I know she wasn’t using it in a malicious way. She loves Daniel. However, he was sitting at the table. I felt so sad for him. I wanted to tell her that the terms, developmental disability or special needs, are more acceptable. But I didn’t say anything to her. And I felt that I let Daniel down. I went back and forth between feeling heartbroken and angry at myself. There are times when I will either become very sad, where I can’t control the tears, or I will start to feel anger. And you never know which it will be. It depends on the day.

It also bothered me because Seth has no idea about that word, but I know he will hear it at school. Because kids can be so mean, and that’s a word that is used. I want him to know it is not okay to use that word, even though grandma used it.

The day-to-day juggling can be hard when you have a second child. The emotions and behaviors can be difficult. But in the big picture, it’s also easier because I just feel like a family. Seth has brought a lot of love and laughter to us, and it’s made Daniel happier. I think for Daniel, it’s nice to have that little voice and that relationship. And he just lights up whenever Seth climbs up and gives him a kiss. So, there is definitely more work, but I think in the long run, it’s a good thing.

**Public Life**
I definitely feel socially isolated at times. The most obvious place has been Seth’s parent’s day out program.
Most of the time, Daniel is in school when I drop off or pick up Seth, so the other moms really have no idea about Daniel.
The other moms and I have always had nice, easy conversations. But when I have Daniel with me, it feels awkward. There is a little bit of a jolt. I don’t think they know how to act or what to say. They seem shocked or surprised to see Daniel. He is out of the ordinary. I welcome questions, so a lot of times, I will say, I don’t think you’ve met my son, Daniel. He’s Seth’s older brother.
After a while, one of the other moms began to reach out to me because her mother was hearing impaired. And once she started talking and other people overheard our conversations, suddenly the barrier came down and everybody was chatting.

At the playground, I always feel a little bit removed. I’m just wheeling Daniel around the perimeter of the playground and keeping an eye on Seth. Or I park Daniel near the swings, so I can push Seth. And usually the other moms don’t interact too much with me.

When we are out as a family, I just want to be treated like everybody else. It’s always a question of where will Daniel’s chair fit in a restaurant. And sometimes, it causes some commotion to make room for his chair. I hate the moments where I feel like everyone is looking at us. But we try and play things down as much as possible. And once we get seated, all eyes are usually off of us. We always try hard to go out and make it work. Recently, we went to a Rockies’ game. We had accessible seats, but we had to think about a lot of logistics. Where were we going to park, where would be the best place for Daniel’s chair . . .

We were traveling this summer, and Daniel was sleeping in his wheelchair. Another little boy looked at him kind of funny and asked if he was dead. And my nephew, who is six months younger than Daniel, became very defensive of Daniel. He has always been kind to Daniel, but I had never seen him stand up for him.

Before I could say anything to this little boy, my nephew said, he’s just fine . . . get away from him.

I was like, wow. I just kept my mouth shut and let him talk. That was kind of cool to see. It moved me.

A lot of times, I think other moms don’t know how lucky they are. I know everyone has their challenges, but I just think they don’t realize how hard this can be.
Sometimes, when we travel, we think how easy it would be if we didn’t have to always think about everything.
Lifting him on the airplane, dealing with his wheelchair, making sure we have an accessible hotel room, and an accessible van.

Transformation
I think Daniel’s disability has made me much more outgoing. I used to be very quiet. In fact, my first employer suggested assertiveness training for me and paid for it.
I wonder, how did I have a special needs child, because you certainly have to be an assertive advocate.
But I think he has done more for me than any class could ever do.
I am more assertive and stronger.
It has deepened my faith.
Overall, I have a more positive outlook on life because I realize how much I have.
Look at Daniel. He’s smiling and happy through all of the challenges that he has.
I think if he can be positive and happy, then I should be able to follow that and do the same.
Also, I have more patience.
I think you’re always patient to a point as a mom.
But I think with Daniel, the disability has taken me to a level that I probably wouldn’t have found.
I also think that as a mom, it has made me appreciate all the little things along the way.

I always get sad when I hear friends saying, I can’t wait until my kid is at this stage, or I can’t wait until they are at that stage.
And I’m thinking, just enjoy where you are. Enjoy every stage.
Because for us, Daniel is probably always going to be where he is.

Marriage
I am so grateful to have a husband who is totally involved with both of our children.
Having one child with a disability and one child who is healthy is a challenging family dynamic.
It’s a lot of work.
We are always striving to improve our communication, but we are a very good team. We complement one another. I couldn’t do this alone.
The disability has bonded us and strengthened our relationship. We know we can do anything.
We have been through some real difficult times, and each of us has grown and come together.

Motherhood
Before I became a mom, I was very naïve. I just assumed that things would flow according to plan.
I’ve realized that motherhood has no plan. You have to take it day-by-day and hour-by-hour. That’s much harder than I realized. And much more rewarding. I always had this vision that I would be a great teacher for the kids. Honestly, they are teaching me every day.

Because I didn’t have much experience with disability before Daniel, I had no basis or guideline. I just assumed that his life was going to be the worst. I just thought he would not be able to enjoy life. The truth is that he enjoys life more than anyone else I know. He is always happy. I couldn’t really imagine him with peers or at school.

I feel such guilt that I can’t spend more time with Seth. But his brother’s care requires my time to be focused away from him.

I find that I am overprotective of Seth because I don’t want him to be injured. Seeing what Daniel has to deal with, I don’t want Seth seriously injured. When you spend a lot of time at Children’s Hospital and you see all of those children . . . We know way too much. Seth recently had a friend over. I heard him telling his friend to be careful. Of course, he gets that from me. I am paranoid and need to let him be a kid. But when you’ve been on the side of “it only happens 3 to 4 percent of the time,” you realize just how fragile life is.

It makes me so sad to know that Daniel will never have the fun experience of a sleepover at a friend’s house. As Seth is getting older, there are things that he will be able to do that Daniel just can’t. It’s so hard. As the boys grow, I know this will be a daily challenge. We have always done everything we could to adapt an activity for Daniel or seek out accessible activities. It’s getting a little tricky now that he is getting so big and heavy. How I miss the days when he was little and I could scoop him up and take him anywhere. Now, I must check if all new places are accessible. Are there stairs? Are the aisles wide enough? Can we get his wheelchair up the hill?

I watched band practice at Daniel’s school the other day. And I thought, that’s something Daniel won’t ever do. But, then I thought, maybe Seth won’t do band either. Who knows . . . I just see what the other kids are doing and it makes me sad. Depending on how strong I am that day, it can hit me, bounce off me, and I can be fine.
Or it could hit me and burrow deep inside. And then I could be a mess for the entire day. Because we go to Children’s Hospital so frequently, I sometimes look around and think we are lucky.

Even though we deal with a lot, there are others who are worse. Daniel is not on oxygen, we don’t have a terminal diagnosis. Daniel is holding his own. When Daniel goes in for surgery, he will be out of the hospital in three days. Some kids are dealing with cancer and will never get to leave.

I’m much more comfortable with mothering Daniel these days. I have confidence that we know him best. When he was younger, I was always a little hesitant and would think maybe the doctors know more. But I think now I can speak with confidence about Daniel. I feel like I know him, he knows me, and he knows that he can depend on us.

**Future**

When we think about the future, we go back and forth on both sides of the fence. Some days, it’s like we can’t think that far ahead. We don’t want to stress ourselves out. But I think about it more than my husband. I can imagine Seth going to college and getting married and having kids. With Daniel, I know that those things most likely won’t happen. I can see through high school, but not beyond that. My biggest fear is what his life will look like beyond high school. I think he’s bright, but what will he be able to do to contribute? Where will he find his social interaction beyond Larry and me? These are huge worries and fears with a lot of unanswered questions. He’s only ten right now . . . but you wonder.

We have joked that we will just find a retirement community that’s totally accessible. All three of us will move in together. It is kind of a joke, but it’s also probably a reality that Daniel will be with us as long as we’re physically able to care for him. My fear is that I don’t want Daniel to be home with me all day when he’s in his 20s. There’s got to be some value to his life. His physical care worries me. As I get older, I wonder how I will be able to do as much for him.

For Seth, I never want him to feel like Daniel is his responsibility. I think we will always involve him in Daniel’s care, so he’s aware of it. That was one thing that we went back and forth on before we even had a second child. We were not having another child so there would be someone to care for Daniel when we were no longer able. I want Seth to be connected to his brother in whatever way possible, but I wouldn’t expect him to be a caregiver.
If he wants to do the hands-on care, then great. But only if that’s what is in his heart.

The reality is that Daniel will need lifelong care.
And the uncertainty of what his care will look like in the future is always on my mind.
Will the opportunity exist for me to work outside our home? Will it be possible with Daniel’s needs? I do everything for him now.
So many questions.

Advice
Be confident in your understanding of your child with special needs.
Slowly, over the first year, I realized that I’m able to do this.
It is important to believe in yourself, have faith in yourself.
Being creative is important. Daniel is in a wheelchair, which means we need to figure out another way to do things.
We need to figure out a vacation that works or a sport that he can participate in.
Daniel plays adaptive baseball and it’s a great experience.

Barbara

A 40-year-old, married, stay-at-home mother, Barbara is raising her two sons, Sam, age 5, and Tyler, age 3. This gregarious woman had no experience with disabilities before Tyler was diagnosed with profound Sensory Processing Disorder (SPD) at the age of 2½. Here, in her own words, is Barbara’s story:

Diagnosis
I knew something was wrong from the first few days of Tyler’s life.
He was constantly cranky, and then he began missing many of his developmental milestones.
His pediatric team kept telling me he was fine. They told me it was my issue . . . I had post partum depression.
But I knew something was wrong, and everyone was ignoring me.

When we finally got his diagnosis, it was neither a surprise nor an unwelcome confirmation.
I was just so grateful to be acknowledged. Finally, what was wrong with my child had a name.
I knew how to look it up, what types of therapies to pursue, and how to explain it to myself and to others.
After all, this is a society of definitions and labels.
Hearing the diagnosis was definitely heartbreaking, but I harbor a fantasy that everything will turn out fine.
It could be a lot worse.
**Motherhood**

When I became pregnant with Tyler, I desperately wanted a daughter. But I had a very powerful dream that he was a boy, and I knew my dream was real. I could feel it in my gut.

I was not quite 20 weeks along, and I was devastated. I didn’t want another boy. I was so disappointed.

I focused all of my energy on the fact that it wasn’t a girl.

I already had the perfect son, and I didn’t want another boy.

There were other issues going on at the same time. I became suicidal.

I finally came to terms with the fact that I was having a baby whom I did not want.

But by the time Tyler was born, I was able to make peace with it.

And I was so thankful that the birthing process went well, and that Tyler was a “healthy” baby.

Looking back, it’s the most shameful aspect of my life. I am furious with myself for ever feeling this way.

I wonder if his issues stem from my depression, feelings of wanting to terminate the pregnancy, and wanting to kill myself.

I will never be able to forgive myself.

I think having a special kid is like living on the 7 Stages of Grief ferris wheel.

You never ever leave it, you just cycle through it over and f***ing over again.

Things change, but they don’t really get any better.

It’s amazing how many parents of special kids describe some version of that adage.

At times, I do feel angry and resentful.

This last year alone, we spent tens of thousands of dollars on Tyler’s therapies.

And that had a huge negative impact on our family.

We spend about the same on his therapies each month as we do our mortgage.

I know I love Tyler, but truthfully, he’s a big drain on our family.

And at times, I wonder if I shouldn’t have terminated the pregnancy when I was going through my depression.

I’m at the point now where I am unwilling to let him and his disorder be the sun around which we all have been orbiting for so long.

I have given not just my life, but the rest of our family’s life, over to Tyler and his disorder.

I thought motherhood would be fun picnics and reading the newspaper in bed with my baby cuddled next to me.

I had no realistic notion of motherhood whatsoever. None.

And I didn’t have any friends with children who lived nearby. I couldn’t see any mothers in action.

I was totally surprised by reality.

Mothering a child with special needs has been the loneliest experience of my life.
I have never felt so lost.
We were kicked out of Tyler’s playgroup because he was different.
The typical families we meet can be uncomfortable and unwilling to accommodate.
It is hard to connect with other moms who do not have a clue.
Once bitten, twice shy, so I have been reluctant to enter into any social situations.
I have started to pull back.
I also feel lonely because I can’t handle the disingenuousness that goes on between moms.
Women who lie to make themselves feel better. Women who go on and on about how great their lives are.
I seem to keep many women at an arm’s distance because they don’t understand my situation.
And they don’t seem interested in getting it, and they are unable to get it.

I am trying to have a third baby, but it’s not working.
I am convinced that I have not been able to get pregnant because some part of my body doesn’t think I can handle it.
I already work so hard to give Tyler all that he requires and deserves.
SPD is not genetic, so I don’t worry about that.
However, I would get genetic testing for the baby. And if the baby had something severely wrong, I’d terminate the pregnancy.
I can say that because I am not pregnant, so who really knows.
But I know I could not handle severe needs. I just don’t have it in me.
I either need another typical child or a child with very mild special needs, or no can do.

**Family Life**
I have no idea whether I look at my children differently because one is special and one is typical.
Or because they are very different people.
This is just the hand I was dealt. And I don’t know the difference.
I know being a parent of a special child and a typical child is much more stressful than having two typical kids.
And it is lonelier.
This stems from the constant planning and accommodating that has to take place.
When you have one child who is special, it takes a lot more work.
While I feel lucky that we don’t need a special van, or need to bring oxygen with us, or feed from a G-tube, I still live in a bubble.
And this bubble is my world.
There are certain activities where you could bring along a sibling, but if that sibling has a disability, you just can’t.
I can’t take Tyler with me to some of his brother’s events because he can’t sit for an hour or be quiet.
It is difficult.
Interacting with other families who don’t get it and who don’t want to get it makes it even harder.
I always feel like I am not doing enough for Tyler and that it’s my fault he has SPD.
I feel as if we have this evanescent window of opportunity with Tyler.
And if I don’t utilize it fully, we may forever lose a piece of him.
I wonder if I will always feel this way.

I am glad that I had Sam, my typical son, first. It has made it easier for me to meet both boys’ needs.
Sam was 2 when Tyler was born. He was walking and talking, and telling us everything he needed.
It was easier to tend to Tyler’s colicky needs when my older child could be more independent.
I am grateful that Sam is so gregarious, social, and clever.
He loves going to school and for him, learning and creativity are pure fun.
So, I have enrolled him in summer camps full of learning.
I worry that one day, he will think we are farming him out to different camps and schools, so I can devote all of my time to Tyler and his therapies.
But this is partly true.
I do want to be able to focus on Tyler without having to bifurcate my attention for a few hours a day.
But I also want to honor Sam and his outgoing, stimulating nature.

I feel very conflicted. How can I give each child 100 percent of myself?
They deserve it, and I want to give it to them.
Sam wants me more than his younger brother, but Tyler needs me more.
But is this fair?
It scares me so much that Sam might feel unloved, unnoticed, and lonely.
It keeps me up at night. I am so scared about him feeling that way.
But I am not sure how to give him more.

Public Life
I look at other families who have typical kids the same age as my kids.
I think wow, you have no idea.
They don’t have the juggling, or have to make numerous accommodations at home, or drive to therapies, or do constant research.
Just getting up and down the stairs in my house takes a long time. It’s not just, okay, boys, let’s go upstairs and brush our teeth for bed.

When I explain or vent or complain, I don’t want to ever hear another platitude of, “You are a phenomenal mother!” or “You are freaking amazing!”
Yeah, yeah, I know it already.
What I long to hear is, “Wow! That does suck!” or “Holy shit, are you exhausted?!?”
Or “You must feel so lonely.” Or “I don’t understand exactly what you’re going through, but I’m really interested in what you have to say.”
Or “I’m here for you.”

Transformation
I used to be a “yes” person. I would put up with all kinds of bullshit.
I would be taken advantage of because that’s how I was raised. I would put up with people saying unkind things.
Now I am like fuck you . . . I am out of here.
Being Tyler’s mother has made me incredibly stripped down, in terms of stuff I’ll put up with and stuff I won’t.
I think this is probably the person I have been all along, because I have been fighting it inside.
I believe Tyler’s disability has made me a truer version of myself.
Having Tyler has allowed me to be the truest, clearest, most pared-down version of myself.
Being his mom has freed me to be the real me. I don’t need to put on different facades.
I feel so pure.
It has also brought out the mama lion in me.

Being Sam’s mother is a fascinating experience.
But it has not been the same level of truth and comfort with who I really am that being Tyler’s mother has been.
I know beyond the shadow of a doubt that for me, to get to my most primal, most authentic self, I needed to be a special mother.
However, I think I’d rather have an inauthentic life than have Tyler be so special.

Marriage
I don’t think Tyler’s disability has changed my marriage as much as just having children.
But his disability has definitely highlighted the fact that divorce isn’t an option.
At the same time, his disability has allowed me to see clearly the absolutely unfair balance of responsibility.
I saw it with Sam, but I really see it with Tyler.
It’s the principle of physics: There’s a void and I am filling it. But if I didn’t do it, my husband still wouldn’t do it.
I believe that if I am not on top of things, they will not get done well enough . . . if at all.
And I just can’t allow this to happen.
My husband has definitely easily accepted this.
He is not involved on any level with any of Tyler’s therapies. Or setting up activities for Sam.
These jobs are all mine.
I am basically raising these children on my own.
I have read that there is a higher divorce rate in special families, and I can see why.
Future
I don’t actually think much about the future. I make lots of assumptions. I have always done that.
As soon as I found out I was pregnant, I had my kids’ lives mapped out.
I thought, I am going to have a baby, it is going to be healthy, it will go to school, college, grad school, fall in love, and marry.
I guess I assume our children will lead lives similar to ours.
Recently, I have begun to realize that Tyler might not have this life.
He may lead a completely different kind of life.
I do not spend a lot of time thinking about the future. I don’t really look past this year and getting him into preschool.

But I do believe—and his daddy believes very strongly—that Tyler will be fine. He just senses it.
Watching him in his therapies lately, I am beginning to believe it as well.
I have begun to assume that he will be “normal.”
That he will either grow out of his SPD, or he will learn coping techniques to get by.
I don’t know if this is self-protection, or I am merely delusional.
What I do know for sure is that I am not interested in taking care of Tyler or anyone forever.

Advice
I think it is important to know that even though you may feel desperately alone and lonely, there are others out there who really do get it.
Also, it is critical to take care of yourself.
Without a healthy mom, nobody is any good.

Bonnie
Bonnie, a 46-year-old, married, mother of two, is raising Joshua, 16, diagnosed with autism at age 2½, and 20-year-old Addie, a sophomore attending college out of state. Here, in her own words, is Bonnie’s story:

Diagnosis
Joshua was a very difficult baby. He cried constantly.
All of the things that worked with Addie, didn’t work for him.
It was very frustrating.
I used to call my sister, begging for help and advice.
When he was 2, my in-home daycare provider expressed her concerns.
She told me that when he first came in the door, he always walked the perimeter of the room in the exact same way every day.
And he did not play with trucks and go “vroom vroom.” Instead, he just lined them all up.
These were red flags. Shortly after, he was tested and we got our diagnosis.

The diagnosis was not a surprise. Deep down, I suspected it. For the first year, I was okay with it. I just buried myself in my Joshua to-do list. I jumped in and got working on it. Therapies, schools, planning. It was a good year before the emotions set in. But then I became angry at everyone. I took it out on my sister.

**Family Life**
Addie is very independent and social. She loves horses and books. She has always been her own person. For the most part, she avoids Joshua as much as possible. She has never wanted to invite her friends over to our house. When she was 12 year old, I remember asking her why she never had friends here. She said it was because of Joshua. Even today, when she’s home from college, she prefers spending time at her friend’s houses instead of here, where Joshua is. For her, it is easier to avoid him than get into their fighting matches. I see other siblings their age beginning to become good friends and hang out together. It makes me sad. While some of their problems are typical sibling stuff, Joshua’s disability definitely has a lot to do with it. Communicating can be quite difficult.

It makes me upset that Addie would be home more if Joshua didn’t have autism. I talk to her about it. She explains that Joshua is just too challenging to be around at times. So, I try to do things with her alone . . . just the two of us. We almost never do things as a family. I have come to terms with the fact that it’s not doable. We used to when the kids were younger, but it was always such a challenge. Now I have separate special time with each. And when we have to be together for a family event, we keep it short and focused. I am resigned to the fact that this is reality. This is what has to be. But this reality has been a lot harder for my husband. He was always focused on trying to go on family camping and hiking trips. The fact that these outing were such a challenge had a real impact on him. Maybe as Joshua gets older, things will change. Maybe he will become less demanding about how things need to be done.

Living with the unknown has been the hardest part for me. What is our life going to look like?
How far can we help Joshua?

Motherhood
Before Addie was born, I read tons of parenting books.
I had this specific idea of the kind of mom I was going to be.
I was going to be very collaborative, giving my kids choices with natural consequences.
It worked great with Addie.
And then Joshua came along. And that parenting style did not work for him at all.
He needed so much more structure.
So, I found myself turning into a drill sergeant with him.
I resigned myself to the fact that this was the kind of parent he needed, even though it went against my visions of parenting.
I end up being two different types of parents with Joshua and Addie.

I see how hard Joshua has to work. And I appreciate how easy things come for Addie.
She helped me to realize that both kids have strengths and weaknesses.
I value them so much.
Without Joshua in my life, I would have taken a lot for granted.
If Joshua has been my first child, I probably would not have had any more kids.
He was just so challenging. I couldn’t have handled another child.

Some days are especially difficult for me.
This past mother’s day was really hard.

I kept thinking how much easier life would be if Addie were an only child.
Being a mother to Joshua is just plain exhausting. Nothing is ever easy.

Before Joshua, I had a specific image of my family and the things we would do.
I had no choice but to reframe this idea after his diagnosis.
He is part of our family, but I could not let Joshua become our family.
His disability could only be a part.

It has always been important for me to keep Addie’s life as normal as possible.
Horses became her passion, so she was able to throw herself into that.
I was happy for that because she found something to focus her energies on.
I have always tried hard not to let Joshua’s issues and needs affect what Addie does.
That’s one of the biggest challenges . . . to not let the child with special needs monopolize the entire family.
That meant dragging him to all of Addie’s 4-H club meetings and horse shows.
It was always a real challenge to juggle all of Addie’s activities with Joshua’s therapies.
The balancing act was quite stressful.
It really didn’t leave me much time to do anything for myself.
Transformation
Before my son, I had no experiences with developmental delays. Joshua’s disability has given me my career. My life has been directed due to Joshua’s autism. I have met so many amazing people and learned so much about child development. I have come to really appreciate that development. I also have a greater appreciation as a parent.

Marriage
For a long time, Joshua’s needs took all of our time and energy. The disability put a huge strain on us financially. We argued on the money spent on therapies. We argued about family outings. Thankfully, my family lives close by. They basically saved our marriage by helping us with the kids. We needed to reconnect as a couple. We needed to be a couple without the disability having an impact.

Public Life
Social norms are different for Joshua. He just doesn’t understand these expectations. I used to be absolutely mortified by his frequent meltdowns. But I got used to them. Today, Joshua is better, and he doesn’t have as many of these public outbursts. However, I am always a bit on edge where we are out in public. Spending time with Addie is much easier because it is not as emotionally intense. I do not need to watch what I say.

It helps to have wonderful family and friends who are eager to help and give me breaks. I know some of them see me as a saint. Others are glad that it is me and not them. I can’t blame them.

Future
My hope is for Addie to have her own life. I want her to marry someone special and be happy. I want Joshua to have a job. I have a spark of hope that he will even be able to live on his own. That would be the ideal scenario. Whatever happens, I have to be very careful that I don’t put too much pressure on Addie to be Joshua’s caretaker when I can’t anymore. I hope that by that time, they will want to look after each other like I do with my siblings.

I wonder if I will ever be able to stop worrying about Joshua. Probably not. I have never had to worry about Addie in this way.
I think a lot about the pieces that are missing for Joshua. He has no close friends, no advocacy skills, and no ability to problem solve. Sometimes, it makes me angry how much I have to do to teach Joshua the most basic skills. I can only hope that these pieces eventually fall into place for him.

Advice
It is important to connect with others. Share your life and experiences with others who understand. Other moms raising children with disabilities have helped to give me perspective. They show me that I can live with this. I can see the funny side of things, however trying and absurd they may be.

Educating others is important. I go through cycles where I do not mind teaching others about autism. Other times, I hate it. I feel a bit of both. It is nice to educate others but sometimes I do not have the energy for this. This gets tiring.

Sometimes, Addie wants to be a second mom to Joshua. But I remind her that it is not her job, nor her responsibility. She is his sister. This is an important thing for siblings to remember.

You must take breaks. It is important to find people who can give you the alone time and couple time that you need.

Time to be a person—and not just a mom—is essential.

I have a lot of guilt. I will never find out why Joshua has this. And how he got it. But I need to set aside my guilt because I will never know why this happened. You have to let go of your guilt. You need to move on. You must make life as good as it can be.

Brenda

Brenda, age 47, is a single mother (divorced) to two girls, Elizabeth, age 15, and Bridget, age 12, who is diagnosed with Angelman Syndrome, a chromosomal abnormality affecting her 15th chromosome. Here, in her own words, is Brenda’s story:
Diagnosis
As a baby, Bridget didn’t meet any of her developmental milestones. She was failing to thrive.
She began having seizures and received a diagnosis of epilepsy.
She had awful reflux and respiratory problems.
The Angelman diagnosis came shortly after at the age of 3.
It was horrible.
I felt completely despondent and hopeless.
I had done the research and was fairly certain she had Angelman.
However, it was different to actually get a definitive diagnosis from the geneticist.
It felt like a parent dying . . . you know it will happen someday, but when it does, it’s absolutely overwhelming.

Motherhood
I needed time to process the diagnosis.
All I could think about was that I didn’t sign up for this.
But those feelings passed. The emotional state didn’t last. For that, I was very grateful.
I’d be lying if I said I didn’t still get sad and depressed about Bridget’s disability.

My ideas of motherhood were unrealistic and insane.
My “ideal visions” would have required me to be a stay-at-home mom.
But I worked full time.
I always felt like I was falling short of the mark, but then it stopped mattering.
I thought, hey, I am doing the best that I can as a working mom.
My visions just morphed over time.

For me, ideas of motherhood change on any given day.
Some days, I feel like I am doing a good job. Other days, I feel like the worst mom.
Others see me as a saint. I seem to get elevated onto a pedestal.
But I’m not that person. I just want to be like everybody else.

There are times when everything is going along as planned.
But then something happens to upset the equilibrium, and I feel like my life is a mess.
Right now, both girls are sick.
I am so over the medical dramas. I want my quiet, boring life to return.
I feel out of control . . . as though my choices are minimal and not good for anyone.
I need to find a calm and happy place.

I feel blessed to have a typical child. It’s such a different world from Bridget’s world.
I don’t know what I would do if Bridget was my only child.
I like experiencing both worlds. Sometimes, they are mutually exclusive.
Elizabeth had a volleyball banquet last week. I got a sitter for Bridget.
It was nice to be in the typical world. I celebrated having another world.
If Bridget had been the oldest, I don’t think I could have had another child. She was just too difficult. It was overwhelming. The horrible reflux. The failure to thrive. The respiratory problems.

**Family Life**
Elizabeth is a very bright 15-year-old. She’s athletic and compassionate. She handles her sister’s disability very well, but does get angry and fed up every once in a while. There are definitely some feelings of embarrassment at times . . . especially when Bridget acts like a 2 year old. But she has never asked me not to bring Bridget places. In fact, she likes Bridget to come to her volleyball games and calls her a good luck charm. I used to worry that I couldn’t give Elizabeth a typical childhood. I don’t think about this much anymore. All I can do is my best.

I never sent the girls to the same school because I wanted Elizabeth to have her own life. I didn’t want her to be responsible for Bridget in any way. Being separate and building her own life took pressure off Elizabeth. At school, she is not Bridget’s sister. Instead, she is celebrated because of who she is. This is very important to me.

**Transformation**
I think I am far nicer. I’m more flexible and less of a control freak. I am more patient. I’m no longer a perfectionist . . . this is huge. Most of the time, it is good enough to be good enough. I no longer take anything for granted. I appreciate what I have and feel thankful for small blessings.

**Marriage**
We divorced 4 and a ½ years ago. We were in survival mode for a long time. We had communication issues. We were hiding behind our lives. We didn’t know how to nurture ourselves or each other. It’s my one regret. He is still Bridget’s dad and still cares for her 50 percent of the time. There’s no question life would be easier if we lived under the same roof.

Would we have divorced if we did not have Bridget and her disability? She had numerous medical problems. They were stressful. Her inability to sleep was so difficult on us. We never slept together. We were extremely sleep deprived and made some bad decisions. He was drinking.
Elizabeth was 8 when Joe left. She was so angry. Counseling helped her get over the anger.
To this day, I try not to blame Bridget’s numerous issues on the divorce.
They put a strain on our marriage and definitely contributed to the divorce.

**Public Life**
I don’t worry about what people think. I never put myself into a situation where I care what others think.
In fact, I take great joy in breaking free from societal expectations.
I don’t pretend we are normal, and I don’t care if people think Bridget is weird.
If she wants to wear her snow boots in July, that’s okay.
My kids’ happiness and health is my number one concern.
I want them to be themselves.

When the girls were young, I used to compare myself to other moms.
I felt jipped and resentful. I no longer do this.
However, certain situations definitely make me uncomfortable.
Back to school night really sucks. That’s not my real world, and Bridget won’t be able to do these things.
So I stopped going.
It hurts badly to not be able to do these things, but what can I do about it?
I try not to get caught up in it.
I hate the word, should. I do not use it.

**Future**
This is a slippery slope.
I try not to think about the future, but I can’t help contemplate it.
It is not a healthy place to go because many things can change between now and then.
I try not to think about the future for either Bridget or Elizabeth. I’d be insane to have any expectations.
Bridget’s options are definitely limited, but at the same time, I never thought she would have the options that she does today.
I have learned that I am not in control. It’s not about me.
Living day to day is what’s best.

The thought of Bridget not living with me causes me extreme stress.
I am okay with the thought of her being with me until I die.
Elizabeth says she will help care for Bridget if I die because that’s what you do for family.
I am happy that she will not have to pay for Bridget’s care because we have trusts for Bridget in place.
It is extremely important to me that Elizabeth never feels backed into a corner.
I do not ever want her to feel burdened by Bridget’s care.
Advice
Don’t get mired in self pity.  
People don’t want to hear your story.  Everyone has a story.  
Live your life the best way you can.

Every once in a while, I have a pity party but I don’t involve anyone else in this party.  
It is a party for only one.  
After my short pity party, I am okay and the weepiness goes away.  
Just ride the wave and it will be okay.  
Bridget gives me permission to have a pity party.  Everyone has their issues . . . ours seem to be very visible.

Faith has been very important to me.  That and love for my family.  
I’m a praying person.  I ask for God’s help.  
I am lucky to have a great ex husband.  I don’t do it alone.  He makes it easier on me.

Catherine

This 44-year-old, married, stay-at-home mother is raising daughter Emily, age 8; son Owen, age 7, diagnosed with autism; and daughter Molly, age 5.  Here, in her own words, is Catherine’s story:

Diagnosis
We suspected something was going on when Owen was about 3, almost 4 years old.  
He wasn’t focusing.  It was hard to get his attention.  
At Owen’s 4-year check up, I brought it up with his doctor.  
I suspected he might have either attention deficit disorder or Asperger’s.  
While his doctor didn’t think there was anything to worry about, she recommended an evaluation.  
That’s when we got the official diagnosis.  
Actually hearing the diagnosis of autism was very emotional.  
I think I knew by then . . . all indicators seemed to show he was autistic.  
But, still, when you get the official diagnosis . . .  
On one hand, getting the diagnosis is a relief because you now know for sure.  And as a result, you think he will be able to get the services that he needs.  
But on the other hand, you are thinking oh my goodness.  
You hear about what it takes to have an autistic child and the burdens and the worries and everything.  
It’s just an upheaval in a lot of ways.  
But that’s just the tip of the iceberg.  You don’t really know what you’re in for.

Family Life
Emily is very sweet and imaginative.  She is a nurturer.
She is very mature for her age and cares for her brother and sister, although she fights with them, too. But she is the one who has the most responsibility for her siblings and gets the most privileges. Molly is a spitfire. She wears her emotions on her sleeve. You know exactly what she’s feeling at any given moment. She’s generally a happy kid but she can be explosive, too. I suspect it’s probably because she doesn’t get as much attention as Emily did, so I think she tries as hard as she can to get attention however she can get it. Raising three kids with one having a disability and two being typically developing is a constant juggling act.

Owen has his own separate life. It is so different in that he has therapy and goes to a different school and has many supplements and a special diet that we all have to accommodate. Whenever we travel, we need to hide from him when we’re eating foods he cannot have. In a way, because of his autism, he is oblivious, which makes these things easier.

We’re always planning or making decisions around Owen. And then the girls work around that. At any given moment, he gets my attention. I always feel like I have to be very conscious with the girls. Recognizing that they need my time, they need my attention, and what that looks like for each of them is very different. I also worry that I subconsciously expect them to overachieve. I want to be sure they sustain themselves, but also can take care of Owen down the road. And I am constantly trying to teach them about their brother. Especially Molly, who doesn’t have the ability to really understand what autism means. To her it’s just a label. I think she’ll probably understand later. I feel lost when Molly announces to her entire class, “This is my brother, and he has autism.” Should I smile? Should I explain? Is this a good thing? Will they avoid Owen now? If I am lucky, they won’t even know what the word, autism, means.

I think the girls get to do things that most children get to do. My philosophy is to keep life as simple as you can. So, if they compare themselves with some of their friends, they may not get to do as many activities. But that would be the case even if Owen did not have autism. They get to take swim lessons, ballet lessons, and many things that Owen doesn’t do. I think they know their family is important. They see that their parents are doing all they can for all of them. I hope they know their parents are doing the best that they can.
This is our family, and I think there’s a blessing that comes with having a brother with a disability.
It’s a sense of responsibility for other people who are different.
Being more inclusive and accommodating of people who are different.
They get to learn about people in a way that others will never learn because they are not experienced what we’re experiencing.
Others won’t know the hardship of not being able to put your clothes on in the morning or being scared of a haircut.
With the growing number of people in our society with autism, hopefully there will be more mainstreaming.
You may have an autistic neighbor or a grocery clerk with autism.
And I think it is an important ability to recognize that and know that it requires accommodations.

If Owen had been the oldest, it would have changed everything enormously.
I think if he were diagnosed earlier, we probably would not have had more children.
We would not have been able to rely on the oldest for help or to set an example.
When he was younger, Owen was more emotionally volatile, and younger siblings would not have understood.
An emotionally unstable sibling sets the tone in the family, especially if the parents are trying to juggle everything and can’t really manage.

Unfortunately, there is a double standard for my son.
He gets treated differently than the girls because I constantly try to avoid his tantrums or because he won’t understand my answers.
While Emily understands this, Molly does not.
She always asks, why did Owen get that or why do I have to be quiet when I talk about this?
I don’t expect her to understand . . . yet.
And so you feel guilty having to say that we treat him differently because he’s different.
This goes against what you would normally be doing, which is treating all of your kids the same.
It’s equal but different.

The girls come to me when they have issues with Owen.
But I’m not the best person to come to with those types of things because I will defend Owen before I defend them.
Molly is very territorial about her school.
Owen can’t even play with any of the kids at her school without her throwing a fit.
He can’t climb on the fence without her pulling him off, saying you can’t come to my school.
It might be her way of saying that he is definitely a separate part of her life.
I will come down hard on her for that because regardless of where he goes to school, her school family is his school family.
Just like his school family would be hers. I would do that for her, too.
If he were to treat her that way, I’d come down hard on him.
But when she says that’s unfair, why does he get this, we talk about it.
I try and tell her I understand how she is feeling.
I know she does not understand now, but I hope she understands someday.

Emily worries a lot. If Owen is in the room, she can’t relax. I really wish this did not happen.
At Sunday school, they are in the same class together.
She told me she can’t have fun there because she sees Owen just sitting in the corner, and feels like she has to take care of him.
She is worried about him, but she is 8, and should be able to have fun.
Emily should be having a stress-free childhood.
I work hard at giving her this whenever possible.
She goes to a different school, and she gets her own play dates.
When we’re at home, she has her tasks and one of them is helping Owen. It’s a big responsibility for her.
I think a lot of oldest children start taking on a parenting role.
She tells Owen and Molly what to do. She inserts herself in anything I’m trying to say to them.
I have to remind her that I’m the parent. I tell her that I just want her to be a kid.
It’s a fine line because you want them to understand that their brother needs help, and they are responsible for him.
However, at this point in time, they are sisters only and not parents.

Owen doesn’t get invited to birthday parties.
If he goes to a birthday party, it is because he was invited by one of his sisters or a family friend.
I understand why he does not get invitations. In all honesty, it’s a burden to go to a party.
He has fun because he loves cake, swimming, and parks, but he does not interact well.
I think right now he doesn’t notice the lack of invitations. Maybe Owen will get there someday, but I don’t know.
We would love nothing more than for Owen to have a little friend or buddy.
I end up feeling bad because I “force” my girls onto him.
Since nobody else plays with him and he has no other friends, I make sure the girls spend time with him.
Is this fair?

Motherhood
I had no set ideas about motherhood.
Nothing more than simply bringing people into the world and trying my best to have them be socially responsible citizens.
I never thought about having a disabled child.
I don’t think anybody does unless they have disabilities in the family.
I don’t know if it’s motherhood per se that’s hard. I think it’s daily life. Someone up there believes that I’m strong enough to handle this. But I wonder on most days. I focus on all of my kids, but especially my son because he’s the one I worry about the most. I didn’t expect to be spending so much time splitting between two schools or going to so many meetings for my son about IEPs or therapies.

While I still have some of my dreams and future goals for Owen, I know they’re less realistic and probably won’t happen. Whereas before Owen’s diagnosis, I would have made sure they happened. For example, I’m Hispanic and my family lives in Argentina. I have always wanted to move there for a year, so my kids could get to know their cousins and immerse themselves in a different culture. But now it can’t happen because Owen would have no support there. It would be really hard to get services for Owen. We just can’t go.

It is really a struggle to try and do things for myself. Doing things for yourself that are meaningful take time, and it’s hard to find that in my day. I wish I were using my brain in a way that I used to . . . on a regular basis. Also, I have constant work to do that never goes away and probably never will. And that affects my quality of life. The constant worrying takes a toll. It stems directly from the disability. I look at my two daughters, and I don’t worry about them very much. But Owen . . .

I think I have aged faster with all of the added stress in my life. I think about going back to work, but wonder how I would handle having a full-time job and being a parent to three kids, one of them with extra special needs. Can I really dedicate myself to a job the way I did before?

Through all of the struggles, I truly feel blessed to have Owen. It is as if God knew that I am a strong, capable, trustworthy woman, who can handle his care. However, I feel like my happiness on any given day is directly related to Owen’s behavior, performance, and accomplishments. I could win a Nobel Peace Prize, but if Owen throws a tantrum in the supermarket on the same day, that’s what I would concentrate on. I become so focused on his ability to live and exist in society.

At the same time, I feel honored to be an advocate and spokesperson for Owen. But at other times, I also feel cursed to be this advocate and spokesperson. I feel like I wear a “badge of autism.”
I play the evangelist role for my son, teaching society how to accept and live among individuals with autism. After all, he may be their next door neighbor someday.

**Transformation**

I think I’m much less relaxed than I used to be. I am much more consumed by whether I’m meeting my children’s true needs. Especially their emotional needs. I don’t think I would have been this conscious about their needs if I did not have a disabled child. I think I would take more for granted. Because of the mental energy that it takes to raise a disabled son, my daughters end up having more needs as a result. Being siblings to a child with disabilities also requires more support.

**Marriage**

I think we both have different approaches and different views of our son’s autism. I honestly think my husband has a harder time having a son with autism. Not for the macho reasons or anything like that, but I don’t think my husband really enjoys Owen that much. I think it’s hard for him to know how to “be” with his son. And it’s hard for me to see that. Also, there are huge amount of stress regarding juggling Owen. Who is going to do what and how much time is it going to take? Never mind that you have two other children. It’s just a lot of extra stress in that sense. My husband has a harder time understanding Owen’s behavior. Disciplining an autistic kid is different than disciplining a typical kid. It’s a lot different. And it’s hard for me to see that, too. It is frequently a sore point between us.

I probably rely on my husband in ways that I wouldn’t have before, for better or for worse. I think in a way it’s like he’s the only person who really understands and that’s a huge burden. I have little adult interaction, and when Owen is throwing a complete fit or whatever it might be, my husband is the person I call because he will get it.

And I won’t have to go into a huge explanation. I don’t have to temper myself. However, that’s a big burden for him.

**Public Life**

I don’t think I’m really aware of what’s going on around me in public. It is definitely stressful when my child is being disruptive in public, but Owen’s behavior is a lot better these days.
I remember being so consumed with trying to get Owen to contain his emotions and understand what’s going on.

Clearly, we don’t have a normal family, and I’m fine with that. Most people don’t know half of what it is like to have an autistic son, even our closest friends, even my mom. I mean they have an idea, but I don’t think they really get it, so I don’t pretend. There’s no way I could handle the burden of trying to pretend and act on top of it. Owen will be part of society, whatever that looks like, so we better get used to it now.

If you want to know why my son is doing this or that, you can just ask. And if you care to ask and understand, you’ll know it’s not because I’m a bad parent, but it’s because my son is autistic and this is what it looks like. I don’t blame my friends for being clueless. It’s not hurtful. They don’t live our daily life.

My sister is an OT, but she doesn’t have kids of her own. While she has an intellectual understanding, she does not go home with this kid or worry about his future. And my mom is extremely interested, but sometimes it’s too much to handle. I constantly tell her that I don’t know why he does what he does. Sometimes, I can’t overanalyze him or his behaviors.

**Future**

I envision a short-term future, meaning until they’re 22, 25, 28, when they will have a separate life. And they will do whatever they want. I have all the confidence that they can do whatever they want.

But there is the expectation that they will start stepping in and taking care of their brother, whatever that looks like. And it may just mean living in the same town. Or it may mean Owen has to live with them.

We want Owen to be as self-sufficient as possible. I suspect that he’ll have his own place, but he’ll probably have a roommate who understands autism and will help him. And ideally be his friend, too.

I would love for him to be able to find a partner in life and go forward and have a fulfilling life.

Given what I know of Owen, however, I don’t really see that. But I do see him being able to live on his own with support.

We talk about saving enough money to buy a property, so he can live on his own and contribute to society by working for something that is really important to him.

This past summer, I got a plot in a community garden so that I can hopefully teach Owen a life-sustaining skill.

I look at it as one thing I can do for Owen’s future.

Society always tries to fit autistic square pegs into round holes. Why don’t we make the hole a little bit square?
We can only do this if society helps.

**Advice**

Rely on complete strangers, whether it is a stranger on the street or anyone who’s willing to give you anything. Even if it means swallowing your pride or your privacy. It is so easy to get caught up in this world that you’re living each and every day. Owen and autism are always in my head. Any little thing that can help you get perspective is important. Selflessness is the definition of motherhood.

You would do anything for your child, probably at the expense of your own life, because you spend so much time worrying and stressing about it. So you have to work extra hard and take more time to manage the stress.

**Cindy**

Cindy, age 44, is a married, stay-at-home mother raising three boys with her husband. Drew is 12, Paul is 9, and Evan is 7. Evan is diagnosed with Cri du chat syndrome, a rare genetic disorder caused by a missing part of chromosome 5. Its name is a French term (cat-cry or call of the cat) referring to the characteristic cat-like cry of children with this disorder. Evan is G-tube fed and recently began walking independently and learning to talk. Here, in her own words, is Cindy’s story:

**Diagnosis**

After Evan was born, I took him to the doctor every other day because he refused to eat. A few weeks went by before the doctor pulled out a big book of syndromes. He told me that we would begin to search the book when he returned from his vacation. But I couldn’t wait. I searched the web and entered “cat like cry.” Cri du chat came up over and over again. I kept trying to disqualify it, trying to find anything else to explain Evan’s cat cry, but I couldn’t.

I called and asked my doctor to order tests of his fifth chromosome, and we waited. I remember praying that it wasn’t true, but the test came back positive. Evan was 3 weeks old. I did not pray again because I felt like God had given me something I couldn’t handle, something that would break me. I told my in-laws that I didn’t want a child with special needs.

After Evan’s diagnosis, I sort of floated through life for a long time. I thought, now what? Now what do I do? I didn’t know what my next step was. There’s no guide out there to help you cope. I felt lost. I remember looking at other mothers and thinking they had no clue. The things they were worrying about seemed ridiculous to me.
I constantly wondered if people thought I did something bad during my pregnancy to give this to Evan.
One neighbor asked me what happened during my pregnancy to cause this.
I told her nothing . . . it happened during the first cell of life. I have never forgotten that.

**Motherhood**
For the longest time, I found myself wondering what Evan might be doing or what he might look like if he were typical.
I don’t do that anymore . . . it is too painful.
Now I just try to appreciate him for who he is. But I still feel really sad about the situation.
I feel as if I have lost control of my life. Of life in general.

All too often, I don’t feel like I deal with my life very well.
I feel a lot of guilt in that so much attention and energy goes toward Evan.
I wonder if everyone else is getting his fair share of mom/dad time, activities, and his own identity beyond the disability.
I don’t cope with Evan very well.
I often feel overwhelmed, discombobulated, and sad.
I never thought motherhood would be 24/7. I am never at rest.
Where is the joy inside of me?
I constantly feel like I am not doing enough for each child.
I feel depressed and crazed, constantly seeking an escape from all of my feelings.
And what about me?
For too many years, I have tried to be everything to everyone in the family and outside.
My personal journey has been put on the back burner for so long.
I struggle to rediscover what I want for myself. I used to plan on going back into teaching, but that has yet to happen.

Motherhood has involved so much more heartache than I ever expected.
It is so much harder than I thought, but it is also rewarding to see how well we are doing.
Evan did not sleep through the night for his first four years, but we are all still strong.
While raising Evan can be a struggle, it has also been a gift to me personally.
He certainly changed my perspective on life.
This has forced me to slow down and experience life.

**Family Life**
My oldest son, Drew, is a caregiver to Evan. He has always been very comfortable with the situation.
He is willing to help out with Evan, which makes it easier on me.
His friends seem to be very accepting of Evan because of Drew’s ease with the situation.

Paul is closer in age to Evan. He was only 20 months old when Evan was born.
I often wonder if this has made him more insecure and angrier.
With so much attention on Evan, Paul had to fend for himself.
Evan overwhelmed the household with his constant crying and doctor visits.
I try to make sure Paul knows how important he is in our family, but he is so needy and gets angry quickly.
It makes me feel like such a failure as a mom.
Did I neglect Paul when Evan was a baby?
I think I let the boys get away with too much because I feel so guilty about Evan.

I am glad Evan is the youngest.
His brothers are great role models for him.
And who knows if I would have continued having kids if Evan had come first.

The most important thing to me is making sure that my children have positive feelings about their family life as they grow up.
I want them to have a variety of experiences.
I do not want them to look back and feel like they lost out on anything because of Evan.

Recently, Peter and I took the two older boys to New York City.
I wanted to have a vacation with Drew and Paul in which we did not have to focus on Evan’s needs.
I felt so much guilt about going and leaving Evan with family, but I knew we really needed it.
He would have struggled in a busy place like New York City, and I wanted to concentrate on the other boys.
It is very important for the boys to have their parents’ undivided attention.
It is especially important for Paul, who needs to be reminded that he is a significant member of our family.

Public Life
Evan has a high pitch voice, which draws attention from strangers.
This makes Drew feel embarrassed. He will immediately shush him and try to quiet him down.
He doesn’t like the fact that Evan draws attention to us.
It’s a tough situation because I am embarrassed, too. I don’t like feeling on display when we are out.
But Evan has every right to be out in public.
It crushes me to see Drew embarrassed by his own brother.
I worry about him and his feelings about Evan. Will he develop into a confident human being?

Most people are generous with encouraging smiles, but some just stare like he is a freak of nature.
As much as I feel like they are judging Evan and the family, I guess I am also judging them.
I focus too much on trying to be a normal family.
I am constantly trying to normalize my family. I probably stand out as being phony.
I worry too much about where we stand in the community.
I think I hold myself hostage because I am so afraid to put Evan out in public.
Sometimes, I find myself wishing that Evan could stay a baby. Then it would seem okay
that he is not acting like a typical 7-year-old boy.
Nobody would questions why he doesn’t talk or walk, like a typical kid.
I am just too sensitive.

I sometimes look at other people and admire them. They have no idea how hard it can be.
I think they have the perfect life.
I wonder why this happened to me, and so many other people have perfection.
Why don’t they have more of a clue?

I feel isolated because other people don’t know how to act.
We don’t get invited to play dates after school.
The other moms would not understand how to deal with Evan in their house, so they don’t invite him.
Or they do not know him and do not know how he will behave. It is scary and different for them.
Peter always says that if people would take the time to get to know Evan, they would love him.

I always tell other kids to ask me anything they want.
If they ever wonder why he has a feeding tube or why he has a high voice, they can ask me.
I love spreading the word.
Educate. Ask me questions instead of staring or wondering.
Sometimes, when someone is being rude, I have to stop and think that I might have been that same way before Evan.
I need to give them more slack because I might have been as clueless.
A friend once asked me what I thought would be the right thing to say. What a good question.
What I don’t want them to say is what a saint I am. I hate that. After all, this is my kid.
Am I a saint for not leaving him on the curb?
I also hate when they say what a burden it must be or that’s your cross to bear.
And they only give special needs kids to people who can handle it. That’s what people say when they have nothing else to say.

**Transformation**
I have had to come to grips with my emotions and insecurities.
I feel like I am much more forgiving and accepting. I realize life can be very difficult.
I had no idea how much coasting I was doing before Evan’s disability.
I have had to accept that it is no longer “those” people. Now we are “those” people.

**Marriage**
We clung to each other for a long time after getting the diagnosis.
Sometimes, Peter tells me that he is sick of my self-pity. It is good for me to hear this.
We are just so tired. We have no time for each other.
But we do lean on each other.

**Future**
It is really hard to think about the future.
I am not sure where Evan will be, and I’m just afraid to think what would happen if
something bad happened to me or Peter.
I am sure the other boys would be willing to take him, but I don’t want to change their
life in that way.
Not burdening them is important to me.
It is hard to wonder what will happen each year. And if Evan will make any progress.
Each new year creates a little slope of depression for me.
If I didn’t have Evan, I would expect everyone to go to college on money we had been
saving for years.
But I have no control.
I talk to Drew about keeping good grades, being well rounded, and helping in the
community, but I would never push Evan like this.
It’s just the way it is.
My husband and I never talk about Evan going to college. He makes jokes about it,
about Evan being a Wal-Mart greeter.
Hearing that makes me kind of sick.
When Paul was younger, he would say things about all three boys being married. I
wonder if Evan will even be able to have a girlfriend.
I don’t know what it will look like, which makes it so hard.

**Advice**
Don’t lose yourself in this experience because it is hard to recover that loss of identity.
Find balance in what must be done. Does the driving in rush hour outweigh the benefits
of a 50-minute therapy session?
Exercise for your sanity.
Search for your spirituality because this can help you deal with emotions.
Know when to let go.
Realize that we do not control things in life.

**Denise**
Denise, 44, is a married, stay-at-home mother to Samantha, age 11, and Hannah,
age 6. She also works as a certified nursing assistant for Samantha, diagnosed with
tuberous sclerosis complex, a genetic disease that causes epilepsy, autism, developmental delays, and “tubers” that grow throughout her vital organs. Here, in her own words, is Denise’s story:

**Diagnosis**
I had a scheduled C-section. But the doctors couldn’t find a heartbeat, so they moved up my surgery. It turns out Samantha had a bunch of tubers in her heart, which slowed down her heartbeat.

After she was born, she was taken the Children’s Hospital for testing. That’s when they found out she had tuberous sclerosis complex. It is on chromosomes 9 and 16. Now they have the ability to test for this disease in utero, but we had no idea.

I was in total shock. I was devastated. It had taken us 4 years to get pregnant. I thought I had done something wrong. The doctors did not know anything about tuberous sclerosis complex. They pulled out an old medical journal and showed us one small, vague paragraph about the disease. I looked them in the eye and asked if she was going to die. They said they had no idea. They handed us that page from the medical journal and told us goodbye and good luck. We took Samantha home, not knowing what the heck to do. Or what to expect.

I vividly remember the first night she came home. It was 2 in the morning, and she wouldn’t sleep. I walked around in the dark, wondering how in the world I was going to do this. It wasn’t like having a typical kid and wondering if she was hungry. This was different. I had no idea what was ahead of us.

I wasn’t afraid of disability. Growing up, my sister was a teacher for the hearing impaired. I was always involved with disability. I was very sympathetic and understanding of people with disabilities.

**Motherhood**
Motherhood is nothing like I thought it would be. My image growing up was marriage, babies, and the happy, little picket fence. I was going to attend school for interior design and then work from home and take care of my kids. I got my design degree, tried to get pregnant, got pregnant, had Samantha, and then realized there was no way I could continue.
With Samantha, I just could not work. That was very hard to let go of because it was all I had ever wanted to do.
I still wish I were an interior designer.

What makes me so angry with this disease is that fact that you don’t know which end of the stick you are going to get.
I know a woman with a Ph.D. who has TS. She was diagnosed later in life. And then there’s Samantha.
Why can’t they just say, here’s the disease, and here’s what will happen to you in your life?
You never know from one day to the next what it will be like.
I just have to guess.
Samantha has tubers in her eyes, her brain, her heart, her kidneys, and she has all of the skin manifestations.
She could get the ones that develop in her lungs when she is in her 20s. Then she could lose her capacity to breathe.
She could have a lung transplant or a kidney transplant.
I just don’t know.

I hate to say this, but I used to think, I’ve got a mentally retarded kid, so what’s the use in me even trying?
She is never going to be any different. Nothing will change, so why try?
I felt that for a long time. I feel so bad about it now, but that was part of my healing.
I am sure others feel the same way.
I felt so sorry for her and for me for so long.
And I remember my sister, who is a teacher, saying that Samantha is probably where she will be for the rest of her life.
But I started to see her learning things. Things we never thought she could learn.
And lobbying in Washington, D.C. helped me open my eyes to her potential.

Everyone thinks I am such a supermom. They think I’m like a superhero, a sliced bread kind of thing.
Because of what I do, how I deal with this situation. Everyone says, I could never do what you do.
Yeah, yeah, yeah. Whatever.
I didn’t think I could do it. It wasn’t a choice I got.
What am I supposed to do? Send her back?
I am not that amazing.
I’ll tell you . . . it is not an easy ride.
It has been the hardest, most difficult time in my life. Ever.
And the most difficult job I have ever had.
I take issue when people say that God gave you what you can handle.
It’s just something to say when people have no idea how to respond.
There are days when I look at married couples with no kids and think that would be so nice.
I have to be a very strong mom because I am a mom with a child with a disability.
It’s like you need to be two times as strong as the mom with a typical kid.

In the last year or so, I have finally come to the conclusion that I must accept the disability and stop bitching about it.
I rarely get sleep and then I get mad and grumpy.
But it’s not going to get better, so why make my life miserable and complain about not sleeping?
I do not want to spend the rest of my life complaining.
I’d say my quality of life averages a five out of ten. It all depends on Samantha’s mood, my sleep, and my husband.
The most important thing to me is being happy.
Am I? The answer is no.
I need a husband who is more supportive, a husband who’s more involved, and a husband who appreciates me for what I do.
I don’t feel I have any of that.

**Family Life**
I always wanted a lot of kids. My husband wasn’t even sure he wanted one.
But he brought up having a second. He was worried about what would happen when we get older.
Who will take care of Samantha?
It wasn’t the main reason to have another child, but it contributed.
My husband is 56, so it was an issue for us.

Samantha’s disease was a spontaneous mutation, so we assumed it was something that just happened.
Neither of us thought about getting ourselves tested to be sure. We were in such denial.
I think that if I knew I were a carrier, I wouldn’t have had another child.
The disease gets worse the further in the generation it goes, so I would have been so scared.
They came out with a genetic test for Samantha’s disease right around my second pregnancy.
So, we didn’t actually have the testing until after Hannah was born.
It was definitely stressful.
There were quite a few times throughout Hannah’s pregnancy where I kept thinking, it’s going to happen again, I just know it.
But Hannah’s test came back negative.

Having both girls is challenging. It can be hard to switch modes.
I feel a lot of guilt because I worry that Hannah is getting the raw end of the deal.
The guilt is 24/7.
There are so many things that we can’t do as a family because of Samantha. And it’s not fair to Hannah for her to miss out on things. There’s not a lot of division of labor where I can take Hannah somewhere and my husband takes Samantha. I do it all. On my own. I am pretty much a single parent. I do not have the support of my husband. He is not very involved in our daily lives. Hannah has had to accept the fact that she can’t do a lot of things because of Samantha. We try to make up for it with other things, but it is hard. It’s hard on both of us because I feel as bad as Hannah.

I also worry about Hannah a lot. She’s only 6, but her resentment is already starting to show. She acts out in different ways to get attention however she can. I don’t want Hannah to feel responsible for her sister, but she already helps take care of Samantha. She will tell us her sister is having a seizure or will wipe her face. It’s already part of her life. She has a hard time playing with others and is still learning how to do this. Having a sister who doesn’t really interact with others has not helped. Hannah has not been able to learn from Samantha about how to deal with social situations.

It would have been easier if Hannah had been the oldest. We would have had a normal family life where we were not afraid to go out and do things. I think we would have just kept going in the same direction if Samantha had been born second. Also, it is painful to watch the younger child pass the older one. I can still see the day when that happened. We were getting in the bath, and I asked Hannah not to do something. She did it anyway. That day is forever in my memory.

I always wanted two girls. That’s all I ever wanted. So, now I have two girls, but it’s not what I had hoped. We don’t do the things that I had dreamed about doing together. We never play with dolls together. Maybe it’s because I am so exhausted all of the time. I feel like I am missing out on so much with her. I don’t spend a lot of quality time with her. I get upset and angry quickly. It is a very hard balance. I spend so much time being an advocate for Samantha and managing all of her behavioral and health issues, I feel like I neglect Hannah. As a kid, I was never allowed to watch TV. Now, it is my easy way out with both girls.
When Samantha is in school, I try to spend time with Hannah.
This summer when Samantha was at home, Hannah told me that she misses our time together.
I know she loves her sister, but things are just so much easier when Samantha is not with us.

There are constant challenges that I face every day.
Do I have enough energy to take both girls to the store or wait until my husband gets home to do it?
Simple things have become very challenging and lots of planning is needed for everything.
It can be truly exhausting.

**Public Life**
I feel isolated everywhere I go with Samantha.
She’s a big kid who is 11 years old, and I can’t just let her walk off in a park wherever she wants to go.
We were at a graduation party and a boy Samantha’s age asked me why I always follow her around.
He wanted to know why I don’t just let her play on her own.
I thought, wow, I really wish I could do that.
I didn’t know how to respond, so I told him that she had seizures and could fall and hurt herself.
I never really know what to say.

We don’t go many places because of Samantha. It’s just so hard.
We are going on vacation in a few months, and it will be the first time all four of us are away together.
I am terrified. Thank God for Xanax.

Whenever we go out in public, I get nervous and try not to draw attention to ourselves.
I keep my guard up at all times.
I used to feel like I had to put up a wall anytime I left the house.
The wall kept us safe. It was like, don’t talk to us, we won’t talk to you, and we will just do our thing.
However, if people ask me questions or stare at Samantha, I am ready to tell them anything they want to know about TS.
It took me a long time to deal with the staring, but I am much better now.
I used to not want to go anywhere. I was a little ashamed and embarrassed.
I did not know how to explain Samantha to people. I didn’t know what to do with the stares.
But things have been better the last 5 years.
I go to Washington, D.C. every year to lobby for TS funding. This has helped me be more outspoken and assertive.
It has helped me out of my shell. Lobbying and talking to senators from different states about TS forces your wall to come down. This has also helped me to grow personally. To just accept the disability and move on.

**Transformation**
There are some days that I am still trying to accept Samantha’s diagnosis. I definitely have bad days, but I also feel like she has been a blessing. I think she has made me a much better person in every aspect. I’m definitely more caring. I am not afraid to help people in any way. I just see things a lot differently now. Because I have to be Samantha’s advocate and have to do everything for her, I can’t be shy. It has made me come out of my shell. I have to be spontaneous, even though I would like to be structured. I am forced to go with the flow. But there are still some bad days where things are very hard to handle.

**Marriage**
We have been married for 15 years. Samantha is 11. Maybe 4 of those years have been good. We have talked about the big D. There were times where one of us discussed leaving. Every single day, it shows its ugly head. We are struggling to keep our heads above water. My husband believes that working toward Samantha’s independence is ridiculous. He feels everyone should just do everything for her. We completely disagree. And there has been no sex for a long time. If you combine 11 years of sleep deprivation with stress, you have nothing left. I walk around like a sleep-deprived zombie, and sex is on the bottom of my to-do list. There’s nothing to give.

I think most of our problems stem from Samantha. Jim seems to have a lot of guilt because even though it wasn’t his fault, he thinks it somehow was. He is not the smartest man, and I think he believes he passed that on. And there are also his insecurities. Because he’s older, Jim feels like his swimmers weren’t good enough. I have always told him that is ridiculous, and he needs to get over it and move on with life. Jim is also jealous and insecure about how involved and outspoken I am in the TS Alliance.
I organize a walk, a conference, and do lots of activities. He sits back and watches television. Sometimes, I think that the only thing that connects us is Samantha. We rarely go out alone because he doesn’t trust anyone to take care of Samantha. He thinks I should be the only one who takes care of her. And he thinks it is silly that we need alone time.

**Future**
I need to figure out what to do with my marriage. I am Catholic and took my “until death do we part” vows, but I don’t know anymore. With Hannah, I think about her going to college, marrying, and living happily ever after. Hopefully, we won’t screw her up, and that can be her reality. I want to create a special needs trust for Samantha so that she is taken care of. I honestly don’t know where she will be. The girls will lead separate lives, but they will always be connected in some way as sisters.

I never want to put Samantha in a home. As long as someone I know can take care of her and help her, that is my goal. I think about having a house for adults with disabilities, and their parents take turns staying and helping care for them. They could live independently, and the parents could still have some freedom. A lot of my friends’ kids are married and having kids. But I think Samantha will always be with me. It is going to be until death do us part. I never see her living independently. Health-wise, she needs somebody with her because of the seizures. And because of the autism, she’s a wanderer.

**Advice**
Take care of yourself and take time for yourself. Everybody says it, but it is so important. It doesn’t matter what it is, just do something. It helps you stay healthy. I am not sure if I have ever or will ever come to terms with the disability. It might get better, but it never goes away. There are constant challenges that I face every day. Simple things have become very challenging and a lot of planning is needed for everything. This is my reality.

**Donna**
Donna, age 38 and married, is mother to Jack, 8, Emma, 6, and stepmother to Mary Ellen, 14, who lives with Donna and her husband on a part-time basis. Jack is diagnosed with shunted hydrocephalus, triplegic cerebral palsy, atrophy of the optic nerve, cortical vision impairment, nystagmus and strabismus, and epilepsy. She is home schooling her daughter, Emma; working as a certified nursing assistant for her son; and
employed as a freelance web development consultant. Here, in her own words, is Donna’s story:

**Diagnosis**

Jack was a preemie born at 32 weeks. I had toxemia, so I ended up having an emergency C-section. When he was first born, Jack was fine. He had APGAR scores of eight and nine. He was in the NICU on nasal oxygen only. On his eighth day, the doctors removed his oxygen, and I went home for the night to get some much needed sleep. When I returned the next morning, the nurses said Jack had been fussy all night. I found him seizing in his incubator. He had a grand mal seizure due to a massive brain bleed. They had removed the oxygen too early. He was put on life support, and we were told to pull the plug. They said he would be dead by age five, he would need to be institutionalized, and he would never interact. They were adamant that he would have no quality of life, and we should just end his life now. We took him home instead.

We were in shell shock for the first year. Jack threw up and screamed bloody murder all day and all night. He had weekly CT scans, neurology appointments, and pediatrician visits. We lived in the car or at a doctor’s office. They thought his screaming was due to reflux. But his head didn’t look right. Finally, he was diagnosed as needing a shunt in his brain. He got the shunt, but three weeks later, got a shunt infection and almost died. We lived at Children’s Hospital for the next six months. He had 13 more brain surgeries. That first year was a total blur.

The following year, I got pregnant with Emma. I was petrified to be pregnant again because I knew way too much. I insisted on seeing a high risk obstetrician, who diagnosed me with a blood clotting disease. They presumed that during my C-section with Jack, a clot had moved into the placenta. This, combined with a lack of oxygen, had most likely caused the damage to Jack’s brain. Kind of like a stroke. At least we knew what happened.

**Family Life**

Having two kids—one typical and one with special needs—sucks. That’s the truth.
At this point in time, we have learned how to accommodate and balance the family, but it still sucks.
I go to the grocery store and ask Emma to run to the end of the aisle and grab the peanut butter.
I can’t do that with Jack.
You see other families, and it is so easy for them. They just pick up and go fishing, no big deal.
But that’s a major outing for us.
And it’s so not fair to Emma and so not fair to Jack.

We are blessed that Emma is an old soul, and she gets it. She understands and does what she can to help.
The other day, I heard a noise and went into Jack’s room. Emma was trying to get him back into bed because she heard him fall.
She got up and tried to get him into bed all by herself.
She plays with him and talks to him, but she wants a brother who can run around.
At times, she has commented that she wishes her brother could talk and play more.
When her stepsister, Mary Ellen, is here, it is really hard because Emma has to transition into having a typical sibling.
Then there are times when the girls will do sisterly stuff, and I will have to ask them to play in the same room as Jack and include him.
It can be confusing and challenging for Emma.

Emma is home schooled now, which has been great for her.
She gets one-on-one time with me, her dad, and her school friends.
But no matter what, I always feel such guilt.
When Emma and I are having a blast together, I always feel bad that Jack is not sharing in the fun.
And when Jack is home, I feel like I am ignoring Emma.
I wonder if parents of all typical kids ever feel this way.
Are other people better able to balance their kid with special needs with their other kids?

Since I have been working long hours recently, I’m exhausted when I get home.
But I want and need to play with the kids when I get home.
Inevitably, I end up helping Jack and focusing on him.
I feel so bad because it’s not fair to Emma to be “penalized” because she’s able bodied and independent.
At times, Jack becomes all consuming. I realize that I haven’t seen Emma in a while.
I feel like I miss large gaps of her life and that life has flown by so quickly already.
She has done everything so fast, so early.
Andy gets frustrated and says the focus of our family is too much on Jack.
While I can see his point, I don’t necessarily agree.
Jack does get a lot of attention, but I think it is appropriate. He needs to be a kid, just as Emma does.
And to do that, he needs a lot of help and support. Without a communication method, it is so hard to know what Jack wants and needs. It stinks to have to guess for him.

I have a friend with three kids. Her youngest child has severe special needs. Her grieving seems worse than mine because she knew what it was supposed to be like and how easy things should be. I had no idea.

For two years, I thought this is bad, but it is not too terrible. We can get through this. It wasn’t until Emma came along that I was like, wow this is really much worse than I’d realized. But I do think that if Emma had come first, I would have wallowed in the grief so much more.

We had to put aside our grief and move on. There wasn’t time for it because we had to deal with so many immediate issues.

A colleague of mine has two little kids. They take off and head to the mountains to ski and fish. I find myself wishing life was that easy for us. It makes you feel isolated. But I tell myself to get over it. It could be worse. It is what it is. It doesn’t help anybody to get bitter or jealous . . . just find a way to do what we want to do.

We are actually lucky. One of us has always been employed, we’ve always been able to cover our needs, and we have a nice home. And Jack doesn’t have behavior issues.

We have had the most amazing people come into our lives because of Jack. I really believe Jack is here for some huge reason. He could have died, but he wanted to live.

Something big is going to come out of this, I just don’t know what.

Public Life

Jack’s disability creates a lot of isolation. The older Jack gets, the harder it is. When he was little and in a baby carrier, you could blend in and it was not so noticeable. But as they get older, there’s complete and absolute isolation.

We will go to other families’ houses for dinner. And the kids play while the parents talk. But it is awkward because Jack can’t go off on his own to play.

So you either keep him with you while you talk to the other adults, or you stay with him and the other kids.

But the kids don’t want you there. It’s not a good situation because it becomes a weird scenario.

We have talked about how to handle these situations. Maybe hiring an aide would help, but it would have to be a female aide. Because if the kids are all playing in the basement, nobody wants a strange man down there.
For now, we have date nights by ourselves with grandma watching the kids. And Tuesday nights are my nights out and Andy has his nights out.

I don’t relate to most moms who have only typical kids. They seem to be wrapped up in worlds where they are worried about kids being popular and what their kids wear. I have nothing in common with them because I’m more worried about how I can get my child to read. I tend to find that people who have typical children have no exposure and no concept of what it’s like. And the only thing they think about it is my gosh, how horrible that life must be. They never understand the joy that can also come with this life. The child’s first step is so much more potent. I still remember the first time Jack said mama. These milestones are so spontaneous and make you cry. I don’t think they understand that Jack is really incredible. It strips away people’s outer shell. He is a “real person” barometer. You can find out quickly what people are like just by that fact that Jack is in the room. It shows if they are uncomfortable and superficial. Or comfortable and good hearted. It is pretty instant.

When our family is out in public, we don’t really blend in. I always feel like there’s a stereotype of people with disabilities, so I try to make sure we are all presentable. Basically, it’s a kind of Teflon coating when we go out with Jack. It’s like I just ignore everyone because parents will stare, and the kids will ask their parents about Jack. I try to ignore all of it. Sometimes, it hurts, like if you hear a particular comment about Jack. But he looks typical, so kids can get confused. I try to portray a positive picture. That it is not overwhelming our life and that we have our act together. Part of it is that I don’t want pity. There’s no reason to pity. One in five people are disabled. Jack just happens to be a little worse.

Transformation
One thing that hasn’t changed is my belief that anything can happen. Nobody has a crystal ball, and nobody can predict the future. Don’t ever tell me no, that cannot happen. I don’t believe in the word, can’t, because it is all choices. What has significantly changed is my level of compassion and patience with people. I never cried before, not at bad things, not at Hallmark commercials. It took a lot for me to cry.
Now I cry at the drop of a hat. At everything.
I also find that I have become a loud advocate now.

And I have become very family oriented and compassionate to people’s needs.
I am now more patient and gentle with others.

**Motherhood**
Before I had kids, I never actually wanted kids.
That was not my passion.
I was very corporate, very work-focused. I was quite driven to be successful.
I never ever wanted to be a stay-at-home mom.
I had a hard time begin motherly to my step daughter because I did not find it natural or fun.

After Jack was born, it took a long time to get through some of the human elements because you are so shell shocked for the first few years.
You are not acting as a mom. You are just in medical emergency mode, kind of mechanical.
It’s not really living because you are constantly fearful that he will die any day.
So you do all the loving and parenting that you can muster, but you are still distancing yourself a bit.

When Emma came along, we started to feel more like a family. She brought us some balance.
There had been no husband/wife relationship before Emma, but she forced us to look away from Jack for a few minutes.
We had been so engrossed in him, but we were forced to acknowledge that another person needed us, too.
That’s when we started to have a more normal family life.
And when we realized that somebody needed to stay at home.

As Jack got older, we began to see the differences in what he could do compared to other kids.
And that’s when your protective feelings come out.
I think that’s when I started becoming more motherly. I became more compassionate to other people in general.
I was not so corporate driven anymore.

There are so many things about having a child with special needs that hurt.
It’s like a million little paper cuts. Each one stings but you have to keep moving on and try to forget.
Jack had field day recently.
There’s nothing like seeing your kid totally isolated without a single friend or buddy in front of the entire second and third grade.
That sucked.
And on those beautiful summer nights, when all of the neighborhood kids are out playing in the street, I miss that part of childhood.
I miss that part of growing up for my kids, Andy, and for myself.
I remember tons of nights when the neighborhood kids played while the parents chatted.
We haven’t found a solution yet, a solution that will allow our family to have these nights.

Yesterday, I ran into a friend who has a child with a fatal, genetic disorder. He won’t live past his teens.
You can see the toll it is taking on her. The frustration and the despair of knowing that you will outlive your child.
There is also pain because nobody can comprehend what it feels like to go through this.
People believe that his death will bring relief. But it won’t.
No matter what people think, losing a child with special needs would not be a relief.
It may take away some of the chains and heartbreaks, but it is still losing a beloved child.

When I get exhausted or down, I have nightmares. The kind that comes with your eyes open in the middle of the day.
I think back to Jack in the NICU, alone and crying all night without me there to help him.
Suffering from a massive brain bleed that was so bad it was killing him, his optic nerve, and his major brain parts.
Nobody even realizing what was happening to my tiny baby.
These thoughts are always my downfall.
I wish I could scrub these memories out of my brain, forgetting them forever.

I am so tired of being worried.
There is so much to do all of the time, so much to worry about. It is exhausting.
Andy is always about fun. He never seems to worry. I guess that’s my job.
And even though it drives me nuts, I know it is better for the kids to have one parent like that.

Marriage
We are both very solid in the sense that no matter what happens, we will not divorce.
Knock on wood!
This is not something we feel we could do alone.
We just couldn’t do it. There’s already enough crap in our lives. We could not add to it.
But it is definitely harder. We don’t do all of the fun stuff we used to do.
We have a boat . . . it has been in storage for six years.
We used to ski, rollerblade, hike, bike, and mountain backpack.
Life is much more limiting now.
We do not have a lot of time together because we work and then do kid stuff.
It is really hard to keep connected and loving toward each other.

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There is so much guilt and pain. Some days, I don’t know how it doesn’t crush us or our marriage.
Guilt stemming from thoughts about how easy and mindless life could be if we weren’t in this situation.
Pain about all of the little things. I am thankful I married a funny man.
When Andy gets frustrated and says the focus of our family is too much on Jack, it spotlights one of the frustrations of our marriage.
To this day, all research, therapy, networking, goals, solutions, and schooling have been on me.
He has never cracked a book or website on CP, low vision, or special ed.
All work and no play definitely make for some grumpy marital moments.

**Future**
I think about the future a lot.
I want Emma to find her passion.
I hope that includes college, marriage, and kids, but if that is not what she wants, so be it.
I don’t want her to find a job or a career. I want her to find passion.
I want her to be happy, have good balance, and know she is loved and wanted.
For Jack, I hope for the same things, but they just look different.
We are working on communication right now. That is the key to Jack’s independence.
I want him to be as independent and happy as possible.
I really worry about his social life and his lack of friends because he is nonverbal.
I hope he has a love of learning so that he can learn his entire life. Maybe he will go to college someday.
I am not going to say no. Why close out the potential?

**Advice**
Get a lawyer and an advocate before you visit a potential school for your child with special needs.
Focus on getting a good preschool placement because it is so important.
Finding other parents and resources has been so important to me. Connect with these parents as fast as possible.
The independence piece is critical. Start thinking about this early. This is your goal.
Believe in your child. Always assume that your child will be able to do anything that you work toward.
Never give up. Think long term.

**Ellen**

Ellen, age 41, divorced her husband of 14 years about one year ago. This single mother is currently pursuing a graduate degree, while also raising Julia, age 9, and Henry, age 6. Henry was diagnosed with autism spectrum disorder when he was 2 ½ years old. Here, in her own words, is Ellen’s story:
Diagnosis
When Henry was a baby, he was constantly sick with croup. His body was frequently swollen, which appeared to be some sort of allergy. The doctors could not figure out what was causing the swelling or his wheezing. We finally realized that he was allergic to our dog of 11 years. It was a very bittersweet time, but I was thankful to figure out what was making him so sick and miserable.
At the same time, Henry’s developmental milestones seemed delayed compared to Julia. Because each child’s development is so different, it was hard to gauge. But I felt that something was off.
Henry didn’t seem interested in what kids his age were doing and didn’t seem excited about the environment around him. He had no interest in airplanes, trains, or toys. His fine motor skill development, such as feeding and picking up objects, was slow. He also was very weak physically, didn’t have a lot of muscle tone, and drooled. He became so fixated that he would start flapping his hands, which was his way of expressing himself. During these times, it was hard to get him to focus on anything else. His doctors didn’t seem concerned. But I decided to get him tested anyway.
He was diagnosed with autism spectrum disorder shortly after. We were so surprised and sad. We didn’t know how to take it. The psychologist who did the evaluation told us he would probably get worse with age. So, we decided to use all of our resources and start OT, PT, and speech therapy. We put him in an inclusive preschool for children with disabilities. Over time, he began to blossom into a very social, affectionate little boy.

Family Life
Julia is our little, red, curly haired girl with a lot of personality. Everything she feels is so extreme and comes with lots of passion. She has a very strong will. She is very determined, mature, and resilient. Julia has always been very attentive to Henry. Sometimes, she gets frustrated and upset when he gets lots of attention. But Henry has always demanded more. It has always been very challenging for me to give them both equal attention. Now that he is in kindergarten, I am trying to give them both the attention that they need. I am realizing that Julia’s needs are just as important. I need to find time to be with her and make her feel as important as her brother. She is now a lot more expressive in the things she feels and needs. As Henry has gotten older, he has learned to be more verbal and independent. This has also made it a little easier to be attentive to both children. Now they play and entertain each other a lot more.
Being a single mom takes a lot of juggling and can be very trying at times. The evenings are difficult. Henry tends to cling to me. I try hard not to lose my patience.

**Transformation**
This experience with Henry has forever changed my life in a way that I never thought it would.

Everything that I thought I was or could be . . . I realized I wasn’t.

Before my son was born, I wanted to be there for everyone. When Henry was born, he was the priority.

It was so hard to watch him be sick, watch his slow development, and not be able to help in the way I wanted to . . . and still be there for my family.

I felt very judged as a mother.

I didn’t know how to keep up with everything and be the person I thought I had to be.

I became depressed because I felt so unsure of myself and my marriage.

I feel like I have evolved into more of a woman. I became an advocate for my needs and for my children more than I ever felt or thought I could be.

I value the things that are close to my heart and dear to me in my life.

I appreciate life.

Slowly, I have learned to be truer to myself and truer to what is important to me.

My son has shown me my own strength as a mother.

I have become more forgiving and do not take life so seriously.

Now, I take things as they come in a more accepting and patient way.

Also, I feel I have become more resilient at expressing what’s important and honoring those needs.

My priorities include taking care of my children and having a peaceful life that has love and happiness.

I think my quality of life has slowly improved as my perspective has changed.

I feel more at peace in accepting my life, its challenges, and all that has changed.

I still feel like I will always be up against something, but rather than trying to control it, I try to take it as it comes and make the changes I can.

I feel that I am closer to my children and they feel closer to me.

After the diagnosis, I was very scared and didn’t want to believe it.

But today, Henry is doing great.

He has changed so much. I never believed his progress would be so good after hearing the news that he would only get worse.

He has come a long way with early intervention. He almost seems like a different child.

He is a very smart boy, who has become very articulate and inquisitive.

At times, he still has a hard time with his social boundaries in how he relates to others and plays with peers his age.
But every day, I look at my son and feel so happy and blessed that I have him. He is my light, and he shines bright on me. When I feel down, he changes my perspective because he is so lovable, happy, and accepting of everyone around him.

I feel that it has been essential to maintain a good relationship with my ex husband and continue to work on our communication. It so important that he is part of our children’s lives, but especially for Henry. Other things that help me are staying connected to Henry’s school and teachers for support. I also focus on my own individual therapy. My friends are a lot more supportive than my family. Having them around to hear me, even though they don’t entirely understand, means the world to me. I know my family cares, but they do not really know how to be supportive, especially since I chose the path of divorce.

It’s important for me to be around healthy, positive people who also appreciate life and do not judge. I feel I have become closer to my spiritual side. I feel that someone is looking out for me, which keeps me going. This helps to ground me during the trying times or when I feel scared that I can’t give my children what they need. I try to remember to do things for myself, so I have more to offer my children. Painting has always given me a sense of peace. Every day, I try to read something positive that helps remind me to have a different outlook on life. I need to be reminded that what I was given has made me stronger.

Marriage
My mother died of cancer a few weeks before my wedding. It was so hard. Then, my husband lost his job and couldn’t find any work. He became depressed. I had multiple miscarriages before having Henry and Julia. As a baby, Henry was so sick. I couldn’t sleep because I worried he would stop breathing. I became depressed. Needless to say, there was a huge strain on our marriage, and we just seemed to move apart. My husband found another job and went back to school. He wasn’t around very much. I wasn’t as patient as I used to be. I started to feel resentful. We went to therapy, but it didn’t help. We seemed to be in such different places in how we were dealing with Henry. We did not make our relationship a priority and set good boundaries. We did not ask for help.
Family wasn’t really around for us, and we didn’t have reliable sitters to help give us a break.
I felt as if my in-laws were judging me as a mom.
I still wish that I didn’t give up on us, but nothing was getting better.
Today, I realize that it takes two people who want the same thing and are willing to look at the core issues and work at it.
We were not doing that. We were not coming together.
The disability was very trying on our marriage.
Instead of coming together as a family, the strain of Henry’s disability seemed to tear us apart.
After 17 years together, I left a marriage that I never thought I would ever leave.
I’m not sure if I would have left if this didn’t happen to our family.

I do feel lucky now because we are able to help each other, which makes things easier on our children.
Especially for Henry, who has a hard time being apart from each of us.
My ex husband and I are very close and remain supportive of each other and our children.
We were able to grow up and come together on a different level and in a healthier way.
We now have a more hopeful perspective on life.
While it can still be hard at times to be on the same page, we both make our kids a huge priority.

**Motherhood**
This is not what I thought motherhood would be like. But I wasn’t really sure what to expect.
I have three sisters and one brother.
Three of my sisters have kids, and they made it seem so easy.
It also seemed that everything went so much easier for them because they didn’t have a child with special needs.
I definitely judged myself more because of my insecurities.

Before my son was born, I always tried to be what I thought was the perfect mom.
But I really didn’t have a lot of confidence in myself.
Since Henry’s birth, I have become a better mom who is confident in my son’s needs.
People questioned what we were experiencing with Henry.
I was able to feel confident enough to trust myself and continue advocating for him, regardless of what I was told.
I didn’t stop fighting until I felt he was getting what he needed.
It’s so important as a mother to trust your own instincts about your child’s needs.
You know your child better than anyone.
It is so easy to dismiss your intuition and listen to others.
But a mother knows what her child needs.
And if you listen well, your child will tell you what they need. Even if it is not in an articulate way.
I feel like I am a very good mother. I do the best that I can. I love my children and would do anything for them. I have always loved being a mother, but these days, I feel more connected to my children and more sensitive to their needs.

Being a single mom can be so tough. There are times where I just want to give up. However, I somehow find more strength within myself. I realize the blessings that I was given and this keeps me hopeful. I feel like I have become a more sensitive person, yet I am a stronger woman who is more confident from all that I have faced. When I had Henry, I really grew into myself as a woman and a mother in a positive way. It was such a difficult time, but I was able to pull myself through, trusting myself more.

I could never compare myself to any other mothers. Every mother faces her own challenges, whether personally or with her family. I can only look at my life. My experiences can be far different from another mother who has a child with special needs. I just feel blessed to have Henry. He has grown into an amazing boy and has touched our life in an indescribable way. He is my bright star.

I was really looking forward to being a mother and having a family of my own. I always wanted to have a big family but felt blessed with two beautiful children. I’m not sure I had any specific expectations of what motherhood would be like. But I knew I wanted to be more attentive and available than my parents were to me and my siblings. My parents divorced when I was in the first grade. My mother was always working and my father lived out of state. My mother was there for us, but she was very busy with her own life stresses. So, being there for my children has always been very important to me. Being a mother is hard. And being a single mother is even harder. It is challenging to give both children the attention they need without feeling impatient and exhausted. I wish I could do more things with my kids. We don’t venture out the way I wish we could. An extra set of hands would make my life a lot easier.

Public Life
People think they understand what it is like. But unless it’s something they experience themselves, they just can’t understand. It is always hard to go out in public with Henry and do things as a family.
It’s tough if your child behaves in a way that makes others feel uncomfortable. Being a single mother is especially hard for me when I go places with my children far from home without any family around.

At times, I still feel anxious because I am so oversensitive about Henry and his sensory issues. I don’t deal well with my own anxiety. Maybe it all goes back to society’s expectations. Feeling like you need to be the “normal family” or what “normal” is for everyone else. I hope that over time, I will become more comfortable and more patient. I don’t want to spend time worrying about what other people think. While I don’t worry as much as I used to about what people think, it does hit me in waves. However, I am better able to tune it out and focus on what is important.

**Advice**
Reach out for help even if it’s help from other support systems and not family. Do not give up. Make your relationship a priority and take time for each other and yourself. If you don’t, you will have nothing left to give your children or spouse. Stay positive and hopeful. Be a true advocate for your child and especially your child with special needs. Take advantage of all of the services available to you. Get your child tested as soon as possible to take advantage of early intervention services. Get help to clean, cook or watch your children, so you can have a break. If you do not take the time you need, you will have nothing left for yourself or your kids.

**Emma**

An attorney by profession, Emma, age 45 and married, is currently a stay-at-home mother to Simon, age 4, and Holly, age 3. Simon was diagnosed with Down syndrome in utero at 15 weeks. Here, in Emma’s own words, is her story:

**Diagnosis**
One of my prenatal screenings came back with elevated blood levels. I went for a genetic ultrasound at 15 weeks, and the perinatologist realized my baby was missing a little bone in his pinky. He said there was a 99 percent chance that Simon had Down syndrome because he was missing that bone. Then, I had an amnio to be 100 percent sure.

My husband was flying through Chicago on his way to London at the time. I had the ultrasound done while he was in route. I called him while he was in Chicago and told him our baby probably had Down syndrome.
He turned around and came home.
We stayed in bed the next day and didn’t do anything.

Initially, I felt like we lost the child we thought we were going to have.
And the guilt of having those feelings was very surprising.
I still feel guilty for having those feelings.
When I was having the genetic ultrasound, something as important as the gender didn’t matter.
I thought, who the hell cares whether it is a boy or a girl . . . it will be a baby with Down syndrome.
It was just so disrespectful for me to treat Simon that way.

I didn’t enjoy my pregnancy after I knew. People would get excited and ask me about the sex.
But I didn’t care.
I had such negative feelings toward Simon after getting the diagnosis.
I had really low expectations for him.
I grew up with a next door neighbor who had Down syndrome, so I did have some experience with it. I had some idea about what to expect.
But my husband didn’t even know what it was.

And then the local Down syndrome organization sent over two families to visit us.
One family had a toddler with Down syndrome and the other had a teenager with Down syndrome.
We talked for a long time.
I realized that these are normal people with normal jobs. Their lives were not over.
It made me see Down syndrome in a new way.

**Motherhood**
We had always planned on having a large family, so we got pregnant right away with Holly.
I felt so nervous about having another child. What if she had issues, too?
We watched everything and had many ultrasounds.
It wasn’t until she was born that I actually looked at her and thought okay, you are here and you are mine.

Recently, the four of us went out to dinner and sat next to a pregnant woman.
I caught her looking at Simon several times. I wondered if she was thinking about her own baby.
Was she praying her baby didn’t have Down syndrome? Did she feel happy that she dodged a bullet?
Did she look at me and feel sorry for me?
There seems to be a recent push by the medical community to do prenatal testing to detect Down syndrome. We did prenatal testing and knew that our baby would have it. We did not terminate. Do people wonder if we ever had Simon tested? A pediatrician once asked me, “Didn’t you have an amnio to find out?” Sometimes, I feel like a parent to a child who some people think shouldn’t have been born. Do they think we are irresponsible for knowingly bringing a child with Down syndrome into the world? But what business is it of others to question our choices?

I think I would be a better mother to Simon if I had had Holly first. Then I could see what a child should be doing. I baby him too much because I just don’t know any better. When I see Holly getting dressed by herself, I wonder why I am getting her older brother dressed.

I always thought motherhood was about sitting and playing with your child. I thought it was all happy, fun, and loving with lots of hugs and kisses. Life is not how I envisioned it to be. These were just dreams in my head, maybe from watching TV and seeing the diaper ads. Where’s the cute and cuddly stuff with my kids?

Right after having Simon, I felt robbed of those sweet diaper ads because I had to focus on every little part of his life. I had to make sure that he was eating and drinking and pooping. I thought the Down syndrome was taking my dream baby away from me. And then after having Holly, I realized that the ads on TV are a joke. They make you want to have a baby and buy Aveeno to have a calm kid. It’s a marketing ploy and it worked.

I do not like the term, disability. I think of Simon as having some delays. There are some things he doesn’t do as well as Holly, and things he may never be able to do. But I wish we could talk about Simon as we would talk about someone who had bad vision. Bad vision is not stigmatized. Or if he had only one kidney, for example. If his issues were on the inside, people wouldn’t assume that he couldn’t do certain things.

Because Simon’s delays are on the outside, people look at him differently. He has to fight even harder to prove that he can do things. We also have to contend with strangers calling him a “beautiful angel” and telling him he’s doing a great job.
“Simon looks like he is doing so well!” Oh, I hate that comment. Who and what are they comparing him to?
I know people say it with the best of intentions, sincerity, and honesty.
It’s a compliment that drives a stake through my heart.

It saddens me to have weird people touching him, trying to heal him, and making odd comments about him.
And when people say that Simon is so cute, I wonder if they are saying that only because he has Down syndrome.
I just want him to be the same as everybody else.
I don’t want him to be picked out for any particular reason.

The other night, after I put the kids to bed, my husband said that we really do have a great life.
While I am stressed out because of the kids, just trying to get to 8 pm every night, we try to make it an easy life for them.
We don’t yell at each other, we are not homeless, we have a stable job with good money, and we are not divorced.
We are lucky.

Family Life
Simon was our first child, and we built our world around him and his needs.
We continue to do that.
Sometimes, I feel like Holly is tagging along.
Our life with Simon is therapy, therapy, therapy, and Holly comes along for the ride.
I feel a lot of guilt about it.
Simon ends up getting a lot of attention because he has extra needs.
It is a challenge for us to make Holly feel like she is number one without spoiling her.
I am concerned that Holly sees all of the attention that Simon gets.
I worry that she may end up resenting him, resenting us, or doing negative things for attention when she gets older.

A pregnant friend of mine once told me that she would have to terminate her pregnancy if her tests showed any kind of disability.
She said it wouldn’t be fair to her other two children to have a child with disabilities.
This fairness comment struck a chord in me. Is this even a question of fairness?

So far, Holly has not questioned Simon’s differences.
I don’t know how I would handle that.
She is little miss why, why, why. I am sure it is coming soon.
But I do not want her to think he is different. He’s the same.

Every meal in our house is a fine motor and oral motor therapy exercise disguised as eating with Simon.
Holly just eats.
I hate that I can’t stop analyzing Simon’s eating and just enjoy our family time.
I do this with everything he does . . . his motor planning, speech, etc. I hate that I do this.
I try to sit back and let Simon be who he is, but I always end up analyzing him, trying to make him more “normal.”

Transformation
Simon’s delays have changed my life in a good way. I am more sympathetic.
I am very sympathetic to what people have going on in their lives. You need to give others some slack.
It has calmed me down.

Was life easier before I had Simon? Yes.
But was it meaningful?
Before Simon, I was a career woman, a transactional attorney caught up in the business world.
Now I wonder if it really matter if case X affects Y.
I used to love drafting contracts, but now things are different.
While I miss the excitement of closing a big deal, my excitement and passion have turned to someone pooping on the potty.

Marriage
This experience has been tough on our marriage.
We have a lot of arguments about what we are doing with Simon.
We just don’t have the time to sit down and discuss our strategy and what we need to work on with Simon.
My husband travels a lot and his job is stressful.
So, I end up doing my thing. And I’m not a good communicator.
He feels a lot of guilt that he is gone a lot. Then he comes home and becomes the celebrity dad.
All he wants to do is have fun and play. But I do all of the day-to-day work.

Public Life
While I don’t focus on what our family looks like in public, I always dress Simon in nice clothes.
I buy Simon expensive clothes.
He gets brand new, really nice clothes because I don’t want him walking around in ratty, old t-shirts.
I don’t want people saying, oh, look at that poor child with Down syndrome. His mother can’t even dress him nicely.
But then I dress Holly in hand-me-downs from my sister and sister-in-law.
There are days when I pick her up from school, and she’s in her extra set of clothes looking like she walked off the trailer park.
Maybe by focusing on Simon’s clothes, I am also making sure people don’t pick on him. I want to be sure nobody is ever making fun of him about his clothes. He’s got enough of his own delays. I don’t need to make him a bad dresser, too. I can give him a step up on that.

Simon went to a birthday party at a gym recently. What a disaster. All of the other kids could run and jump and do everything. But Simon doesn’t have the same physical ability and can get easily injured doing a lot of things. I wondered why I even bothered taking him to the party. I almost broke down in tears watching what the other kids could do. I also didn’t really know any of the other parents, which made me feel more isolated. Sometimes, when I take Holly someplace, she chooses to do her own thing, which is fine. I give her a lot of leeway. But with Simon, I want to make sure he is doing what the other kids are doing. Not because he wants to but because they are doing it, and I think that he should be as well.

We threw Simon a birthday party recently. I wondered if anyone would come. I wondered what the other parents thought. Did they send their kids to the party to support Simon or do the kids come because they really like him? Does Simon get invited to parties because the other kids like him or because parents don’t want to exclude the boy with Down syndrome? What will his friendships be like? Holly names all of her buddies, while Simon names Holly as his buddy. I don’t think this would bother me if he were a typical kid.

I feel like the more people that see Simon out in public doing things other kids are doing, the more he will be accepted. If it’s visible, it might become part of our society. Maybe people will no longer think that people with Down syndrome should be terminated. They deserve the right to live. We need to make others aware that there is nothing to be afraid of. Simon might not be doing the same stuff at the same pace as others his age, but he doesn’t have to be considered scary or different.

Simon doesn’t fit in because he has been excluded and labeled by society. It is up to me, my family, and friends to include Simon. But will that only happen if he can walk, talk, eat, and drink like typical children? If I fail, does he fail? Does he even want for himself what I want for him? Are these the same questions that parents with only typical children ponder?
I’d rather people ask me questions instead of staring. Maybe that’s because I want to ask questions.
I was at the mall and saw a child wearing a helmet.
I felt like since I have Simon, I’m clued into other people’s issues.
Maybe this gives me a free pass to ask somebody else personal questions. I just want to say, tell me about your daughter.
It’s a little bit of curiousness, as well as an interest in somebody else who has a child who isn’t perfect.

**Future**
I’d like for Simon to be an independent adult. I want him to have a job, friends, and get married.
I want him to do everything that I want for Holly.
But with Simon, I have to think about the things I want for him.
Whereas with Holly, I assume she’s going to do it. I don’t worry about her.

When I see an adult male with Down syndrome, I wonder what that person’s life is like.
Will that be Simon?
Why do I think Simon’s life could resemble another’s life just because they both have Down syndrome?
Am I selling him short and being disrespectful to his individuality, solely because he has a diagnosis of a genetic condition?
And in doing so, is it a self-fulfilling prophecy that he will be so?

I have concerns about Holly having to take care of her brother when she gets older.
When we were trying for a third child, I worried about having another baby with Down syndrome.
Then Holly would have to take care of two siblings.
I want to make sure that we raise her so she never has a sense of burden.
It is also my responsibility to make sure that Simon is not a burden to his sister or to society.
Just the way that I expect Holly will not be a burden to Simon or society.
How I achieve that, I don’t know. I don’t have a plan yet.

**Advice**
Your child with delays is just another child. Treat him or her like your other kids.
People told me this when I was pregnant, but it just went right over my head.
Now I get it.

**Gabrielle**

Gabrielle, a 42-year-old, married English professor at a local university, is raising fraternal twin boys, Charlie and David, age 5, and Brody, age 2. David was diagnosed at
age 3 with partial trisomy 16, a rare chromosomal disorder affecting his 16th chromosome. Here, in her own words, is Gabrielle’s story:

**Diagnosis**

I thought something was up from the moment we took David home from the hospital. He was definitely a different kind of baby compared to his twin brother. Because he was a twin, I always felt like I had a center of comparison. He didn’t cry very much. He wasn’t very demanding. An incredibly placid baby. He also was a bit funny looking. Flat and less defined. Charlie looked different and was much more alert. And so much more demanding.

As the boys developed, David met his milestones, but they were significantly behind Charlie’s. But I was not too worried. I just believed he was a little delayed, and he’d eventually catch up. After all, he always kind of got to where Charlie was, just in his own time. But my in-laws and my mother urged us to get him tested when he was 3. I didn’t think anything would come of it. I was totally shocked when the tests came back indicating he had partial trisomy 16. Although I knew there was something wrong, I didn’t actually feel that it was chromosomally related.

Brody was a baby when we got the diagnosis. And I didn’t even think to do any kind of testing with him. It wasn’t even on our radar. Now I am shocked that I didn’t have him tested. In fact, now that I live in the world of special needs and chromosomal mutations, I am shocked that I did not have an amnio for all of my kids.

After the diagnosis, I was totally disoriented and depressed. I felt less hopeful about his potential for transformation. For me, the diagnosis felt so devastating, so much more than my concerns about his delays. It felt final and absolute, in a way that his delays never felt to me. Intellectually, I know the diagnosis shouldn’t make me feel this way. But psychologically, the diagnosis was so traumatic. He wasn’t going to grow out of it. He would always have difficulties.

There’s also the stigma attached to it. I have my own stigma attached to chromosomal abnormalities. My husband’s aunt is severely developmentally delayed, so we have experienced it firsthand. There’s a realization that it is permanent. And that it affects every single cell in his body.
Motherhood
Some days are good days when I think David is going to be okay.
He may never go to college, may never even finish high school, and may never be able to live on his own.
And even so, it’s all okay.
Then there are other days when all of this just feels like the tip of the big, toppling iceberg.
Where it’s dark and depressing and vaguely hopeless.
Where I’m really resentful and sad and angry.
Angry at David; at my doctors who told me my babies in utero were fine; at my husband; at everyone I see with typical kids; at my stinking bad luck.
What makes me saddest on those days is not David himself, but my reaction to him.
The fact that my love for him feels compromised.
And the fact that I just can’t seem to accept the situation and make the best of it.
I realize this would be the best thing for me and my family. But it’s me. It’s my expectations and demands as a mother.
I have such a rigid understanding of kids and motherhood, one that can’t take into account difference and non-conventionality.
It’s not David that’s the problem. Just me.

I’d pray that I could change, but I am not religious.
So, I just obsess and self-blame and wonder until I am back where I started.

I definitely had ideas about what motherhood was like.
They were far more naïve and pastoral than what I experience now.
It’s not all David. My other kids can drive me crazy, too.
Sometimes I wonder why I wanted this so much. Like, what’s the upside?
I think of myself when I see the book, I Was a Great Mother Before I had Kids.
I have a bunch of nieces and nephews. I was a wonderful aunt. I never experienced being with them as burdensome.
Also, I had this idea of what being a mom was going to be like.
And it didn’t include getting so incredibly frustrated at my kids.

If someone had told me that when I grew up, I was going to have three boys, one with special needs, I would have been like, no, not so much, I don’t think so.
It’s much better when I don’t think in terms of this is what I expected, and this is what I actually got.
Or in terms of what other people got seems so much easier than what I got, or more desirable in all sorts of ways.
It’s much better when I don’t think about these things.
When I can just live in the moment and enjoy what I have . . . and there really are tons to enjoy . . . I’m fine.
It’s when I take a step back and look at it from a long-term reflection angle that it’s problematic.
Or when I think about not having a daughter in the long term or having a special needs kid in the long term.
Then I can be overcome with feelings of this is not what I expected motherhood to be.

David just makes everything harder. Everything becomes exacerbated.
It’s not the labor as much as the anxiety with David.
I can handle the labor, but anxiety induces this reaction in me that’s much more severe.
It can make me really depressed.

I see how not having a child with special needs has a kind of ease and conventionality to it.
At times, I envy this.
But at times, I also begin to see this as something that prevents life from being really richly lived or really fully experienced.
In the way that only some terrible traumas can do.
There are times when I’d love the conventionality, ease, and blandness of a typical kid.
But since I can’t have that, I need to sort of recuperate the life I have.
You need to come up with some kind of narrative that makes each day easier to love.

I struggle with my frustration and guilt over David.
There are things that I want him to be.
On some level, I just want him to be different than he is.
He can’t be different. And I am angry at him for that.
It is totally irrational. How could I possibly blame him, he didn’t ask to be brought into this world?
I recognize that, and yet I feel angry. This misplaced anger leads me to feeling guilty.
When David feels at his most limited, that is when I feel most upset.
But it is also where I should be at my most understanding.
The fact that I can’t get there is a source of pain for me.
And the fact that I sometimes resent his existence is incredibly painful for me.
I’m his mother!

He is so incredibly dear to me, but there are also these ways in which he makes my life really hard.
Sometimes he can act in ways that make him hard for me to love.
Saying that is painful.
There are so many expectations of what mothers should be like.
Having kids makes you come up against those expectations in painful ways.
But having a kid with special needs does this even more.
It makes you aware of how much you don’t fit the model of a completely loving, nurturing presence to your child.
I have a friend who has a child with issues. She says she wouldn’t want him any other way, wouldn’t want to change him at all.
And I think, really? Do you mean that?
I am currently writing a book. I’m really into it. It’s quite satisfying, but I’m also aware that it is a huge escape for me. It wards off depression and anxiety, mostly about David. If I let myself think about the disability too long, I get really sad. So, I don’t. I work instead. It feels a bit like living in a bubble. Mostly, I try not to think too much about anything. I get through my days, take care of my kids, and get as much pleasure and escape as I can out of my work. But I am also aware that there’s this big, looming elephant just in the background that’s always haunting me.

**Family Life**

David’s disability affects the entire family. I worry about it all the time. I think there will come a time when David is more aware of his limitations, and Charlie and Brody are aware as well. So far, it hasn’t been much of an issue. Charlie knows he is capable of things that David is not. He also has registered somehow that he is older than David. He’s actually only one minute older. But we have not dissuaded him of this idea. It’s been helpful for everyone to establish that Charlie is the oldest. So whatever privileges that Charlie gets that David does not can be explained in part through that.

I am very excited about taking Charlie to his first movie in a theatre. But of course, my excitement is tempered by guilt and sadness in relation to David. He probably won’t last through a feature film. He’d be confused by the darkness, unnerved by the seats, and scared of the noise. It feels so easy to identify with Charlie. He feels so incredibly familiar to me, down to his interest in movies and his disinterest in sweets. David can sometimes feel like a foreign presence. What a terrible thing to say about your own child. I need to expand my sense of satisfaction with my kids. David is not limited. I am.

Charlie has play dates, but David doesn’t. This makes me so sad. But I know it is important for Charlie to have independence and a social life that’s of his own making. I need to remember this.

I worry all the time that the disability affects my relationship with Charlie and Brody.
I worry that I’m a more anxious and depressed mother than I would be without David . . . and that has an impact on my parenting the other kids. That doesn’t feel like a good thing. David can transform my experience of motherhood. And I feel cheated on some level. I also feel like my other kids get cheated. Mothering typical kids is hard, but the disability adds an extra layer of frustration and sadness.

At this point, Brody is still behind David in development. But there will come a point where he will surpass him, and it will be very difficult. There’s something painful in seeing a kid who is older than his sibling but less capable of doing the same things. If Brody and Charlie were twins and David were the youngest, that would actually be easier.

Our family has a lot of goofiness, happiness, and laughter. And a real sense of affection. Sometimes, that can get dissipated by me . . . by my worry and anxiety in relation to David. But I try and remember my childhood, which was full of love. My house was the house where friends wanted to come and sleep over. They would express a desire to be adopted into my family.

We were incredibly devoted to one another with a real sense of affection. I try to remember that a lot when I strive to create specialness in my own family.

**Transformation**

I think as a person and a mother, I’m more anxious. I’m probably more unhappy. And a little more obsessive. I can’t help it. My husband keeps telling me to relax . . . that David is just a kid with delays. Some days, I can actually live with that. Just give him tons of love, therapy, and support, and things will be fine. Other days, it feels completely life altering and debilitating. A devastating fact in my life that I can’t seem to get over or beyond. I can’t always account for why I feel a certain way. A lot of it is just me or sleep or my exhaustion level or what’s going on at work. I don’t always know what makes for the difference. This week is a good week, but sometimes I can’t get through the week without crying.

I’d like to think the disability has made me more compassionate and understanding. More aware of people around me, aware of my students. In the past, if my students didn’t work, they got a D. Now, I listen to what’s going on in their lives. I am more sympathetic to their issues.
I am more interested and sensitive to delays, disabilities, and dysfunctions in general.

**Marriage**
We have an incredibly strong marriage to begin with.  
I am very aware that if we didn’t have such a strong marriage, we would be in trouble.  
We definitely have our disagreements and it’s definitely an added strain.  
Even before we knew there was something wrong with David, it had an impact on our marriage . . . from exhaustion to different ideas about parenting.  
The biggest thing with David is that at times, I can get really depressed about him.  
And I don’t always feel like I can talk to Jack about how upset I am.  
It’s not that he won’t understand.  It’s more that it is not very functional for our family to have us both in a state of despondency.  
It’s not productive for me to talk to him.  It just feels too burdensome.  
He’s also exhausted by work and parenting.  
I think he feels that when we have free time, we should be spending it in a positive way.  
We still have deep conversations, but the depressive aspect of it makes him feel like he needs to take care of me in addition to the kids.  
It’s hard on him emotionally, too, so when I feel depressed in relation to David, I have learned to turn to friends and family.

**Public Life**
There are some people out there who don’t have any idea what it’s like and who are not particularly empathetic.  
They are just measuring their kids by other kids.  
I no longer do this.  I have no patience.  
My neighbor was bragging to me that her son started to skip.  
Apparently, there’s a correlation between skipping and reading.  She was waiting for him to start reading.  
He’s 3 and ½ years old.  
I was just like fuck you.

Going out in public is easier now because David is a bit better.  
He no longer acts so immature or eccentric.  He doesn’t scream without any instigation.  
I used to feel so nervous, wondering what he would do next.  
He’s also young enough that a lot of his “stuff” can be chalked up to being young.  
He registers as cute and younger than his actual age.  
I try not to care about what strangers think.  
I’m definitely aware of people staring, but I try not to worry about what he will say or do.  
At times, I’m envious of families that I perceive as not having that kind of anxiety.

**Future**
Generally, I try not to think about the future.  It’s better for me not to think about it.  
Living in the moment is better for my mental equilibrium than thinking in terms of the future or even the past.
Like thinking in terms of “before David” and “after David.” Both are equally unproductive.

I don’t think about the boys in the same way. For me, David is always in his own category. Of course, I have hopes for him, but the hopes are never quite the same as they are for my other kids. And I never imagine him in quite the same position. I always think that there’s going to be some special circumstance surrounding his. And on the rare occasion when I don’t think that, I generally tend to think that I am kind of delusional.

What’s hard is the line between being realistic and not being delusional. And still having a lot of hope. Needing to encourage and support your child as far as he can go. It’s a really hard line, especially with chromosomal disorders where they just don’t know . . .

I have a vision of Brody and Charlie’s future, but I don’t know how to picture a future for David. It’s hard.

There are days when I look at David, and he seems so very vulnerable to me. His hands and feet are impossibly small. He’s still a bit wobbly on his feet, even after turning 5. I look at him and think, how can he possibly make it in the big world? And then I need to remind myself to take it one day at a time, to not think about the future.

I have bad days and good days. I need to try and remember how good life with David can be. I have to remember how much pleasure he can give me if I just accept him a little bit more without fretting so much about his future.

Advice
My support group of other moms raising kids with special needs has been very helpful. I feel like the experience of being with other moms is important. Their experiences are distinct, but also comparable. Everyone is feeling the same feelings . . . anxiety, guilt, sadness. This has been so helpful.

Even just the knowledge that there are people out there like me. I had no exposure to the world of special needs kids. But realizing I am not alone has been great.
Gail

Gail, age 45, is a married, stay-at-home mother raising four kids with her husband. Her oldest son, Ethan, is 16; Michael and Julie are 14-year-old twins; and Wyatt is 11. Wyatt has a brain injury due to a cord accident at birth. He is nonverbal, wheelchair bound, and has very little head and trunk control. In addition, Wyatt is G-tube fed and has breathing and swallowing issues. Here, in her own words, is Gail’s story:

Diagnosis
After two C-sections, I wanted to have a vaginal birth.
I make big babies, but my midwife assured me that Wyatt wasn’t too big.
After being a few days late, I was induced. It took three days to put me into labor.
Labor was slow, tedious, and long.
When I got to 10 centimeters, I pushed once and Wyatt’s heart rate dropped.
It continued to drop and never recovered.
The cord was compressed. They tried everything to take pressure off the cord, but nothing worked.
They rushed me into the operating room for an emergency C-section.
My husband almost fainted. He was terrified he was going to lose both of us.
By the time they got Wyatt out, his heart rate was 30.
His Apgar score was 1. He wasn’t blue, he was white. They intubated him and performed CPR immediately.
He came home at 2 and ½ weeks.
We knew he had a lack of oxygen to the brain, but did not get a diagnosis of CP from the neurologist until he was 3 months old.
It was not a shock to us.
An MRI at 5 months showed most of the damage in the basil ganglia, in the center of the brain.
It’s the muscle motor control area.

From the beginning, we knew Wyatt had a purpose here on earth.
He had so many opportunities to die in his first 24 hours of life, but he didn’t.
He was a fighter. Otherwise, he wouldn’t still be with us.
We felt like God had a real purpose for him to be here and for him to be the way he was.
Or he would have taken him.
We may never know that purpose, but we need to love him unconditionally and do the very best we can.
We feel all people deserve respect and dignity, regardless of mental or physical disability.

You don’t ever think about bringing home a baby that’s not okay. Nobody does.
I think I was too darn busy to be depressed. There was no time to sit and dwell on our situation.
Ethan was 5 and the twins were 3. And Wyatt needed constant care.
There wasn’t time to sit and contemplate for even 10 minutes. That was good in so many ways. I couldn’t dwell on the negative stuff. We had great support within our family and our church. We were not alone. They helped take care of the older kids and helped keep the house running. We focused on our faith, and our belief that Wyatt had a reason to be here. It was key.

**Family Life**

It’s good that Wyatt was the youngest. Because he was the baby, I felt like I could invest the time I needed in his care and therapy. If he had been the oldest, I would have struggled to care for him and an infant. Having the older ones in school freed me up to concentrate on Wyatt.

I can’t imagine the bravery it takes to go and have another baby. You know so much and everything that could go wrong.

I think it’s good for Wyatt to have older siblings because he loves them and gets to spend time with them. He is part of their normal world, their baseball and soccer games, recitals, concerts, and church activities. But it is also good for the other kids to see him and understand that not everybody is the same. They need to learn compassion for others who are different.

For Julie and Ethan, it has become a natural thing for them. They gravitate toward others with special needs. But for Michael, it has been harder. He seems angry. I think he is more resentful that we spend time with Wyatt. Michael loves Wyatt, but struggles a bit more than the others.

We continue to try really hard to give all of them as normal a life as we can. There are music lessons, soccer, and school activities. They are involved as much as they want to be. But they also need to understand that there are times when I can’t be there because I have Wyatt.

Maybe I can’t take them places. Maybe somebody else needs to do that. Or they ride their bikes. I think it is important to teach them that this is life, and everybody has something in their family. We are a family and there are things we have to do—or not do—because we are a family. While we want them to lead normal lives, Wyatt is their brother and part of this family for the rest of their lives.

There’s a lot of stress in our lives. We are often in crisis mode with Wyatt. So the kids have to step up and do a lot on their own.
I think they have become more self-sufficient, doing things on their own sooner than I would have liked.
We are a different family than most, and they know it.

**Public Life**
I don’t spend a lot of time caring what others think, but getting Wyatt’s first wheelchair at age five was tough.
I wasn’t excited about the wheelchair.
We had been pulling him from place to place in a wagon for several years.
The wagon was more normal. It was not so unacceptable to see a kid in a wagon.
But he outgrew the wagon.
I felt more self-conscious about the chair when we first got it.
I did not want the chair to be who he is. I didn’t want people to see that as who he is.
In fact, I never liked taking family pictures with Wyatt in his chair.
My brother got married several years ago, and we took family pictures.
I had a grieving episode at the time because Wyatt sat in his chair for the photos . . . for the very first time.
And that was a big deal for me. I cried knowing he was going to be in that picture in a wheelchair.
But the chair makes life possible for Wyatt, so it has to be okay. I am used to it now.
It just hits me hard at times.

I have never felt unwelcome anywhere. It has mostly been issues of accessibility.
Like going to a place with a bunch of stairs, or a pavilion with nowhere to lay Wyatt, or a park with no shade.

**Transformation**
Wyatt has given me a focus. He has given me something to concentrate my life and energies on.
I am not sure that I knew what my life focus was going to be before Wyatt.
A lot of peripheral stuff just goes away, and you’re more focused on what is really important.
This has sharpened the way I think.

The disability has challenged us all in so many ways.
It definitely challenged our faith in that we were asking why in the world God allowed this to happen.
Thankfully, we didn’t lose our faith. It was strong enough to withstand our doubts.
Our faith is stronger and more real today.
People tell me that they admire me for my strength and perseverance.
I am sane today because God gives me the strength and ability to live each day.
I don’t know how families who do not have faith make it.
We believe in working to help Wyatt reach his full potential here on earth.
And we know that someday, in heaven, Wyatt will be able to stand, run, sing, talk, and have a body that is whole. This helps us with the reality of today.

Marriage
Thankfully, the disability has made our marriage stronger. It has sharpened and focused what is important, what is real, and what is needed. We don’t have a lot of time to talk with each other, which is a disadvantage, but we try hard to make time for that. We try to carve out time for dates as much as possible, usually every two weeks. They are snatches of time.

Motherhood
This is not what I thought motherhood would be like. Wyatt changed our lives forever. It was a huge point in our lives. It was a huge point in time that I will always refer back to because our lives became so different from that moment on. It is a dramatic change in your thinking, your responses, and the way you act as a family. Wyatt currently has some medical issues that are getting worse. He may not be with us forever. And even though we may lose him in the future, our lives are forever different whether he is with us or not. I certainly would never look at another person with disabilities in the same way. It could never be the same.

Some people probably believe I am too protective of Wyatt, too focused on him and his needs. But I feel like I have to protect him. His safety is my job to ensure wherever he is. I was definitely not this overprotective of the older three; however, Wyatt’s safety involves breathing. It is life and death with him. Can he breathe? Is the person caring for him knowledgeable about his breathing issues?

I feel like so many things in my life are completely out of my control. That’s why I enjoy volunteering at Wyatt’s school library. I can reshelf books and put things back in order. Then, I can see the difference after I am done. I feel in control.

Future
We would like to have the older kids go to college if we can afford it. But our plans are to have Wyatt with us until we die. I have seen what’s out there and there is no way anybody else can care for him like we can.
Looking to the future, I see him living out his life with us. We will never be empty nesters.
It makes me sad at times.
I don’t really let myself think about what will happen when we are gone.
In my mind, what I hope will happen is that my other kids will want to commit to caring for him if we can’t.
I could see his siblings taking some kind of supervisory role over his care, if not actually doing it themselves.
I don’t worry about burdening them because in my book, that’s what our family does for each other.
That’s what we do.
I am hoping they will feel that way down the road. We need to be talking about it more.

Advice
Throw out the non-important stuff. Focus on what’s important.
Be a family. Take care of each other.
Do things together as a family. Don’t sit at home.
Find your support group . . . wherever this may be.

Georgia

Georgia is a married, 42-year-old mother of two children. This full-time benefits administrator is raising Phoebe, age 8, and Mason, age 6, with her husband. Mason was diagnosed with cerebral palsy shortly after birth. Here, in her own words, is Georgia’s story:

Diagnosis
Mason had oxygen loss at birth.
He was resuscitated twice. An MRI showed a hole in his brain.
He couldn’t eat after birth and got a feeding tube at 3 months.
We knew brain damage was a possibility, but I refused to believe it. Total denial.
I felt devastation and such anger at the nurse and doctor that made the mistake during his birth.
They weren’t watching the monitors as Mason’s heartbeat plummeted.
It should never have happened.
We took them to court but lost the case.

Motherhood
I love Mason so much, but I hate his disease.
Sometimes, I feel so guilty thinking that because at the end of the day, it isn’t me that’s stuck with the disability . . . it’s Mason.
He has more spirit and character than I do. That was true from day one.
He’s our brave little soldier.
I am generally a positive person, but when it comes to all of this disability crap, I hate it.
Mason got robbed.
I would much rather be tripping over legos and fire trucks than wheelchair parts and assistive communication devices.
I am so grateful that Phoebe was delivered by a doctor who was paying attention.
I pray she stays healthy.

I am glad Mason was the youngest because I would have been terrified to have another child after Mason.
Phoebe and Mason had identical labors, but her doctor noticed a dropping heartbeat.
We wanted a third, but I was in no place to think about another child after Mason.
At times, I regret not having a third because I worry about Phoebe having to care for Mason by herself in the future.

A lot of people admire me. They wonder, how do you do it?
I plug along just like everyone else. I’m no hero . . . just a tired mom.
Nobody would ever want to trade places with me.
I don’t care what others think. I just worry about Phoebe.
Is she doing okay? Is she embarrassed? Is she struggling?

**Family Life**
Phoebe loves her brother, but isn’t very patient with him. I don’t know if that’s age or the disability.
She is angry that Mason is not a playmate.
My dream for my kids was to be best friends and playmates . . . just as I am with my siblings.
This is one of the biggest hurdles to clear . . . my kids can’t really play together like I had dreamed.
I dreamed of taking my kids to the beach to play in the sand. I dreamed of hiking and biking as a family.
Just being an active family.
I also swore that the TV would not be on in the house to any degree. Now we buy tons of videos.
However, when one child has CP and is a quadriplegic, non-verbal, can’t eat, and hates restaurants, traveling is hard.
And as a result, TV becomes a major source of entertainment.
I am so sick of the TV set being on in our house.
I wish we had more family fun. I feel like our life got stripped by the CP.
We either leave Mason at home with a sitter, which is hard, or we bring him, which can also be difficult.
This is not the life I had dreamed of.

I feel guilty that we don’t involve Phoebe in many family activities.
We all miss out on outdoor things, such as sledding and skating.
I try to spend a lot of mom-daughter time with her. Mason stays with the sitter or with Eric.
I also spend mom-son time with Mason by going to the mall or the grocery, which he loves.
It’s hard to shop with his wheelchair, but we manage.

Last night, we had some family time.
I made a nice dinner, put on music, and we danced and read.
Phoebe asked to dance with Mason on her back.
She carried him around in circles in the family room. He smiled from ear to ear.
This warmed our hearts because she typically doesn’t play with Mason.
She was so proud that she was strong enough to carry around her brother.
Mason loved having his sister’s attention. Eric and I were touched.
These seemingly small moments are powerful and beautiful. Watching them play together was so great.
This is what I imagined . . . having kids who are playmates and best friends.
Having Phoebe be proud of her brother is wonderful. And seeing his happiness and adoration for her is priceless.

Our family life varies day by day.
Some days, Phoebe is Mason’s protector. Other days, she’s embarrassed by him.
I tell her that the disability is not his fault, and we need to be compassionate.
We need to just love him and accept him the way he is.
This is hard for her.
Other kids stare at him because he makes noises in quiet places, like church.
She gets embarrassed, so sometimes we split up or get a sitter for Mason.
We hardly go out to eat because he hates restaurants. He can’t eat and the stimulation can be overwhelming.

I’m so thankful for Phoebe.
Eric and Phoebe are very close. He gets to be a dad to someone who can respond to him in a typical way.
We would have felt robbed without having typical experiences, such as school plays, concerts, and sports.
Phoebe got robbed by not having a real playmate.
Mason got robbed by not being able to be a playmate.

We got a special invitation to trick-or-treat at Invesco Field because the parent of one of Mason’s classmates works for the Denver Broncos.
This is one of the small perks of having a kid with special needs.
Like getting to the front of the line at Disney World.
Sure, it’s nice, but I would prefer to wait in a long line and not have Mason saddled with his challenges.
Although challenges considered, some days I feel grateful that he is as “healthy” as he is when I see what others must deal with.

**Transformation**
I am more patient, compassionate and understanding.
Part of me is more realistic. I was always saying things like, “It will all work out.”
But now I know it doesn’t always work out. Anything can happen.
I panic at what else might happen.
I am overprotective of my healthy child. I need to keep her safe and healthy.

I also find myself feeling jealous. I’m not jealous of others’ accomplishments or maternal things.
Rather, I’m jealous when I see a family with healthy kids. How is that fair?
Especially big families with all healthy kids. And I just have two.

**Marriage**
It’s been hard on our marriage, but we both recognize that we can’t do this by ourselves.
The disability took us from “this is really fun” to “we have a job to do.”
We never get a break. It takes both of us to keep our head above water.
I pray nothing happens to Eric.
I can hardly keep it together. How do single parents do it?
Eric is very supportive. This is so important.

**Public Life**
I can feel people stare while we are out in public.
At church, I see pity on people’s faces.
I am sure they are saying a prayer for Mason, specifically for healing, while they are on their knees praying.
I can’t help but think that many people do this.

Sometimes, when we are out in public, people approach us.
Recently a man who used to work for Colorado Cerebral Palsy offered us information on sports camps for Mason.
Another man with some type of disability, maybe CP, talked to Mason and shook his hand.
An older couple at a restaurant told us about their son, who had his hips dislocated by the doctor who delivered him at birth.
Everyone has a story.

It’s hard for Mason because he can’t play like other kids. Parks and playgrounds don’t accommodate him.
I worry about the social piece for Mason. I feel bad that he doesn’t have friends.
He has been invited to play dates, but most people don’t have wheelchair accessible homes.
He can’t be on a sports team. He doesn’t get many birthday party invitations.

**Future**
I don’t think about the future. It’s too overwhelming because I don’t know what it will look like.  
I just get through today. I will deal with tomorrow when tomorrow comes.  
Some moms spend a lot of time dreaming about college, marriage, and grandkids.  
I don’t.  
I am hopeful for medical advancements for brain conditions.

**Advice**
If you are not prepared to have a child with special needs, you should think hard about having kids.  
You can’t be selfish . . . especially with a child with special needs.  
You should reach out to other parents raising kids with special needs.  
My son’s preschool saved me. It allowed me to retain some sort of normal life for myself.  

Faith is so important. I would be sunk without it.  
There are no answers to why this kind of thing happens, so you have to be okay with it.  
Faith helps you accept.  
You don’t have to understand.  
Faith will help you get through it.

**Jessica**

Jessica, age 32, is a full-time production manager for a busy print company. An unmarried mother of two, Jessica lives with the father of her children. She is raising Grace, age 8, diagnosed with both epilepsy and severe autism, and Max, age 7. Here, in her own words, is Jessica’s story:

**Diagnosis**
Shortly after her first birthday, Grace began having seizures.  
She was diagnosed with epilepsy and given barbiturates to control the seizures.  
I was 9 months pregnant with her brother at the time.  
Her development began to decline. Her few words faded away.  
A year and a half later, she was diagnosed with severe autism.  
Life has never been the same.  
I am still waiting to hear her say, “Mama.”

When we got the diagnosis, I had never heard about autism. I had no idea what it was.  
I felt devastated for Grace. I wanted so much to be the one suffering.  
I started attending autism functions to learn more. I met other parents and kids.
And then it really hit me, and I went into denial. It has taken me about 5 years to fully come to terms with her diagnosis. I am trying to accept it and be more proactive, instead of reactive. I am trying to be a good advocate for her and give her a voice, since she has no communication. I always wish I could take away her afflictions, but at the same time, it’s what makes Grace who she is.

**Family Life**
Raising Grace and Max is very difficult. It’s exhausting and stressful. I feel racked with guilt, pressure, and sadness. There’s also an overwhelming lack of confidence as a mom. There’s a constant need to switch mentalities.

Max gets jealous because he takes a back seat to his sister. He knows he has to, and that’s so sad. I have drowned myself in the world of autism and Grace’s needs. I feel like this makes it difficult to get close to Max or relate to him. Grace takes so much time and energy, and he gets what’s left over. And by then, I have nothing left.

We may have just arrived somewhere, like Chuck E. Cheese, but if Grace can’t handle it, we leave immediately. Max has been raised to accept it. He understands the need to be second to his sister and her issues. I know he wishes that we could stay, but he never pushes because he knows it is what it is. But I feel constant guilt. Max makes so many sacrifices for Grace. He is having behavior problems, and I worry it’s because of all of this. I wish more than anything that I could give him normalcy, but it’s impossible. There are so many sacrifices. I save all of my days off from work to attend Grace’s IEP meetings and therapies. So when it comes to Max’s fieldtrips and games, I can’t be there. He misses out on a lot. And we are on a single income, so I work constantly. I wish things could be different. It breaks my heart that he is missing out on a “normal childhood.” I feel like he’s the lucky one to be typical.

We talk about why things have to be this way, and he says he understands. He tries to be strong and independent. I think he says a lot just to appease me. So I don’t worry or get my feelings hurt. This makes me feel worse because I worry that he is putting on a happy front and burying his pain. He sees the school psychologist. He has a lot on his plate.
He runs around like a happy kid, like nothing bothers him, but he lives in his own little world. And he tries to interact with his sister, but she is very aggressive towards him. She pinches, bites, and scratches. It’s hard to know what will set her off. She constantly picks on him, but he is not allowed to fight back because she doesn’t understand her actions.

Through it all, Max never says that he doesn’t want to go somewhere with his sister. In fact, he wants her to go. He loves it when our family is all together. He likes the foursome unit. He is a very caring soul to his sister. He is a big helper. He’s my second hand because she needs constant supervision. I am very thankful for this.

**Motherhood**
I never wanted kids. In fact, when I found out I was pregnant with Grace, I was close to not keeping her. I thought about an abortion. But decided to keep her. I was trying to make everything right because of the expectations of what it is supposed to be like. So we got the house, the dog, and the car. I even got engaged. But then it stopped from there. We were planning to get married when Grace was a baby, but the stress of everything postponed our plans. And the extreme stress of our lives has continued to postpone everything. We just blew everything off.

And then I had another child because I was an only child and didn’t like it. When Max was born, I was dealing with all of Grace’s epilepsy issues. My mom watched him a lot. I worry that he missed out on my nurturing. I think he had to forgo the intimate mothering and babying connection because of his sister’s needs. He has been forced to grow up quickly. I sometimes wonder if that affects his behavior now. Does he act out to get attention?

I had no direction before Grace. I partied a lot and was selfish. But Grace more or less gave me purpose. She has helped me buckle down and stop being naïve. Her disability has helped me become a woman. If she didn’t have this, I would probably be more of a friend than a mom. It has forced the issue of motherhood and strength. It’s a hard thing, but also a good thing. There is no textbook on how to raise special needs kids with typical kids.
So I have had to gain confidence, find a voice, and become independent to help my kids. This has helped give me direction and settle the dust around me.

I feel emotionally and mentally exhausted. There’s a loss of self. I would say there’s not a lot of sincere happiness. My kids give me joy, but I still feel like I am missing something. I wish I could have more things for just me. Like one day a week at the gym. Or pick up a fun hobby. Something to feed my soul. Less working, more fun time. Maybe a life coach or someone unbiased to talk to.

I feel alone. Isolated. It is so nice to meet someone who understands, even just a little. Like other moms in my situation. It could be another mom raising a kid with a completely different disability, but there’s a connection there. She gets it and that goes a long way.

I envy the moms who can do all of the normal, bonding family stuff. There is no way we can do those things. So I have to rewire my motherhood to fit our needs. Our society is not accepting, and this makes my job much tougher. A mother can’t be a good mother unless she learns the ability to hang all of those issues out on the tree before engaging with her kids. Adapt and overcome.

I still have a lot to learn. There are times when I feel like a disappointment because Max has his issues. Because I can’t do the million and one things I need to do for Grace. Because I don’t get the quality bonding time I need with my son. Because I can’t get it all done.

**Transformation**
I have learned pure emotions through Grace. Deep sadness and true joy. I have learned unconditional love from both kids. It really doesn’t matter what other people think.

My kids have made me a better person. Period. They gave me life.

I now have confidence. I can advocate. It has opened my eyes instead of always keeping my head in the sand. I now listen to the world around me. I am able to sympathize and empathize more. And I place a lot more value on family and support. I understand what others go through.
Grace has basically brought us together and torn us apart.
The disability is so hard. The amount of pressure and stress is overwhelming.
The disability has changed the way we have to raise my son.
We are trying to do the best we can for him, but I don’t feel like I am doing it right.
You can’t give him 100 percent unless you are with him by yourself because Grace takes so much.
But when he gets your 100 percent, it is obvious that he so enjoys it.
But it’s so few and far between.

**Public Life**
I can never have normal parent experiences.
I don’t get to sit and chitchat with other parents.
I feel like people don’t even know how to relate to me because our worlds are so different.
A lot of times I feel like people shy away from asking anything about Grace because nobody knows what to say.
And nobody wants to be rude, which is totally understandable.
But I guess I’d feel better if people did ask because then maybe they wouldn’t stare.
I don’t even look at people’s faces anymore. I try not to think about it. I’m closed off.

I don’t keep in touch with that many friends from childhood because it’s just so hard.
Those friendships have been reduced to random emails and phone calls.
They have no idea. But at the same time, I don’t know what it is like to raise two typical kids.
Even my family can’t fully grasp my daily struggles.
I wish I had the problems that they seem to have. But you can’t fault them for not knowing.
If I open up to them even a little bit, maybe it will raise some awareness and help them to understand.

When I take Max to his soccer games, Grace wants to be in the car. She needs the enclosure, the safety.
I have to keep one eye on her, so I can’t really watch the game.
All of the parents are sitting on the sidelines, watching their kids on the field. And the car is parked far away.
I am standing in the middle, so I can watch the car while I am trying to see the game. It’s impossible.

When we used to go out in public, I would get flustered easily.
If Grace had a meltdown in a store, I’d notice lots of people staring. They would say rude things.
I would go out to the car and just cry.
We would try to be normal, but the reality was that we couldn’t be normal.
I had to learn to suck it up and put blinders on.  
It has taken a long time to be okay with everything.

**Future**
I try not to think about the future because it is so overwhelming.  
Grace’s issues are so day to day.  
What happens when she hits puberty?  Do I get her a hysterectomy because she doesn’t understand things?  
This scares the crap out of me.  
I know I will never put her in a home.  I know that for sure.  
But other than that, I just don’t know.  
For my son, I hope he has everything.  
We don’t have the money to save for college, but when we do, it will ultimately be for Max.  
I accept the fact that Grace won’t be going to college.  
That’s the way it is.  
Unless she has some miraculous recovery.

**Advice**
I feel like there are two types of people, optimists and pessimists.  
There’s no room for pessimism.  You must be constantly optimistic.  
Denial is natural, but optimism and hope are key.  
I choose to be positive.  I try to view obstacles as learning experiences.  
Always retain hope.  
Don’t be afraid to cry.  
Be selfish when you can.  
Remember you were chosen to receive this gift.  
Seek out support groups so you don’t feel so alone.  Online support groups can be therapeutic.  
No matter what you have going on, there’s always someone else who is going through something more difficult.  
Don’t give yourself unachievable realities.  Do not set the bar so high that you’re just setting yourself up to fail.  
Be accepting of your mothering capabilities and the mother that you are trying to be.  
Accept that you are doing your best.  
Acknowledge yourself and your feelings.  Believe that it will be okay.  
When I feel like I have nothing left, I fill my head with positive sayings.  
“Adapt and overcome.”  
“Dig down deep and find it.”  
“God doesn’t give you more than you can handle.”  
“I was chosen for her.”  
I pride myself in my ability to pick myself up and dust myself off.  
You have to be selfless, so suck it up.  Reach in and pull it out from somewhere deep down.
There’s no time for self pity.
Do the best you can. Know there is so much love in the end.

Jill

Jill, age 43 and married, is a former project manager for a financial services company. She has traded life in the corporate world to be a stay-at-home mother to Sarah, age 4, and Toby, age 3. Sarah’s diagnosis is partial trisomy 21 (Down syndrome) and partial trisomy 10. Sarah is missing the “critical region” for Down syndrome, so she does not present with the classic features associated with Down syndrome. She has global delays, is fed through a G-tube, and is nonverbal. Here, in her own words, is Jill’s story:

Diagnosis
When Sarah was born, it was the happiest time in our lives. Gary and I had waited 14 years to have children, and our baby was finally here. My first memory of Sarah was at 10 minutes old when she stuck her tongue out at me. I thought she had such spunk.
Little did I know that tongue protrusion is a physical characteristic of Down syndrome. The first nine weeks at home with Sarah were glorious. She was so precious and sweet. I wondered why I had waited so long to have her.
What was I scared of? Sarah was absolutely perfect.

I never had an amniocentesis with Sarah.
None of her tests showed any markers for chromosomal abnormalities, and we feared causing a miscarriage.
We had an amnio appointment, but we changed our minds at the last minute and cancelled it.
I want to believe that divine intervention was at work.

Shortly after her birth, Sarah stopped gaining weight and was diagnosed with failure to thrive.
Her pediatric gastrointestinal specialist ordered a host of tests to “rule out the bad stuff.”
On her nine week birthday, I got a call from her doctor.
The tests revealed she had trisomy 21, or Down syndrome.
Stunned doesn’t begin to describe how I felt.
Sarah was napping in her crib, and Gary was still at work.
When he came home, I had to find the words to tell him that his beloved daughter had Down syndrome.
We held each other.
My worst nightmare was coming true. We had a baby with special needs.
I didn’t stop crying for weeks. I couldn’t get out of bed.
I woke up each morning and relived my nightmare over and over again.
At the time, all I could think about was that I couldn’t handle this.
I wanted a diagnosis of cancer or a heart defect, something that could be treated. I did not want a mentally disabled child. When Sarah was first born, I remember thinking how Sarah’s full name would look on a business card. But after finding out about her diagnosis, I realized that grocery store bagging personnel don’t have business cards.

Because Sarah didn’t present with typical facial features of Down syndrome, we took her to a pediatric geneticist when she was 5 months old. We hoped she had a mild case of Down syndrome. Instead, tests revealed she had didn’t have classic Down syndrome, but rather a rare chromosomal disorder. Her extra 21st chromosome was missing the critical region for Down syndrome. In its place was a small section of chromosome 10. Because Sarah is the first documented case of this disorder, doctors couldn’t advise us on what to expect.

I loved Sarah, but a part of me didn’t want her if she were not perfect. I could not look at her without imaging her potential . . . if not for the extra 21st chromosome that was present in every single cell in her body. Looking at her, I saw my failures. My body had betrayed me. I failed at reproduction, a basic human function. How could this have happened to us? I felt like I had disappointed everyone . . . my husband, family, friends, and most of all, Sarah. I sank into a depression and began fantasizing about escape routes. Giving her up for adoption, leaving my family and starting a new life, and even suicide.

I became a hermit following this news and only left the house for Sarah’s doctor appointments and dog walks. Slowly, I came out of my depression. I told myself to be grateful for my daughter and stop obsessing over who she is not. I needed to celebrate who she is and be thankful for every accomplishment. I had to concentrate on living and enjoying the present moments with her instead of worrying about the future. I began to pray for strength and courage, not for escapes. I also realized that while I do love my dear sweet daughter, accepting her disability will be a lifelong journey.

**Motherhood**
My biggest mistake in life was waiting so long to have children. I blame myself for Sarah’s disability. After we got married 18 years ago, we planned to start a family after five years of marriage.
But after five years, I still was not ready.
I was scared I wouldn’t be a good mother. I was afraid of the sacrifices required by motherhood.
I did not want to give up my personal goals. I actually feared having a child with disabilities.
And then it turned out that I was a carrier for Sarah’s translocation.
The guilt was overwhelming.

Coping is a day-to-day exercise.
Accepting Sarah for who she is—and not wishing she were a typical version of herself—is a daily struggle.
Seeing pregnant women is still difficult for me, even after 4 years.
I see cute little baby girls and it crushes me with painful thoughts of what Sarah could have been.

While it is getting better as she develops, the old feelings of sadness rear their ugly heads at unexpected times.
My emotions vacillate constantly. I’m proud of Sarah, embarrassed by her, love her more than life, and wish she were never born.
It’s emotionally exhausting, which often translates to physical exhaustion.
At times I feel like a strong advocate and loving mom. Other times I feel like an unstable failure of a woman.
I resent the extra time and energy that everything takes with Sarah.
When I spend time with the local Down syndrome support group, I feel like a fraud.
Most are pro Down syndrome and are against terminating.
I would feel horrible if they knew that sometimes, I wish I had an amnio to detect Sarah’s disability.
Just to have had the choice to terminate.
Some days, I believe I would have terminated because our lives would be better.
Some days, it is a struggle to take care of her.

I feel so guilty if I don’t complete all of her therapy homework prescribed by her therapists. Her to-do list is 4 pages long.
I can’t just play with her and be a mom. I need to constantly “work” with her.
She always needs help, while Toby can easily play on his own.
I feel a great sense of responsibility in Sarah’s accomplishments. I link her failures to me.

Recently, I attended a ladies luncheon fundraiser. It was a rare chance to get away from my mom duties.
It gave me a glimpse of the life I could have had if Sarah were typical.
I sat at a table with a group of women who chatted about their kids’ success stories.
I felt crushed. Even when I am away from Sarah, all of the memories are with me, haunting me.
It was my afternoon away.

I used to equate being a good mother to whether your child was successful. Now, I see the role of mother to look at a child and see what he or she needs to grow and become the best they can be, regardless of society’s view of success.

In 2007, I received a diagnosis of breast cancer. It would have been devastating had I not lived through Sarah’s diagnosis. Yes, it was scary, but it was treatable and curable. The breast cancer was a good thing for me because it put Sarah’s diagnosis in perspective for me. I was alive, she was alive. Not perfect, but she was alive.

**Family Life**
Gary and I had planned on having only one child. But almost immediately after we discovered Sarah’s diagnosis, I dreamed of having a typical child. I yearned to return to the beautiful moments that I experienced before we knew about the Down syndrome. I wanted to be back in the “healthy baby mommy’s club” because I didn’t get to be there with Sarah. Instead, Sarah was a misfit toy on the island of the misfits.

Because of my advanced maternal age and being a carrier of Sarah’s translocation, we were given no chance of having a healthy genetic child. I wanted to try, so we did, and Toby was conceived with fertility drugs. It was a very stressful pregnancy. I only knew disability and was scared to death, but I desperately wanted to have another child.

Before Toby, I didn’t really know what typical development looked like. Having a typical child in the house can be difficult at times because we compare Sarah’s development to Toby’s. I see everything that Sarah is not doing. Sarah’s disability makes me appreciate nearly every interaction with Toby . . . even the most challenging ones. I think I would have enjoyed Toby’s babyhood a lot more if he were the oldest. But I knew too much about childhood development and all of the things that can go wrong.

I think that some parents who have only typical kids take their relationships with their children for granted. Toby and I have wonderful conversations, and I cherish that time with him. I don’t think I would appreciate these the same way if not for my experiences with Sarah.
The other day, I was strapping him into his car seat. I gave him a kiss on the forehead and he said, “Mommy, thank you for taking care of me.” I was blown away. Toby validates me as a mom and makes me feel like I can do something right.

We spend a lot of time doing things for Sarah. Right now, we do a good job including Toby in all of her appointments, but we need to be sure to keep things balanced. I never want him to feel like we spend more time with Sarah. I also worry about how he will feel having a sister with disabilities down the road. Will he resent the extra attention that she demands? Will he be embarrassed by her? Will he resort to drugs and alcohol to cope? I hope that he will take our lead on accepting Sarah. We are not going to have a third child, so he will need to deal with things on his own. I know we will have some tough times ahead. We will need to help him feel confident in himself and help him be supportive of his sister. I hope he will become more compassionate and caring of people.

Toby provides an excellent model and play companion for his sister. They love each other. It warms my heart to see them enjoy each other. I think our lives would be very sad if we only had Sarah.

Transformation
Before Sarah, I didn’t even know there were medical devices, such as G-tubes. It has been a huge eye opener for me. I believe I’m a more compassionate person. Little annoyances used to upset me. I wasted so much energy worrying about stuff that didn’t really matter. But the life-changing experience of having a child with special needs puts things in perspective. I no longer critically judge other people or their actions because I don’t have any idea of their life experiences. I am more caring toward people with disabilities and parents of people with disabilities. I didn’t know anyone with a disability before Sarah, but now I have a connection with them.

I would like to find a purpose. I’d like to help people with disabilities and their parents. I want to make something good come out of our tragedy. Having the perfect house and the perfect life is no longer important. My priorities have changed.

Marriage
When we first found out about Sarah, I fell apart and fantasized about running away.
This put a big strain on our marriage. But Gary is a dear person and stuck by me. Because of Sarah’s medical needs, we haven’t been able to get away overnight since her birth.
Gary and I used to take great vacations. I miss those.

In the long run, the disability has brought us closer
We have a bond because of the caretaking and advocacy for our daughter and her needs. We are stronger because of Sarah, but there’s a certain sadness in our relationship that I don’t think will ever go away.
It is hard for me to look at our wedding pictures or pictures from happy times before Sarah.
It’s like we had so much potential for a great life and look what happened.
I screwed up by not having kids earlier.
I strongly believe that our friendship got us through Sarah’s diagnosis.

Sometimes, I resent Gary because he’s the one who really pushed for us to have a family. And here I am, experiencing the most significant life changes due to Sarah.

**Public Life**
Going out in public can be difficult.
So many people ask if Sarah and Toby are twins.
Tube feeding her in public makes me very uncomfortable. Her inability to talk is obvious.
We might pass as “normal” at first glance, but as soon as we pull out her feeding supplies, the jig is up.
I used to feel the need to explain everything, but not anymore.
I need to be proud of her and expose her to everything that another child her age would be doing.

I try hard not to care what others think. Sometimes, I am strong. Other times, not so much.
Recently, Toby had an end-of-the-session potluck for his French class.
Sarah’s preschool was closed, so I brought her to the lunch.
It was noon, so I pulled out all of her G-tube stuff and some of the kids began to stare.
I began to feel very self-conscious and immediately wondered why I thought this was a good idea.
I just wanted to run.
My “typical mom” cover was blown. I was no longer a member of the “healthy kid” mom club.
I had so enjoyed taking Toby to class alone, being a normal mom, but now everyone knew about Sarah.

I do feel like I need to continue taking Sarah out in public.
We are out there being an ambassador for people with disabilities. Sarah has every right to be there. Maybe it will minimize the scariness of difference.

When I look at other moms who don’t have a child with special needs, I feel jealous. I feel sorry for myself and wish I had it easier. I carry a majority of the responsibility for Sarah’s care. Our days are filled with doctor appointments, therapies, and to-do lists from her therapists. It’s a lot. Sometimes, I feel that we don’t have time to just be a family. When I hear other moms complain about their child’s poor eating habits, I think ha! At least your kid eats.

Having Sarah has made me realize how distanced the general population is from people with disabilities. People with typical kids don’t have to educate society about differences. That seems to be our job. Perhaps if I did not have Sarah, I would also feel uncomfortable around disability. I hate the fact that Sarah will be discriminated against. She’s invisible to society. It’s so sad.

**Future**
I am fearful of the future. What if Sarah never talks or is never potty trained? Will I be taking care of her for the rest of my life? Will I ever get to travel again or pursue my own interests? Will my life be a constant battle for her rights and getting her the services she needs?

I suspect that taking care of Sarah will only get harder. She will get bigger and more independent. What happens when she reaches puberty? I also worry about the statistics on sexual abuse of people with disabilities. It scares the hell out of me.

**Advice**
Friends who have kids with disabilities are a great source of support for me. Yoga, meditation, exercise, alone time, and time with friends help keep things in perspective. I also see a psychiatrist. Make time for yourself. Mothering is not about molding your children into perfect human beings. Instead, look at your children and give them what they need to grow to be the best they can be. Try not to worry about the future.
Plan for the future, but focus on what you need to do today and six months ahead.

Kate

Kate is a 50-year-old, married mother to Dean, age 20, and 17-year-old twins, Henry and Nathan. Born at 28 weeks, Henry and Nathan are diagnosed with cerebral palsy due to prematurity. Henry’s only voluntary movement is hitting a switch with his head. He doesn’t speak, doesn’t use his hands, and doesn’t have head control. He has titanium rods from his neck to his hips. Nathan doesn’t stand or walk, but he can talk. Dean currently attends college in a neighboring state. Here, in her own words, is Kate’s story:

Diagnosis
At birth, Nathan weighed 1 pound, 14 ounces. Henry was 2 pounds, 15 ounces. Henry was discharged from the neonatal intensive care nursery at 52 days, and Nathan was discharged at 82 days on oxygen. They sent us home and told us the boys were “just like full-term babies.” This set us up for failure. Completely and totally. Henry cried 22 out of 24 hours. Nathan was on oxygen, aspirating, and basically trying to die. Both boys were on monitors. Henry screamed continuously and Nathan didn’t breathe continuously. And Dean was a typical 3-year-old in the middle of everything. I was sleeping one to two hours a night, completely sleep deprived. And then I collapsed from exhaustion.

Family Life
After my collapse, a friend told me that if my family was going to go downhill, I needed to save Dean. That gave me permission to have alone time with him. We both needed this. When Dean was 6, my parents took me, my husband, and Dean to Disney World. And we had a fabulous “typical family” experience. I always tried to be very involved in Dean’s school and make things as normal as possible for him. Once when he was a teenager, I asked Dean why he didn’t do drugs like some other kids. He said, “Mom, I know firsthand what brain damage looks like.”

We used to take him to a child psychologist. He learned a lot about feelings and verbalizing them. He became good at problem solving. We developed the phrase, “Nike, just do it,” for Dean. That meant when I would frantically ask Dean to get me a diaper, I’d say “Nike.” He knew he could either do it the easy way or the hard way.
The easy way was to get the diaper and go away. The hard way was to refuse and get screamed at for the next three hours.

It has always been so important for Dean to have his own normal life experiences. Recently, Nathan was in the hospital. Dean and his girlfriend came to visit. As they were leaving, I asked him why his visit had been so short. He looked at me and said, “Mom, I am not the parent here. I get to leave.” He was right. And it made me happy. Very happy.

We have always taken the approach that we can do what everybody else does, it just looks very different. I constantly have to adjust my definition of success.

Transformation
I think I’m a better person. I now work in public policy because of the twins. I am able to do things I have always wanted to do, but in a way that I never dreamed about. I can make connections for people that are life changing. Getting a family on Medicaid changes their financial status forever. I get to work with phenomenal, brilliant, and incredibly kind people that I never would have met. I have much more compassion and empathy.

I was raised to believe that there’s only one way to live your life. It’s not so much keeping up with the Joneses, but rather that you have a vision of the way your life will be. And you make your plan, work your plan, and life is only good if your plan works out. However, this implies that you actually have control over everything, which you do not. Instead, I have learned that you need to make the best out of everything. Would it be nice if I had three typical kids? Hell yes! Do I wish they didn’t have to live in pain? Absolutely. And no more chronic surgeries? Absolutely. Would I change it at this point in time? I wouldn’t give my kids back for anything. In spite of the bad stuff, Henry and Nathan are who they are. Who’s to say they aren’t made in the image of God? Or who’s to say they aren’t perfect as they are? You can choose to look at the glass half full, or you can choose to look at it empty. And there’s no rational reason other than life is easier if you look at it half full.

Marriage
You must have a sense of self in order to do the “business of disability,” the “business of parenting” both twins and Dean, and maintaining your marriage. I can’t lose myself in my kids. My mother has always said it takes two whole people to come to a marriage and each gives 80 percent.
And so you have to have a sense of self to bring to the marriage.  
And there’s no time, which is probably the hardest thing on the marriage.  
Lack of time together makes things even harder.  
The wear and tear is so destructive.  
There’s also a lot of anger on my part.  
Over the years, there have been many hurtful words said back and forth that neither Greg nor I is proud of.  
I always figured this was okay because he wasn’t going to walk out on me and eventually would forgive me.  
But the bottom line is that I need more help with primary care.  
Greg didn’t learn how to G-tube the kids until they were 6 years old. For 4 years, 12 times a day, he was deliberately stupid, leaving it all to me.  
But that’s because in his world, Greg was keeping a roof over our heads, food on the table, Dean in private school, cars in the garage, and medical bills paid.  
He was trying to keep it all together.  
We may have gotten divorced, but I have always insisted that the one who walks out, gets the kids.  
So, we are still together.

**Motherhood**

Having kids with disabilities is a mixed blessing.  
I know things that I never would have known. I would have been blissfully ignorant.  
But knowledge is also power.  

I feel so sad for families who only have one child with disabilities.  
Not because of their life, but because they don’t get to experience a foot in each world.  
Dean learned to drive, so I got to experience that. And I don’t feel sad that Henry and Nathan won’t ever drive.  
They have no expectations, and I have no expectation.  
While some families brutally mourn that fact, I don’t feel sadness because of Dean.

I have come to the conclusion that it’s not the sex of the child, but the parent/child relationship.  
I wanted Dean to be a girl. I always thought I’d have girls. Instead, I have three boys.  
In many ways, I think we have been successful because Dean is a boy rather than a girl.  
I just couldn’t do the emotional needs of a girl at the same time I was doing the emotional needs of two kids with severe disabilities.  

I had very high ideals about motherhood.  
My own mother, who had a difficult life, wanted me to be a country club mom who played bridge and golf.  
I never knew that motherhood could be this much work.  
I remember only having Dean and thinking it was awful that some man didn’t hold the door open for me at Target.
I thought, doesn’t he know how hard my life is? I didn’t sleep last night with my newborn. How dare he?
Everybody thinks their life is the hardest.
What was I thinking?
What you learn with disability is that no matter where you are on the continuum, somebody is worse off and somebody is better.
And so your life is never the hardest.
It is a reality check. It makes you less greedy and much more grateful.
I used to think the early years were going to be the toughest, but actually, the older years are harder.
You just don’t know what you don’t know yet.

I feel like I have a second life.
While most parents have a “before kids” and “after kids” experience, it is quite different in the disability world.
There is no “after kids” experience.

It is as though I forgot who I was before the twins.
Their entry was such a shocking and traumatic experience.
Delivering the babies so early, life in the NICU, learning about medical care, IEPs, and ADA.
But I had a life before. I used to work in sales and marketing for 10 years before the twins.
It has been a long process reconciling who I was before the twins, and who I have become because of them.

Public Life
The older you get, the more isolated you feel.
Parents of kids with severe disabilities will always be parents of newborns and toddlers, so to speak.
But being a parent of an adult child, by definition, changes how you advocate and how you respond.
You are more aware of the boundary between yourself and your child.
Even though on a daily basis, it doesn’t look a whole lot different.

Our quality of life is good as long as our house of cards doesn’t fall. And a house of cards by definition is just so fragile.
We are always on the edge of losing Henry and Nathan’s health, my health, and Greg’s health.
And we are on the edge of financial devastation.
While I think we have a good life, the threat to our sustainable life is ongoing and increasing.
This can be a hard way to live.
Future
Dean attends college, but Henry and Nathan don’t have the cognition for college. And they are medically fragile.
I would like for them to have a college experience, but it will probably entail visiting their brother in his dorm.
I don’t have a very good view of the future.
Medicaid funding is being cut quickly.
Society does not value individuals with disabilities.
I am angry, and under that anger is fear.

Advice
Know what you can handle.
I had to stop going to the twins club when I could no longer hear how hard it is to raise healthy twins.
In order to raise a family, handle the business of disability, and maintain a marriage, you must have a sense of self.
You can’t lose yourself in your kids.

Kelsey
Kelsey is a 47-year-old, married mother of Jessica, age 18; Beth, age 15; and Dillon, age 11; who has a rare genetic syndrome that remains undiagnosed. She works part time at child advocacy organization. Here, in her own words, is Kelsey’s story:

Diagnosis
As soon as Dillon was born, we knew something was wrong.
He was immediately whisked away to the NIC unit.
We heard many different things from the neonatologists. They didn’t really know what was wrong.
Turns out he was blind, deaf, and had an underdeveloped brain.

After 5 weeks in the NICU, he went home on oxygen.
We were numb. We were in shock.
After all, I had an amnio with Dillon. And everything looked perfect.
This wasn’t supposed to happen.
I remember wishing his diagnosis had been Down syndrome.
I thought I could handle having a child with Down syndrome.
It’s funny to think about that now. That seems easy compared to what we got.

Dillon was born in August and was in the NICU when Jessica started first grade.
But I wanted her first day to be perfect. I wanted it to be as normal as possible for her.
I took her to school, trying to be happy and excited for her, and then went to the hospital for our reality check.
What do you tell people? They don’t know what to say or how to act.
I remember seeing families with three healthy kids on the playground and hating them. These were immature feelings . . . I know.

Having two other typical children made Dillon’s disability easier to handle. The girls were always a great support for me. They have given me physical and emotional support. They helped a great deal with Dillon and forced me to stay in the typical world. That way, I can’t focus only on the disability. At the same time, it has always been difficult balancing both worlds. There is only so much time in the day for everybody. For the first 7 years, about 95 percent of my time has been focused on Dillon and his health issues. But things have become easier over time.

**Motherhood**
I used to think that you just followed the plan. Get married, have kids, and take them to sports activities. I never thought about things too much. I had the traditional mommy time with my girls. And then Dillon came along. I learned that you can’t plan on things happening a certain way.

I am doing the best that I can as a mother. I have a lot of guilt that the girls didn’t get their perfect childhood. This guilt stems from my “mother” perception of the things a mom is supposed to do. But the girls never put this on me. It’s me. It also stems from watching my mom friends raising typical kids and all they do.

I am glad Dillon was the youngest because the girls have been such a help. I could go to the grocery store when they were old enough to watch Dillon. And my husband and I were seasoned parents by the time Dillon came along. I am also glad Dillon came last because it would have been difficult to think about having more kids.

The girls were neglected after Dillon’s birth. They were on their own. I basically breathe for Dillon. He depends on me for everything. Dillon’s health and well being is the most important thing to me. It colors how I look at everything in life. A huge layer of stress falls over our family when Dillon isn’t doing well. It creates angst and tension for all of us.

If I asked Beth and Jessica if they would want a life without their brother, I have no doubt they would be shocked at the thought. Hard as it is sometimes, I could never imagine my life without his.
I can recall the dark times when Dillon was younger and I wondered if it would be better if he didn’t survive. There were times when I wondered if both of us should just give in to the life forces that seemed too much to bear. However, I can’t imagine our family without him . . . just as I really can’t imagine him without his disabilities and challenges. They are as much a part of him as Jessica’s blond hair is a part of her. I don’t know how long Dillon will live. I can’t imagine him dying and how it would devastate us. I can’t imagine myself dying before him. But I do know that his sisters will be there for him, as much as we all are now. It’s just the way it is.

Sometimes, I just wonder how much longer I can do this . . . but I have to. Ever since Dillon was born, it has been the girls’ faith and acceptance that has kept me going. I keep it together for them. I felt such guilt when Dillon was born. I was unable to give them a healthy, “normal” brother. But they loved him exactly as he was. So then I worked hard to keep the family strong and as “normal” (I hate that word) as possible. I wonder what will happen when they leave for college. Will that motivation still be there to keep it all together when it’s just the three of us?

Marriage
The disability adds a layer of stress over everything in our lives. I snap quicker because of this stress. But I know that Larry and I can withstand anything. After we got through the first few years of crisis mode, things began to settle down a bit. However, all of our energy goes toward Dillon. Not us. We are very aware that we need to spend alone time together, so we try to do this. We employ caregivers to help, so the burden does not fall on the girls.

We have seen a marriage counselor. He once commented that Larry and I don’t communicate about mundane marriage issues that cause conflict. This is because our threshold is so high. And when Dillon is doing well, we don’t want to rock the boat and upset one another with “normal” problems. Until the next Dillon crisis, and then all of our issues leak. My husband is at the bottom of my list after the rest of the family. I just feel so sapped. I am constantly exhausted and stressed. Larry ends up at the bottom of the list.
Transformation
We are a closer, more resilient family thanks to Dillon. The entire family is richer because of our experiences with the disability community, as well as Dillon’s joys and sorrows. I believe that our quality of life is better because of Dillon. We take nothing for granted and try to live life well. He has given us a very deep capacity to love. He’s tested this so much.

Dillon has changed me for the better. He has given me a deeper meaning of motherhood. I no longer take anything for granted. I can’t. I don’t take things too seriously. I am not afraid of anything, not even death.

Life is hard, but I have learned to live day to day with Dillon. I just appreciate the good days. I need to remember that we will get through the bad days. Dillon has given meaning to my life and has given me a career as a parent educator. He has carved out my path.

I have learned to be assertive and aggressive on Dillon’s behalf. I never had to advocate for the girls. I no longer care what people think. I am so used to our situation. I no longer care about G-tubing him in public. Now it’s normal. We are what we are. There’s no way we could appear normal. So here it is, here we are.

But going out in public still causes me pause. There is always that initial hesitation . . . is this going to be awkward? My kid is in a wheelchair. Are you going to be uncomfortable, are you going to be patronizing, or will you be overly nice?

Family Life
We recently took a family portrait. This was very important to me because I have three beautiful children I am so proud of. And because they grow up so fast. Pictures bring order to chaos. If we take enough shots, we can get a few pictures where we all look “normal.”

And because I don’t want any regrets . . . if Dillon isn’t with us someday. I want these beautiful photos to hang on to. It has been ten years since Dillon was born. Ten years filled with lots of moments. For me, it has been like the blink of an eye. And part of me is really glad because it has been so hard.
But the other part is sad because I know these days filled with craziness and chaos and hard times and good times will end in another blink.

When I look around my oldest daughter’s room, I see a very happy childhood. I have no regrets. When my daughters were younger, it was so hard. I probably overcompensated. I didn’t want them to miss out. I remember wanting them to learn to swim and signing them up for swim lessons. I would rush them to the pool and then rush back out to the van and stay with Dillon. I’d turn up the CD player, trying to calm him because he was crying so hard. At a certain point, I realized that we didn’t have to do all the stuff that other families were rushing around doing. While swimming lessons were important to me, they were not important to them.

Now we have two of the most incredibly responsible teenage girls one could ever hope for. And they are usually happy to take care of their brother as long as they don’t have to change any messy diapers. People compliment me on my daughters and what a good job we have done. They think I’m kidding when I say it was parenting by neglect. I’m really not kidding. It’s that and luck.

When Dillon was born, and the girls were 3 and 6, I bought plastic cereal bowls and kept them on the counter, so they could reach them. I have never made them a lunch and they make dinner at least once a week. They have had a wonderful childhood because of Dillon and the resilience that he has taught all of us.

I don’t know what it would have been like without him . . . they’d have been very spoiled. I’d have been bored, not sure what to do with my life. Sure, I didn’t make it to school events. We had vacations filled with stress. The girls spent birthdays in their brother’s hospital room. They make their own meals and plan their own birthday parties. But they are confident, independent, secure in love, and don’t drink or smoke. They talk to me and are ready for the world. They are very aware of the world around them and their ability to make a difference. So parenting by neglect seems to have worked.

Beth was upset last week because her friends left her out of an activity. I told her not to worry because this kind of thing never happens to her, so she is due. She told me that it happens more than I know, but she chooses to never tell me about it. I think my girls don’t share that “stuff” with me because my plate is always so full with Dillon. Maybe that’s sad, maybe it has bred independence and reliance. It is what it is.
It’s like they have wanted to protect me from their normal growing up problems because Dillon’s needs have always been so immediate and demanding and draining.

A while back, all five of us tried to go to a museum together. On the way there, Beth warned Dillon not to have any fits and ruin it for the whole family. But he did just that, so I had to bring Dillon home. The others stayed and enjoyed the museum together. It would have been great if it had worked—but it didn’t. It made me sad that we couldn’t enjoy an outing as a “normal” family. I felt so defeated. I was almost mad at Dillon because he “ruined” the experience. Last year, we all went to a baseball game and made it to the end! It was a great victory for us. I don’t even like baseball, but I was thrilled we were all there. Sometimes, I think I just need to let go of the idea that it has to be the “five of us.”

**Future**

I try to live one day at a time, while also planning for the future. At times, I get very depressed about the future. I am not excited about the future. Dillon will live with us forever. Unless we can find another solution for him. There’s another family we know. Their son and Dillon are similar. Maybe we will be able to pool our resources so they can live together. Will Dillon even live that long? It is devastating to think about this. But it would also be easier because then I would not have to worry about his future.

I want the girls to plan their future regardless of Dillon. But they probably won’t do this. I am sure they will always be connected to him in some way. I just do not want them to feel burdened.

**Advice**

I am so glad I never saw into my future. Who knows what I would have done. I have learned as I have gone along. I have grown in the process. Women have an unlimited capacity to mother. We do things we never thought we could do. You will get through this. Believe it.

**Madeline**

Madeline is a 50-year-old, married, English teacher and mother of two. Her oldest daughter, Olivia, age 13, was diagnosed at four months with Osteogenesis imperfecta, a condition causing extremely fragile bones. OI is a congenital disease, frequently caused by a defect in the gene that produces type 1 collagen, an important
building block of bone. Madeline’s family also consists of her husband and typically developing 12-year-old daughter, Abby. Here, in her own words, is Madeline’s story:

Diagnosis
When Olivia was in the ER, they took x-rays. In addition to her broken femur, they found evidence of multiple fractures. We were completely floored. I cannot express how remote the idea of her having any kind of fracture was from our mind. How could a baby have a fracture? And how could they think we caused it?

After she was diagnosed, I felt like I was living in a nightmare. I didn’t wake up for a year. It was like I was in the dark, like it was always night, and I could not wake up. It was so traumatic. I had never experienced any kind of trauma or death in my family. This was the worst thing that had ever happened to me. It sounds selfish, I know, but it was.

Kent handled it so differently. He dealt with it immediately, and then he collapsed. But I collapsed first and then got strong and dealt. It drove him crazy that I constantly needed to talk about it. I was depressed, and he had a hard time handling that. He still doesn’t understand why I can’t be like him. But I do understand why he can’t be like me. When I fall apart, he gets worried that he, too, will fall apart. So he has to be strong for both of us. People cope in their own way, and you can’t control how they will go through it. I think he wishes I would just walk around and be a robot without emotions. It would be easier for him.

I decided I couldn’t talk to Kent, so I saw a genetic counselor. She helped me manage my feelings. If I had not seen her, I think it would have been much harder to turn the corner. I needed someone to listen to me . . . who wasn’t my husband.

I am really glad that I didn’t know about the OI when Olivia was born . . . except for the obvious pain she had to endure. I think it allowed me to form a relationship with her that was not based on anything being “wrong.” We got to know Olivia first, and then realized she had a big challenge.

Motherhood
I knew I really wanted to be a mother.
You picture yourself taking care of these little kids who can do everything. It never ever enters your mind that it might not be this way. I grew up in a family of four kids running around, and you just expect the same image. You can’t conceptualize the amount of self-sacrifice that it demands of you. It doesn’t even cross your mind. But I am grateful that I got to be a mother.

I am constantly amazed by Olivia. She seems to have an impressive level of acceptance. From time to time, she says that if she could wish for anything, she would like to walk. But she never dwells on it. It’s “this is how I am.” As different as her physical appearance is from other kids, it is important to her to be like other kids. For example, doing something as simple as wearing earrings makes her feel included. She seems to accept that she can’t play soccer, be on a swim team, or do gymnastics. I am surprised that it isn’t more important to her, but maybe she doesn’t know what she is missing. I know she wishes she could participate, but she doesn’t spend an inordinate amount of time dwelling.

When she was little, we used to dress her in dresses because it was easier when teachers took her to the bathroom. In the second grade, I finally said it is okay to wear long pants. She was so excited and said, “Oh mom! Now I can be just like everybody else.” I thought that I must be doing something right if she thinks the world is perfect because she gets to wear pants.

Recently, Olivia was invited to a birthday party. The party involved meeting at her friend’s house, driving to the local mall for dinner, going to a movie until 9 p.m., and then driving back to her friend’s house. Because Olivia is in a wheelchair and can’t independently transfer to the toilet, I had to help her. I couldn’t ask her friend’s parents to do this for her. So, I drove her to each “leg” of the event and took her to the bathroom at the movie theater. Having to be the one to drive her everywhere and take her to the bathroom is an obstacle to Olivia’s social life. It also eats up a lot of my time, which can be frustrating. But, on the other hand, I am thrilled that she has close friends who invite her places.

I feel so much guilt from not being able to provide a perfect world for my kids. Kent always reminds me that Olivia and Abby will not have the same childhood as me, but I always think that was the “right” one. That’s the way it was supposed to be. I always feel like as a mom, I should be doing more. I put this on myself . . . I know that.
I also feel guilt when it comes to all of Olivia’s exercises. She needs to do sit-to-stands, where she grasps her walker handles with both hands and goes from a sitting position on the couch to a standing position. She repeats these for gluteus and leg strength, while also trying to build standing endurance. She needs my help to do all of these exercises. It’s difficult because I am working full time, trying to keep up with housework, planning my lessons, grading papers, getting in my own exercising, and helping Olivia shower every night. It is so tough to fit everything into our schedule. The exercises are so important, I know, but they often require more energy than I can muster.

**Family Life**

Abby was born about 18 months after Olivia. I am so glad that we didn’t let the OI scare us off from having more children. Olivia’s doctors told us that we probably had only a 3 to 6 percent chance of having another child with OI because it was a spontaneous mutation. I’m really glad we had Abby because I think that it has helped Olivia to be more adjusted. Abby seems to normalize our family situation. Olivia doesn’t have a distorted view of the world where she’s in the limelight and everyone waits on her. They have the classical preteen relationship of two girls close in age that share the same room and have sibling rivalry. They hate each other and they love each other, and they have fun together and they fight. It’s pretty typical.

I don’t worry much about Abby feeling burdened because she enjoys helping people. She ends up helping Olivia a lot, and she’s more aware of others’ needs because of her sister. However, I do wish she had someone to run with and play outside with. Olivia can’t run around outside; she can just watch Abby play outside. It’s always a struggle to get Abby to be more physically active because she has grown up with a sister who is not active. Sometimes, Abby complains about having to do too much around the house, but I think it is good for her. We’ve always made a point to make Abby feel like she is not used, like she is not in this family only to be Olivia’s assistant. Like Dobby in the Harry Potter books. We joke about it and call her Dobby sometimes. The girls are good companions and they talk a lot. I just hope it helps Abby to have her sister instead of burdening her. Our family often revolves around Olivia’s needs, so Abby probably doesn’t get as much attention as we’d like.
But we do our best.

I already have a large amount of guilt, and it breaks my heart that Abby can’t do a lot of things. Kent isn’t very mobile either because of a bad leg, so we get tied down at home a lot. I wish she could go hiking and skiing, but we can’t do that stuff as a family. I try to capitalize on opportunities such as going on outings with Girl Scouts or with other families.

When Olivia was little, we would go to the YMCA a lot. I remember watching a parent holding a child’s hand and walking together. I would just start crying because I was never going to be able to do that with Olivia. I will never be able to hold hands and walk with my daughter. But when Abby came along, every single thing she did from standing to walking to climbing the stairs to running was amazing. I look at Abby’s back and think, wow, her back is straight, her spine is strong, and she can get out of bed on her own. It makes you appreciate everything and not take things for granted. You realize what an amazing miracle it is—when it actually works.

Transformation
I grew up afraid of handicapped people. They weren’t visible in society when I was young. I only remember gawking at them like zoo animals from behind a fence on the elementary school playground. I was afraid of wheelchairs, afraid to look at the person in the wheelchair, kind of embarrassed and self-conscious. But now I can look at people with disabilities and wonder how they are doing and what they need. They are normal people . . . just needing some assistive devices and extra help. I have overcome my fear.

Olivia has helped me realize what it really means to help a person. I am more patient and compassionate to what others are going through in their lives. I try to be appreciative and not take things for granted. Olivia might not live as long as other people. What if she died tomorrow or in a couple of years? It will have mattered. Every life is so important. I think about the importance and meaningfulness of each life on earth. I also have become resourceful. A few years back, I was in a motel room in Chicago. That night, Olivia broke her wrist. I had to act quickly, so I used the cardboard insert from my pantyhose package as a splint.
I’m proud of my resourcefulness. It’s made me a strong person who is creative and confident in handling situations. I have learned that you can survive anything.

**Marriage**
When Olivia was 10 years old, we made the decision to have her spine fused. It was the most excruciating decision I have ever made. I am still haunted by whether it was the right choice. This was very hard on our marriage because I was depressed for months and months because of the life-changing implications. I think we women tend to get on one thing and expand on it until it drives us crazy. It’s how our brains work. Having gone through all of these experiences together has really strengthened us. It depends on who you marry. When you marry a person and plan on having kids together, you have no idea how that person will handle having a child with a disability. Kent handles it beautifully. He gives Olivia so much strength and spends so much time with her. They share a love of the computer. He has an empowering approach with her.

I met someone who told me that when her son was diagnosed with OI, her husband left the family and said he’s your responsibility. I think if your marriage is going to survive the disability, you need to be with a person who not only loves you, but believes in marriage enough to work through the difficult times. I consider myself very lucky to have Kent. What a happy surprise. It was something I did not know that I would need in a husband, but it is very, very important.

**Public Life**
I don’t think much about how we look as a family. But it is funny because Kent is huge and Olivia is tiny. Abby and I are in between. Everyone remembers us because we stand out.

I get so tired of people staring at Olivia. I feel pain for her. To tell you the truth, I don’t blame them for staring. It is very odd to see somebody who looks so different. It’s a natural human tendency to try to figure it out. But I feel sorry for her. I tell her to smile and wave, but she doesn’t always feel like doing that.

Abby never talks about what it is like to have Olivia as a sister.
She has remarked that everybody knows she’s Olivia’s sister. The sister of the girl in the wheelchair.

Other moms seem so caught up in things that don’t matter. I think I would be, too, if I didn’t have Olivia. They are all caught up in stupid things, and I am thinking, oh brother, who really cares? A lot of people in this community are genuine, caring people, who go out of their way to do nice things. However, some do not appreciate what they have. They forget about the important things. They do not realize how hard things can be for others.

When the kids were younger, people would invite us to the park and playground, but Olivia could never get around the playground easily. It was just so hard to bring the wheelchair. It was always difficult to do something that should have been fun and easy. And then I’d feel so bad because I wanted Abby to be able to do things. Sometimes we would go for Abby’s sake. But it became stressful . . . I was so worried Olivia would get hurt and break a bone. Abby missed out on a lot because things were too difficult.

I also sometimes wonder if we are not invited because of Olivia’s disability. Other kids have told her that she wasn’t invited because they knew she wouldn’t be able to participate. Of course, she’s thinking that she would love to be invited, even if she just watched.

**Future**
Olivia will always have physical challenges to overcome. Although it would be great if she could live independently, I don’t know if this is possible. But we won’t live forever. I find myself thinking, I’ll keep myself really healthy, and then I will live a really long time, so I can always take care of her. I’ll live to be 120, so she is always taken care of. Abby is completely unlimited. She can be a world-traveling journalist if she wants. She can do anything. Olivia can do anything with her mind.

**Advice**
Recognize that you and your partner may handle things differently, and that’s okay. Don’t hesitate to talk to people about what you are feeling. It really helps to talk to parents of other kids with similar diagnoses. This is traumatic and life changing, so don’t expect to bounce back quickly after learning about the diagnosis.
It’s grief, so do not expect to get over it quickly.
It took me a full year to work up the courage to seek help.
I did not want to admit it was real. It was just so scary for me.
I’d see pictures of other kids with OI, and it would freak me out. I was so horrified.
Everyone copes at a different pace, so be merciful to yourself. It is okay if you need lots of time to sit with it.
Take it at your own pace.
Don’t be afraid to ask for help. You might be amazed at how nice and giving people in your life can be.
It will get easier.
I am used to Olivia having OI. It has become a part of my life.
Getting to know Olivia and seeing how adaptable, capable, and independent she is has helped me cope.
Also seeing how independent she can be gives me a sense of relief.

Marcia

Marcia is a married, 52-year-old, part-time banking associate. She is raising Sophia, age 17; Luke, age 14; and Daniel, age 8, diagnosed with Down syndrome. Here, in her own words, is Marcia’s story:

Diagnosis
When I was seven months pregnant with Daniel, we had early warning signs.
Partly because of my “advanced maternal age” and some questionable ultrasounds.
The geneticist told us not to worry, but we ended up testing positive for Down syndrome.
Daniel was born two months later.

I viewed the diagnosis as a family diagnosis because it would affect all of us.
I didn’t know much about Down syndrome at the time, but I knew it would be life changing for us.
I had a hard time imagining what it was going to mean.
My pediatrician was wonderful and told me we could definitely handle it.
The kids were too young to understand.
I remember Luke walking around saying his baby brother had up syndrome because he couldn’t remember the word down.
I just explained to them that their brother might have trouble learning his numbers, and he might learn to sit up a little slower.
But he was their brother.

Family Life
When Daniel was born, Sophia was eight and Luke was five.
Daniel was in the NICU for two months after he was born, so it was hard on the family.
He came home with a trach and on oxygen. Our whole life changed dramatically.
Sophia totally embraced Daniel from the very beginning. She was in the delivery room. She reads tons of books about babies. She became Daniel’s big sister and kind of his mother and protector. She is also his playmate and friend. Luke had a hard time with it at first. He went from being daddy’s only boy to sharing daddy with Daniel. When Luke was eight, he started pretending he had Down syndrome because his brother was getting a lot of attention. Luke loves his little brother and constantly defends him. He has been involved in fights with other kids who have made fun of Daniel or used the word retarded. He’s definitely adjusted to Daniel and his disability, but I think there are scars there that we don’t really understand. They are both great siblings and have grown up always keeping one eye open for Daniel.

Life was definitely easier before Daniel. I tell myself part of that might be going from two kids to three. But Daniel has always taken a disproportionate amount of time and energy. Early on, it was his medical issues. Now, it is things like helping him cut his meat and learning to spell. We try to balance things out with the other kids, but it’s not very effective. Because Sophia is self-sufficient, she ends up getting very little time and attention. This gives me so much guilt. When she comes out of her room and walks downstairs, most of the focus ends up on the boys . . . their behaviors, discipline, and homework. She turns around and walks back upstairs. It makes me feel terrible. I think she feels like this has gone on her entire life. She can’t remember life any other way, where the focus wasn’t always on Daniel and Luke. I do try to make special time for Sophia where we shop, have lunch, or see movies. This is important to me.

Daniel has benefited so much from having older siblings. Even though they are a lot older, they have always been his role models, showing him how and when and where. They just thought of Daniel as their little brother. They never looked at him as having a disability. If Sophia and Luke would have been born after Daniel, the family dynamics would be so, so different. I am glad he is the youngest because it would be so difficult to see the younger ones eclipse the older child. I think it was harder on Sophia and Luke to have Daniel as the baby, but it was definitely better for Daniel and absolutely easier for me to have older typical siblings.
**Public Life**
When Daniel was first born, there was this kind of heightened sensitivity. He had oxygen and a huge trach.
When we took him out to the pool or a restaurant, it felt like we were making a little bit of a scene.
Are people staring at him? At us?
Sometimes, they would approach us and tell us they had a nephew or cousin or knew someone with Down syndrome.
They were trying to relate to us. Tell us they felt our “pain.”
It always makes me sad that people see his disability, instead of my beautiful boy.

These days, Daniel does everything just like everybody else.
We don’t ever really think about him having Down syndrome . . . until something happens and we are like, whoa.
Daniel is still in this little boy stage where he’s sweet, happy, and outgoing.
People are very nice and sometimes over accommodating.
But when he is 25 and does something unusual or inappropriate . . .

Sometimes, I think other families don’t understand how easy they have it.
There are some mothers who complain about things that don’t really matter at the end of the day.
They do not understand what it is like to live with a kid who’s struggling or has to work ten times harder than other kids.
They do not get that piece.

**Marriage**
The disability has taken a toll on our marriage, but we have made it through the toughest stuff.
Early on, Daniel’s medical issues were so stressful.
Also, just dealing with the fact that your kid has Down syndrome is a strain.
At this point, Luke is the one who adds the most stress to our relationship. More so than Daniel.
We have disagreements about how to interact with Luke, and if our expectations are too high or too low.

**Motherhood**
I constantly feel defensive and apologetic about having Daniel.
Actually giving birth to a child who I knew might have complications or issues.
Why as a mother did I do that knowingly? Was it my right or his right?
Or is it an imposition on society? Why is this something a mother has to consider?
Is it not the most natural thing? Why is it a decision rather than a miracle?
We were unwavering about limited prenatal testing and not terminating.
But people are still judgmental today about the decision not to terminate.
The other day, a P.A. at a hospital saw Daniel and said, “Oh, that’s too bad. Obviously you didn’t know about the Down syndrome prenatally.”
I was speechless.
It is heartbreaking that people believe Daniel could be a drain on society.
But society is like that. Sometimes, doctors can be the worst.
This world really isn’t designed for differences of any kind.

Whenever people meet Daniel for the first time, they make an internal value decision about him.
They do the same about me.
At times, I find myself defending my decision and feeling a little apologetic about the decision.
At the same time, I feel strongly that we should not decide who is worthy of birth and life—and who is not.
Why should society make me feel there is anything wrong with imperfection?
Why should I feel anything but thrill for Daniel’s very existence?

I have now embraced Daniel and his disability.
But there was a time when I couldn’t even go to support groups.
I love my little boy, but for a long time, I could not be around a teenager with Down syndrome without losing it.
It stems from feeling of disappointment.
Things are just so different from what you expected. It is scary.

As a mother, did I think about what I wanted from a family or what I could give a family?
No, never.
I thought I would be a good mother, but I never considered what that actually looked like.
And it is different for different kids.
I have to be three kinds of mothers to my children in order to relate to them, teach them, and even show them love.
It’s something I never considered before having kids.

How could I have known how very different my children would be?
Sophia is smart, motivated, and ready to be away from us.
Have I been there enough for her?
Did the time and attention her brothers needed detract attention too much from her?
Does she feel alone and on her own in our house?
Luke struggles socially and academically, but is such a pleaser and loving young man.
However, he makes my hair hurt. I worry that my impatience with him makes things a lot worse.
I begin each day with mantras of how I will nurture him, help him, and listen to all of his stories.
But I often fall short of my goals.
And Daniel is so full of light and hope. He sees the world in black and white.
With him, I worry that his life will be hard. When he becomes an adult, will people see this amazing light and purity? I worry that I will not be there to make sure it is all okay. Will I have prepared him for the world?

Before I was a mother, I never thought I would worry or fret or become crazy with fear. I never worried about control. Some days, I must put my emotions and worry as far from me as I can. On any given day, I may have anxiety about Daniel choking in the lunchroom; falling off the high slide; running and tripping; or wandering out of the classroom and getting lost. If you allow yourself to have any of those thoughts, you almost have to drive to school and make sure everything is okay. I have to harden my brain and heart to those fears and emotions, or I feel crazy with worry. I need to put them far away in a separate place, so I can get on with my day. Daniel’s new thing is walking into school by himself. So I let him. I just watch from a distance and then sneak into the building to see if he is safely in his classroom.

**Future**
I am doing much better now. Part of it is the passage of time. Early on, the disability was very difficult to cope with. Daniel had serious health issues. I was concerned that his cognition was very low. And then when he hit three, I felt like everything would be okay. I realized he would have a good life. I wasn’t sure what his life was going to look like, but I started to become more amenable to the Down syndrome. We have a little guy who has a pretty good shot at living mostly independently and having some kind of job and relationship. But in the beginning, everything was so unclear . . . and that was very hard. I might be living in a Pollyanna world. Maybe I am overly optimistic about Daniel. But you need to be. You can’t live any other way.

Sophia is looking at some great colleges now. I would guess that she will get married and hopefully will have children someday. I hope Luke can get his social piece under control and have some deep, fulfilling relationships. Daniel obviously won’t have children, but he talks a lot about getting married. He says that he is going to marry his friend Piper and work at Target. He loves Target. The food, clothes, toys, and music.

**Advice**
While you need to be optimistic about your child, you also have to be realistic.
There are so many people out there setting boundaries for your child. You can’t be one of those people. Sometimes I treat Daniel like a typical kid when I should not. But I do not want to limit him.

When I talk to expectant moms or new moms with kids with Down syndrome, I always tell them the truth. I say it is hard, but that it will be okay. While they can’t possibly imagine that to be true, I assure them it will be okay. Because Down syndrome is the “cadillac of cognitive disabilities,” our kids have a good shot at leading very fulfilling, happy lives. I tell them not to let the disability run their lives. It doesn’t mean that’s all they need to think about or talk about. Yes, the disability is overwhelming, but it cannot be allowed to take over your life. As a responsible parent, you need to make a separation between your child and yourself. Be sure to stay even keeled and balanced.

Mary Beth

Mary Beth is a 40-year-old, married, full-time high school special education teacher. Her oldest son, Ben, is 9 years old and diagnosed with both Down syndrome and autism. He was diagnosed at birth with Down syndrome and at age 4, with autism. Her other children, Rachel, age 7, and Max, age 3, are both typically developing. Here, in her own words, is Mary Beth’s story:

Diagnosis
As soon as Ben was born, we were told he had Down syndrome. It was a total shock to us. I went through immense grief. It was a dark time. As far as intensity, it was like losing my mom to cancer. Ben was not the baby I expected, and the initial grief was just overwhelming.

And then after that, came the autism diagnosis. It was just four year later. The autism label was so hard for my husband, Derek. He took it really hard. And that made it harder for me. It was just one more thing to try and handle. I had suspected the autism, but everyone told me no way, so I believed them. Who wouldn’t? And then we found out it was really true.

Derek and I went to some support groups.
They were helpful to me, to meet other people, to get those connections. But it did more harm than good for Derek. It was difficult for him to see older kids, to see where they were at.

After the diagnosis, I swore there would be no more children. I did not want to risk having another child with a disability. I couldn’t go through that grief again. But those feelings dissipated. I became a stronger person. Rachel and Max came soon after.

It was tough with Max. I was 38 and worried about my age, especially with Down syndrome. And very worried about the risk of autism because Max was a boy.

Looking at the birth order, I’m happy Ben is the oldest. I didn’t know any different, which made it easier. He didn’t walk until he was 2 ½. So if I had other kids to tow around, or other kids to compare him to, it would have been more devastating. It was still difficult to see friends, who had kids the same age, and were reaching milestones that he wasn’t close to. But in ways it made it easier because I didn’t know any different. I had time. Time to research therapies and to read lots of books. There was so much I didn’t know. I needed to get educated.

I am thankful I had more children. I think the balance has been really good. Ben’s childhood is filled with doctor appointments, therapies, and more therapies. His “play” occurs mainly with adults. But Rachel and Max have friends, play dates, birthday party invites, school events, and sports. Their worlds are so different from Ben’s.

**Family Life**

It’s so hard to find the balance and the equity. The two typical ones are so verbal . . . and so demanding. And I work full time. How do I get it all done? I only let the younger ones be in one activity, but Ben is in a million activities . . . just to keep him stimulated . . . and growing. How can I be fair, yet help them understand he’s different? It’s not fair that he was born with a disability.
And it’s not fair that he’s nonverbal.  
How do I help them understand that?  
I can hardly understand it.

There are lots of places Ben can’t go.  
He vocalizes so much and he’s so loud.  
He gets overstimulated quickly.  
Gymnasiums and basketball games . . . these are really hard for him.  
And the lighting. He has a tough time with that.  
But we try to work around it . . . as much as possible.  
We’ve been big on trying to lead normal lives . . . from the very beginning.  
We work really hard on doing that. We always go places together.  
And if we can’t, we get a family member to help out.

When I think about the future, I have concerns about limitations.  
But right now, he fits in the burley, so we can still ride bikes as a family.  
You know, in a few years, that won’t be possible.  
But now it is.  
He looks goofy in a stroller because he’s big.  
But he fits for now . . .

I worry a lot about Rachel and Max.  
Rachel says she doesn’t want Ben to come places with us.  
She wishes we could leave Ben at home because he’s so slow.  
And everything takes longer . . . and it’s always harder.  
Going to the library is not enjoyable.  
We rush through because Ben is so loud and disruptive.  
I am so stressed to be there.  
Rachel is well aware of this stress.

Last summer, we were at the pool.  
Ben was vocalizing loudly in the water.  
And another boy began screaming, telling Ben to shut up, over and over again.  
I didn’t know how to deal with it.  
It was so awkward . . . for everyone.

I don’t think Rachel and Max are embarrassed by Ben.  
They are both kind and empathetic individuals.  
They have always taken on the role as Ben’s “helper.”  
They are not embarrassed . . . not yet.  
But I know that day is coming . . . and that’s so hard.  
There’s certainly more to come.  
It’s something that I worry about because as Ben gets older, he certainly stands out and looks different.
And his “strange” behavior is no longer cute.
Rachel has always been good about telling people he has autism and Down syndrome.
She kind of teaches them about Ben.
This is so important, spreading the word.
Letting people know it’s okay to have a sibling with a disability.
Tolerance is a societal expectation.

We have a good quality of life.
Mainly because we have family nearby to help us.
We don’t let Ben stop us too much. We still take vacations and go lots of places.
It’s important for us to make a concerted effort to get out . . . and not become isolated.
It’s harder and harder to find babysitters that can handle Ben . . . and everything.
But we try . . . and our family helps us so much.

Many of my friends have no idea what it’s like.
Some try to be understanding and sympathetic.
But unless you’ve walked in our shoes, you don’t really know or get it.
I have a friend with two typical kids who can’t handle them.
I just have to laugh because she has no idea.

Public Life
I’ve gone through tough periods from time to time.
Like being at the pool, and longing for the day I can sit and relax, wondering if it will ever happen with Ben.
But Rachel and Max help me. They help me to stay connected.
Because if I only had Ben, you know, he doesn’t have friends.
And he doesn’t get invited to things.
And the things he’s involved in don’t really lend themselves to much parent interaction.
He has a lot of therapies at home, so I’m connected to therapists, but not to parents.
Rachel and Max are so involved and interact with so many kids . . . it feels like what my childhood was like.
Whereas Ben’s childhood is so different.

When we go out in public, there’s a lot of stress.
In trying to keep Ben quiet, within socially acceptable norms.
Not yelling, not spitting.
If we are at a baseball game, it doesn’t go over too well when he tries to spit on the people sitting in front of us.
So there’s a lot of time spent just trying to do crowd control.
And being normal in that sense.

Transformation
You can only have empathy if you’ve been in this situation.
I’m certainly more empathetic to people with disabilities.
And to people with family members with disabilities. And I think I am more patient than I was before. You have to be patient. As an educator, I work hard to understand kids and take the time to get to know them. And to see their true personality. Before, I probably would have looked at someone and said, oh, he can’t do this and that. But I no longer do that. I work to figure out their strengths because they are always there.

Max and Rachel have never known anything different. They definitely have more kindness in them than many of their peers. I think it’s because what they’ve been exposed to, that they’ve been raised with Ben. And many of their peers don’t have these skills, skills of empathy, because they have no clue. And their parents. I am amazed at how many parents fail to talk to their kids about people with disabilities. You know, even on multiple exposures to Ben, there are some kids that still . . . I understand they’re curious. And it’s really the parents’ fault for not handling their curiosity appropriately . . . and educating them.

Ben was getting a haircut last week. He hated being there and was making loud noises. A little girl who was waiting for a haircut became frightened of the noises. Her mother moved her away from Ben and cuddled her, saying oh, it’s okay, it’s okay. It was as if Ben were some wild animal that had nearly attacked her precious little girl.

**Marriage**

The disability has been good and bad for us. The good is that any time you go through a major struggle together and make it, you’ve grown closer. I think for better or for worse, we know we could never divorce. It’s just . . . life would never work that way. So, it’s helped our marriage through the bond. But I think that the struggles have involved the grieving process. I get down at times, it’s not even predictable. It can be one little thing that makes me feel sad or down. But the next day, I’m over it. However, when Derek gets down, he’s depressed for days. I don’t even invite him to IEP meetings anymore because he’s down for days and days. And I have trouble with the fact that he can’t just get over it. We are allowed our little grief here and there. But I struggle with his not being able to get over it.
It’s really hard for me.

I often wonder what destroys these marriages.
Is it lack of agreement on how to treat the child?
Feelings of inequality in the responsibility of raising the child?
It seems that mothers do 95 percent of the parenting of these kids.
I see it in my own family

**Motherhood**
My mom was a stay-at-home mom with four kids to take care of.
She was my role model.
She was always calm, cool and collected.
Everything was always under control.
She had time to sit down and play games with me.
She never seemed distracted or rushed.
So my ideas of parenting came from her.
But if I sit down and play with the kids, I’m always thinking about something else.
About what else I should be doing.
This is not what I had in mind about motherhood.
I work full time, and Ben has a busy schedule with doc appointments and therapy.
We are always go go go.
There’s no time for games.

Motherhood means a lot of responsibility . . . especially mothering Ben.
I feel socially responsible for him, which is different than for the other two.
With them, I just have to help them navigate.
Navigate through the challenges of their social life.
Ben needs me to help him stay interactive . . . and to make important educational choices . . . being his advocate on everything.
It adds so much stress to our lives.

I feel a great deal of guilt.
For not slowing down.
And for life always being frenzied.
I deal with it by thinking the worst case scenario and comparing it to my kids’ lives.
Most of the kids I work with have horrible homes . . . with no parent to come home to . . .
or parents who are a mess.
So . . . in comparison . . . my kids are doing okay.

Rachel and Max are extremely vocal about their needs and desires. So they get most of my attention.
And Ben is so easygoing in that regard . . . he doesn’t seem to care.
I think my guilt is stronger that he’s not getting his needs met.
But then some days . . . I feel guilt about my expectations.
Because they are higher for Rachel and Max . . . in every way.
My expectations are just different for Ben.
I never lose patience with him. But I do with the other two . . . a lot.

I also feel sadness.
This past weekend, Rachel and Max went away to a farm with extended family.
Nobody asked if Ben wanted to go.
I don’t think they feel comfortable taking him for a weekend.
I know he doesn’t understand and doesn’t care.
But I do. I wish he were a “normal” 9-year-old, who could join his siblings on all of their cool adventures.

**Future**
I don’t allow myself to think too far into the future.
I mean, you have to, to an extent, but I try not to.
There’s a lot of unnecessary pain that comes with thinking too much.
Because you just don’t have any idea . . .
We do what we can to plan financially, setting up a trust and stuff.
But I don’t allow myself to think that far because it’s too overwhelming.
Too scary.
Derek allows himself to worry about the future.
And then he gets frustrated that I’m not worried about it.

I know it sounds morbid, but God forbid anything happens to me or Derek.
While it would be absolutely horrible for Rachel and Max to lose a parent prematurely,
there are also so many relatives that could step in and raise them.
They could lead a happy life.
But there’s really nobody that I would feel comfortable leaving Ben with.
Nobody that knows him well enough.
It’s scary.
When we die, I don’t know what will happen to him.
I just hope that Rachel and Max will always be there to help Ben.
I hope they will want to.
I know Rachel and Max will be fine in life, but I worry so much about Ben.
Derek and I discuss it a lot.
We never come to any conclusions.

**Advice**
It’s so important to get out and get involved.
Do not let yourself . . . or your kids . . . get isolated.
These children need what all children do.
As Ben gets older, it gets harder . . . but I work to keep him involved.
This is good for siblings, friends, and family.
And it helps society understand that these kids enjoy what other kids enjoy.
And should not be feared or stared at.

Also, I think it’s important to just love your child.
I remember feeling so panicked in the beginning.
Like I had to learn everything and do every single therapy immediately.
But my pediatrician said no, just take him home.
Just protect him and love him like any other child.
I did.
That was important for me to hear.

Maureen

Maureen, age 43, was once a very career-focused IT project manager.
However, today she works hard as a stay-at-home mother to two children, 8-year-old Joseph and 6-year-old Nicole. Joseph was diagnosed at age one with hypotonic cerebral palsy. Here, in her own words, is Maureen’s story:

Diagnosis
At six months, it seemed like Joseph wasn’t progressing as he should.
At nine months, he was extremely behind other kids his age.
But his pediatrician told us not to worry. He said Joseph was still within the “normal range.”
At one year, a different pediatrician saw him and said something is definitely going on.
So, we started the process of seeking a pediatric developmental evaluation.
After all of the tests, the doctors couldn’t find anything.
My pregnancy had been fine, delivery was fine, and all the test results were fine.
They ended up giving him a label of cerebral palsy for insurance purposes, but there was never any conclusive diagnosis.

I knew something was up with Joseph, but getting the CP diagnosis was a complete shock.
While it was better than some of the terminal and degenerative diseases they were testing for, it was not a comforting diagnosis.
Sure, it wasn’t progressive, which was great, but it was still very difficult to hear.

For some reason, I went back to work that afternoon after hearing Joseph’s diagnosis.
But I was a complete mess.
I couldn’t handle being at work, so I left and asked for a leave of absence.
Now that we had a name, I needed to take some time to figure out what it meant.
But I knew I was not going back to work.
It’s funny. You go to college, work your way up the ladder, and get to a good place.
And then you drop it all like a rock in a split second.

Shortly after, I found out I was pregnant again.
I had gone off the pill, but because I was in a complete fog, I completely forgot. And then I took a test. I was 8 weeks pregnant. It was unbelievable. I wasn’t too worried about the baby because we were told CP isn’t genetic. Besides, any testing was a moot point by then.

Motherhood
I still wonder why this happened to us. It’s always in the back of my mind. Did I do something? Did I eat fish with mercury? Did I breathe some funky air? It doesn’t matter, but it’s still there. You never really let go of that. It doesn’t hang over me, but it definitely pops up all of the time. It comes back when you talk to other people or when you go to a new doctor who wants to know your life story beginning with your pregnancy.

I never pictured myself as a stay-at-home mother. It just wasn’t my thing. I am not this warm, fuzzy person who likes to make cookies and play games and sing songs. It’s a stretch for me. I am not playing on my strengths. It’s so different being in the professional world one day and cleaning poop another day. You feel your mind turning to mush. But I no longer value what I did before. It is not the most important thing in life. I’m not going to kill myself over some software project. Whereas, I would have before kids.

Staying home has been good for my personal growth. There’s so much value in me being here for my kids, and I didn’t really have a choice with Joseph. He needs a lot of time, attention, and effort. I want to be home to help with therapy and be in tune with what is going on. It had to be like this.

It’s hard for me to see the stark differences in Joseph and Nicole. Nicole is so social and outgoing; it’s so easy for her. Play dates and birthday parties are difficult in our house. Nicole gets numerous invitations, but not Joseph. He will ask us, when are my friends going to have a birthday party? I just sit there with my mouth hanging open and my heart sinking. I feel his pain tenfold. What do I say? I think to myself, what friends? He really likes parties but almost never gets invited now that parents no longer dictate who gets asked. Being a boy, most birthday parties are high energy, and Joseph can’t keep up.

I spend a lot of time plotting.
Maybe I invite his entire class to his birthday party to increase his chances of getting invited to another one throughout the year. But what if I invite everybody and nobody comes? Then we will be really screwed. The other thing is that somebody has to accompany Joseph. He can’t just go off to a birthday party on his own. And nobody’s parents attend parties anymore. It only gets harder.

I cope by talking to people about it. My husband doesn’t like to talk about it much. He believes this is the way it is, so deal with it. Being the typical male, he just wants to fix everything instead of discussing. But it’s not about fixing. I need him to sit and listen. We both have different objectives in having a conversation. But I need to discuss it. I like to reach out to others.

**Family Life**

I’m glad Joseph came first. If not, Nicole’s world would have been totally rocked. She would have taken on the role of spoiled little kid. I don’t know if she would have been resentful of this boy who was not only her little brother, but someone who was very demanding. But as the second child, she grew up pretty much having to scream for attention and getting it however she could. I call her the “forgotten one.” She has adapted to life by screaming for attention or simply getting in my face. I worry about this a lot, but on the positive side, she seems to be exceptionally compassionate for her age.

Through it all, I do believe that Nicole will be okay down the road. She is cute, smart, kind, and has a magnetism that draws other kids to her. I should be more proud of this. But she is never my first priority unless she is bleeding or throwing up. How will that affect her emotional well-being? She is being given the message to fend for yourself. If I didn’t have a child with disabilities, I’d be more ecstatic about her abilities. She deserves to be encouraged and praised. But how do you do that without putting down Joseph?

Is it fair for us to have different expectations for each child? Will Nicole rebel one day? Will she resent us or resent Joseph? Is it best for Nicole that we seem to downplay her IQ and abilities, and emphasize her being a caring, compassionate person? This makes me question the real meaning of life.
What’s so hard about having a typical child and one with disabilities is seeing the clear differences.
You constantly realize that this one is doing this and this one is not.
I remember Nicole leapfrogging Joseph last year. It was rather troubling figuring out how to deal with that.
I didn’t want Joseph to be damaged by it. I wanted to protect him.
He tests in the bottom two percent, while she is in the top two percent . . . if you even trust any of those tests.
If Nicole had been older, she always would have been ahead, so it would not be an issue.

There are times when both Nicole and Joseph get invited somewhere, and Nicole doesn’t want Joseph to attend.
I feel bad that she wants to get a break from her brother. But Joseph can be a burden on her freedom to be a kid.
Can you really blame her? Does she have to carry that baggage around with her everywhere?
She definitely gets short-changed by having Joseph as a brother.
Nicole still has training wheels on her bike because she hasn’t had a chance to practice bike riding.
If it doesn’t work for both kids, then it generally doesn’t happen.
I find comfort in the fact that through everything, they are great buddies.

I feel like our family is so disability focused.
Every day, each adventure requires a certain amount of thought.
Who is doing what? How is that going to happen? What are the limitations?

Public Life
I do feel isolated at times. Especially in our circle of friends.
I know that sometimes we don’t get invited to do things because people don’t want to invite just one of our kids.
There are lots of situations where it would be hard to have a physically disabled child, so neither of my kids will be invited so as not to exclude Joseph.
And then there are a lot of neighborhood issues, such as playing in the neighborhood. Sometimes, I think parents put their kids up to asking Joseph to come over and play.
He usually says no because he knows he will need help. If I don’t offer to go and help, he won’t want to go.
And sometimes, even if I offer to help, he won’t go because he knows it is kind of a drag.
The kids like to run from yard to yard, playing hide-and-seek. Joseph knows this won’t be any fun for him.
I so wish it didn’t have to be like this. There’s no way to feel good about the situation. It makes me sad that Joseph can’t enjoy these activities.
I think it’s a process. It takes time for the parents to understand what Joseph needs and how to help him.
As opposed to me always having to tag along as his shadow.
In some ways, I have trouble relating to other moms who don’t get it. They think their problems are so big. Instead of insulting them, you just have to smile and let it go. How I wish I had their problems. But I also try to picture myself in their shoes, and everyone has something they are dealing with that’s important to them. I guess my problems are not any more important, just different.

When we are in public, I feel like I must keep my guard up because people are watching, looking, asking, and commenting. I put on my blinders. It’s like we are going out there into the big, bad world, and I have to put on my thick skin. My shield is up . . . I am ready for you people. I must protect my soft interior. I hate that look on people’s faces. The look of, “Oh, poor, poor kid.” It’s as if nobody is exposed to “these” kids. Sometimes, when your guard is down, you can get blindsided. When I talk to other moms raising kids with disabilities, I start rehashing the whole thing. I remember back to how hard it was, and I start reliving everything all over again.

**Transformation**
I am much more tuned in to people. I understand what’s important in life as opposed to money and prestige. Your sense of worth changes because you do not get a lot of pats on the back for raising your kids. I feel so much more responsible for helping others in the disability community. I want to fight the battles that need to be fought for those who come after. School and insurance and general stuff. I feel a responsibility to do my part.

**Marriage**
We are still married. It’s hard to say how difficult it is to raise kids versus raising these two kids. But it has definitely been challenging. No question. We go back and forth on the fact that Andre goes to work every day, busting his butt to bring home a paycheck. And I bust my butt every day at home, raising our kids. While we used to be 50/50 with both of us working full time, now we have taken on the classic male/female roles. I often wonder how we got to this place.

**Future**
I have no idea what to expect. My husband and I don’t necessarily agree on how things will end up.
But we are planning for the worst and hoping for the best.
We can put a 529 inside a special needs trust, so we can be doubly covered.
I’m thinking, why would this kid go to college? It’s such hard work for him, why would he go down that path?
Maybe a trade would make more sense for him.
We need to figure out what both kids needs. It will not be the same for each.
But I don’t know if it’s ever the same with any two kids . . . disabled or typical.

When I go to Wal-mart, I get a strange sense of reassurance that Joseph will be okay.
Because everyone from the shoppers to the people working at the checkout seem to be at his level.
I am encouraged by thinking that this might be the worst case scenario for Joseph. And it is not bad by the average American standard.
However, we will still have to deal with his stark contrast to his sister because her options may be unlimited.
But good for her.

Advice
I don’t want to be a downer, but the best revelation that I ever had was that I’m not going to ever be able to coast free.
We are never going to solve Joseph’s CP. There will always be more problems to solve.
I used to think, I just need to get over this one issue, and then all will be good.
But as soon as I stopped thinking that way, things seemed much better.
The truth is that there will always be another battle to fight.
We might have a bit of a breather from time to time, but that’s just a short period to recharge our batteries before some issue hits us again.

Rachel

Rachel is a married, mother of two. Raising Chloe, age 4, who is visually impaired, and Ava, age 7, this 35-year-old full-time mother believes that you never know what you’re made of until you are pushed to the limit. Here, in Rachel’s own words, is her story:

Diagnosis
The doctors told us Chloe needed open heart surgery when she was 10 days old.
Then, at 8 weeks, we noticed that she did not visually track, so we took her to a pediatric ophthalmologist.
They tested her and knew right away.
She had bilateral coloboma of the retinas, optic nerves and iris (under developed).
She also had nystagmus (the dancing of the eyes).
And strabismus (cross-eyed or lazy eye).
And microphthalmos (small eyeballs).
I thought I had done something wrong.
Did I eat something bad? Did I take something I wasn’t supposed to take?
But the doctors told me it just happens.
It happens during gestation for no reason. There was nothing that I did.
But you start to question everything.

I went home and lay in bed for 3 days.
I kicked my 3-year-old out of her room and sent her to sleep with her daddy.
I told her I was taking over her big girl bed until I felt better.
I lay there and cried and slept.
Chloe would wake me up because she wanted to be fed.
I just remember holding her and telling her I was so sorry for what was happening to her.
As a mommy, you carry your baby for 9 months, so you feel completely responsible.
I felt like it was my fault. I felt so responsible.
On the third day, Ava came in and told me she hoped I would feel better soon.
Something just snapped in me.
I knew I needed to get up. I had a family to take care of.
I had grieved. I did my 3 days. It was time to get back to my life.

A friend of mine really helped me. She has two girls with a rare genetic metabolism disorder.
We understand each others’ heartbreak. She told me not to blame myself.
She said it was okay to be angry and sad. It was okay to feel the need to grieve.
She said to go through whatever I had to go through, but the key was getting on the next bus.
It is okay to feel heartbreak, but you can’t stay there. You must move on.

My husband’s reaction to Chloe’s diagnosis was sadness.
He was upset that Chloe wouldn’t be able to drive. Can you believe that?
I told him it would be fine. Her big sis would drive her everywhere.
She would have her very own chauffeur.
“I have a chauffeur, do you?” is what she will tell all of her friends.

Motherhood
I remember feeling so broken hearted. I felt like my spirit was broken.
Lying in bed for 3 days, I was trying to put the pieces back together.
I was grieving the loss of what I had expected.
I had anticipated having another kid like Ava, who rolled over at 4 months and crawled at 9 months.
The open heart surgery was one blow, and then the visual impairment was another. It was too much.
But I had to learn to accept it. I could not bury it.
This is who she is.
Her disability does not define who she is.  
She’s girly, she’s spunky, she’s determined. That’s who she is.  
She’s a tiny dancer princess who will not let you tell her no.

Sometimes, it feels extremely lonely out here.  
I know that I’m not alone. I have great friends who have taken the time to learn about Chloe.  
But they still don’t fully get it.  
They don’t get the moments that break my heart.  
They don’t get the moments when I am reminded of my child’s disability.  
It’s the instant flashes, like when Chloe accidentally walks into a table or door jam.  
I have to keep it together.  
Friends tell me how great she is doing, learning to use all of her other senses in ways we don’t understand.  
I want to tell them to take those wonderful words of encouragement and put them somewhere.  
I just want my baby to not have these challenges.  
But then I get over it and know they only meant well.  
We all have some sort of challenge in life.  
It’s just the reminder of my little girl’s limitations that break my heart.  
I know they just don’t get it. That’s why it’s nice to connect with other mommies like me.  
Their child’s disability may not be similar to my child’s, but we understand that mommy heart.  
That’s encouraging.

A friend of mine and I started a support group for disability at our church.  
Our children are all different, but the parents are so similar.  
One child has autism, another has a rare genetic disorder, and another child’s disability was inflicted on him by his caretaker.  
But our hearts are all the same.  
We all experience the heartbreak of what we “expected” and the pressure to maintain a “normal” home life for our family.  
We are a group of parents joined together through our children, but we are so much more to each other.  
We encourage and support each other. We are not alone in our journey.

I believe that moms think their motherhood journey will be just like the beginning of the “Welcome to Holland” poem.  
This was not the case for us.  
I still have moments of sadness around what I had expected and will never have with Chloe.  
However, I choose not to spend the rest of my life mourning the fact that I didn’t go to Italy because I may never be free to enjoy the lovely things about Holland.
Is this how I imagined my life or motherhood? No, but I would not change it for anything in the world. I imagined motherhood was like the first 3 years with Ava. We’d hang out, go to the zoo, go to the museum, have play dates. I never imagined my weeks being consumed by OT, PT, speech therapy, and doctor’s appointments. Where were the play dates? Zoo visits? Relaxing park outings?

I don’t think that God did this to harm me. Instead, he wanted to show me a different way, and open my eyes to another world. A world I would have never seen because I lived in a bubble. I consider it a blessing that I’ve become a part of this world because I’m no longer looking through tunnel vision. To be honest, I’m kind of glad my bubble got popped. The people I’ve met, the families I’ve encountered, it’s amazing. Chloe has allowed me to not just become the best mommy I could be, but become a better person.

**Family Life**
Before Chloe, the first 3 years with Ava were so typical. It was one on one. I had everything under control. When I was pregnant with Chloe, I remember feeling concern that Ava would be left out when the baby arrived. But after we got the diagnosis, I became a momma bear and became focused on protecting Chloe. I think on some level, I kind of forgot about Ava. I couldn’t be there for her emotionally. For the first year, my husband and in-laws took care of her. She was fine. She was healthy. I wish I could have handled things differently back then. There was no balance. It was all Chloe.

When Chloe’s therapists come to the house, Ava asks why nobody ever comes to see her. It’s hard to explain that to her. She doesn’t feel special and that hurts me to watch. Chloe thinks Ava is the coolest thing since sliced bread, so we point that out to Ava a lot. We tell her Chloe is trying to be like her because she looks up to her big sis. Then she says, oh okay, I thought she was just being a nuisance.

**Public Life**
Feeling isolated totally depends on the social setting. We have good friends who have learned what they could about the visually impaired. They don’t grab Chloe’s hands because that’s like grabbing her eyeballs. They touch her shoulder to get her attention.
And then there are other people who are uncomfortable. They don’t know what to say or what to do. There are people in my life—other moms—who just don’t understand. They just want to feel sorry for me. I can’t stand it. It’s like they live in a bubble.

We get looks when Chloe uses her walking cane. Most kids want to ask what the cane is for. Their parents act embarrassed and try to guide the kid away. But I want their questions. Knowledge breaks down barriers. The adults stare more than the kids. I just smile back at them. I won’t try to hide who Chloe is because this is who she is. Even my mother-in-law gets embarrassed when Chloe brings her walking cane out to dinner. She’s from a very small town and always tries to get her to leave her cane. I think this is what makes Chloe who she is. I don’t see it as a weakness. It’s an opportunity to educate others. Understanding differences has to start when they are young.

Transformation
I didn’t know if I could ever rise to the challenge, but I have. I have learned so much about myself and the strength within me. I have such a heart to advocate for my girls and for other parents now. My mission in life is to let other parents know they are not alone. Before Chloe, I would never have been able to sit and talk with anyone going through this kind of stuff.
I enjoy who I am becoming.
I know in the long run, I am a better person for these experiences. Becoming Chloe’s mom has helped me be a better mom to Ava.

Having Chloe has changed how I see the world. My point of view was narrow, and I got easily frustrated with other people if they did not agree with me. But Chloe has helped me understand how different we all are. I had to get used to giving up control. It took disability to show me how big the world is, and how much we really need to be here for each other. We can’t just think about ourselves, which can be very easy to do.

I think Ava has also been changed. She is exposed to kids with a lot of different disabilities . . . visual impairments, cerebral palsy, etc. She doesn’t even blink twice. It’s like no big deal to her.
Marriage
When we first found out about Chloe, I was the one dealing with all of the appointments and therapies. My husband basically shut down and ignored what he could not handle. We swept it all under the rug. He spent his time working, and I mothered. And then a few months ago, Chloe was diagnosed with functional vision loss and a brain malformation. Everything erupted. All of my emotions came bursting out. I told him I hated him and wished he would die because he was no good to our family. He admitted that he did not want to deal. He felt his only job was to bring home a paycheck. It opened up communication for us. Now he understands how much I need his emotional support. He tries hard now.

Advice
Cry. It’s okay. You need to let it out. Get angry and then get on the next bus. To be the kind of mommy that you need to be, whether for your typical or disabled child, you need to come to a place of acceptance. It’s healthy for you and for your kids. Seek out support because nobody will come knocking on your door. And nobody throws you answers. You need to seek them out.

Rebecca

Rebecca, age 49, is a married, former urban planner, turned stay-at-home mother. She is currently raising her daughter, Laura, age 14, and son, Colin, age 10, who has Prader-Willi syndrome (PWS). PWS is a complex genetic disorder due to a lack of several genes on chromosome 15. Here, in her own words, is Rebecca’s story:

Diagnosis
At first, Colin seemed fine. His Apgar scores were good, he was a normal size, and all his parts seemed typical. But he wasn’t nursing. Upon further examination, the doctors determined he had low muscle tone. So, the doctors put him in intensive care to feed him and figure out why he had low muscle tone. Many specialists examined him, including a geneticist. After three weeks, Colin was diagnosed through genetic testing with Prader-Willi syndrome.

We were in shock. I had a still birth at five months between Laura and Colin, so I thought no, not again. After losing one child, we had pinned all of our hopes and dreams on the next one.
We researched Prader-Willi and focused on the worst case symptoms. I kept thinking why me? Why my innocent little baby? What will his life be like? It felt like a big, black hole of doom and gloom. We were overwhelmed with grief. No parent wants to hear bad news about their baby. It’s crushing to find out your perfect child is not so perfect after all. How would we care for Colin?

I remember calling my parent’s rabbi for support. He had a son with spina bifida. I told him that I was worried about the lifelong burden that Colin would impose. He assured me that we would get used to it, that it would lessen and become familiar. He said that despite the difficulties, caring for Colin would become our new normal. He was right. Now, I am so used to my world. I can’t imagine living any other way.

**Family Life**

I wouldn’t have asked for a special needs child, but now that I have Colin, I see that there are benefits. That sounds horrible, but it’s not all bad. And it makes me realize that Colin’s life is as valuable as anybody else’s.

Laura and Colin are very much like typical siblings. Sometimes, they love each other and sometimes they can’t stand each other. Having the typical child first gave us an idea of what it’s like to rear a child with normal developmental milestones. And then we used Laura’s development as a yardstick for measuring Colin. Not to find him wanting or her wanting, rather to say, she walked at this many months and he walked at so many months. It’s sort of good to have both.

I’m certainly glad I have a typical child in addition to Colin. A great regret of mine is that we didn’t have a third child. So that Laura would have a typical sibling and also have support in helping Colin. And one day, in helping to take care of Jeff and me. I worry a lot about the burden she’s going to have as an adult because it’s very likely that eventually she will become Colin’s guardian. Certainly, that’s our hope . . . that she would become his guardian when we’re no longer able.

In retrospect, I wish I had started earlier and had more kids. But I didn’t, so there’s really nothing I can do about it. But I wish . . . We’ve had talks about it because Laura feels the strain of having Colin, who can be very difficult. One big part of Prader-Willi syndrome is bad behavior. The kids are really anxious and there are a lot of tantrums.
Part of Laura gets so mad. She wonders why Colin isn’t normal. Why he has to be this way.
She’s never quite said that he embarrasses her, but that’s what she means at times.
Laura also defends him and says he’s just like other brothers and sisters.
But I have told her that he is actually not like other brothers and sisters. He is harder in some ways than other brothers and sisters.
I tell her that if she feels angry, it’s okay to feel that way.
She feels as if she has to be perfect all of the time.
We try really hard to make her understand that she doesn’t have to be perfect.
Nevertheless, I think at times, Laura uses that as a crutch when she doesn’t have a good performance in school.
She will sometimes say, you expect me to be perfect because Colin isn’t.
I certainly hope I’m not doing that.
We try to explain to her that it’s okay to feel frustrated because he is, in fact, frustrating. And Colin has his wonderful qualities, but he certainly has his difficult times, and it’s okay for her to say to herself and friends, he is a little more difficult than a regular sibling.
It’s okay to acknowledge that because it is true, and she shouldn’t hold in her frustration or anger if she’s having a particularly bad day.
She should do things to self-calm, like walk away or put on her iPod and listen to music if she is in the car.
Do yoga breathing or things to help take care of herself, so that she can be more relaxed around him.
Because, in fact, Laura does have to help us. We all have to take care of Colin.
But we try not to put too much of a burden on her at this point. Because we want and need her to want to take care of him later.
It’s a fine line because sometimes she acts like a sister, and sometimes, she tries to be a third parent.
But I don’t want her to be his mother now. I want her to be free.
At this age, she should have the typical responsibilities for a sibling, not any extraordinary responsibilities.

Food is a really big issue for kids with Prader-Willi syndrome, so we can’t have any unplanned treats.
We must be careful with setting a precedent with any type of special treat or accommodation because then Colin will come to expect it.
If his expectations are not met (even unrealistic ones), it will lead to dashed expectations, which can lead to a tantrum.
So some of the spontaneity that some families have, such as let’s go to the movies or let’s stay up late, we just can’t have.
And often, if we are going to a family event, we go in two cars so one of us can take Colin home earlier.
That way, Laura can have the benefit of staying. The best we can do is divide and conquer.
I feel guilty that Laura has to deal with this. I try to make it up to her at other times. We try to have special time where I do something with her, Jeff does something with her, or Jeff and I do something with her. Colin is now going to sleep away camp for a week during the summer, which he loves because it gives him a chance to be independent. We love it because we enjoy a little respite from our typical responsibilities. Last year, we asked Laura if she wanted to go someplace and she said no. She wanted to stay home. She wanted to be at home without the constant presence of Colin. Because he doesn’t have many friends and play dates are rare, Colin is always around the house. With Colin at camp, we can all relax. The refrigerator is unlocked and the pantry door is open. We can leave muffins on the counter. Sleep late. Eat at 8:30 at night. Go for ice cream. Laura just loves it.

A big concern is to balance Colin’s needs with Laura’s so that everyone can grow up as fulfilled and balanced as possible. I want them both to be as happy as possible. Part of my concern is what we need to do so that Laura can be as normal as possible. So that she doesn’t feel undue resentment from having a brother with special needs. Is it possible that Laura can grow up without resenting Colin or us? I want her to feel that she has as much freedom and normality as possible, as well as love and support. I really do think we try to be very careful about keeping her life as normal as possible. On the other hand, we also need to be educating her about the sacrifices we all have to make. There are times when she wants to express her frustration with her little brother like anybody else would. But the ramifications of doing this are so much greater because of his tantrums, and in the end, it might be far worse for her to vent that than to just keep it inside. I try to give her some avenues to deal with her feelings so that her frustrations are dealt with properly without spurring Colin into a tantrum. She has no desire to attend any sibling support groups. I think part of her doesn’t want to admit that there’s a problem with Colin, although she knows that there is. When she was ten or eleven, I sat her down to explain mental retardation. She said that Colin was not mentally retarded. I said, yes he is, and asked if she knew what it meant. She realized she didn’t know. I told her that it means less than normal cognition. So, in fact, Colin is mentally retarded even though that is not a common terms these days. I explained that we use the term, developmentally delayed. But when she has friends who use the term, retard, that’s what they are saying. It was an “ah ha” moment for her.
I think of Down syndrome a lot because a person with Downs can typically live more freely than one with PWS.
And my biggest sadness for Colin is that he can’t live freely because of the food, cognitive, and anxiety problems.
He can’t do anything independently.
He has asked me if he will be able to drive a car, and the answer is no.
Cognitively perhaps, but even if he could, the answer is no because we can’t ever let him be in a situation where he could go find food on his own.
Will he be able to walk home from school by himself? No.
It makes me sad that there are so many restrictions on his life.
I try to give him his freedom in the smallest of ways.
When we go to the library, I’ll park outside, and he goes in by himself.
Laura can’t believe that I let him go in by himself, but he can’t get a hotdog at the library.

This past summer, Laura spent a few weeks with my brother and his family in New Jersey.
I was happy that she could experience life in a family without a child with special needs.
It is more relaxing and easy.
I was glad that she could spend time with cousins and receive some respite from her day-to-day life with us.

**Motherhood**
When we first got the diagnosis, I couldn’t bear to think of what our life was going to be like.
I couldn’t think past the first month. And then past the first year.
But then I got to know Colin. He is adorable, funny, inquisitive, and loving.
As he got older and began to develop, I got to know other families and see PWS adults.
Then the reality seeped in, and it’s no longer scary.
As it became familiar, it became less scary.

I never did a lot of babysitting; I never took care of many kids, so I had little knowledge of how to raise kids.
I knew there would be good days and bad days, but I didn’t have any clear cut ideas.
I didn’t have any domestic fantasies. I didn’t feel impatient to have a kid and do all of the parenting stuff.
I certainly never thought about having a child with special needs and the additional strains.
I only envisioned the strains that I knew about, such as conflict with your mother, teaching your children to do things, and trying to steer them in the right direction.
I never ever envisioned the added layer.

I don’t know what was worse . . . having my child die inside of me (a stillbirth) or receiving Colin’s diagnosis.
PWS is not going away, and Colin is going to be a lifelong responsibility in ways that typical children are not. But life can still be really great, even though you have these hard things happening. I feel more optimistic today. Not that I couldn’t deal with it before, but this has really made me wake up. Colin is a wonderful person, and having a child with special needs is not all bad. He has great joys in his life, and he brings us immense pleasure. I couldn’t have necessarily said that when I first got the diagnosis, but now I know it’s true. And I feel like if I can handle this, I can pretty much handle anything.

Life with Colin is hard, but much of it is quite joyful and wonderful. We’re all healthy. I know Colin is not dying of his illness. I try to get as much pleasure out of life as possible. One thing I’ve learned from all of this is that life is short. Bad things can happen at any time. You need to see as many friends as possible and take as many opportunities for joy as you can. Go walk the dog, look at the sunset, have an adventure.

As Colin has gotten older, he is actually harder in some ways. When he was little, we did not have to deal with his difficult behavior, which increases in teen years. As an infant with low muscle tone, he was easy and never cried. He was an easy, placid, happy baby. But when PWS kids get older, the food foraging kicks in and the anxiety worsens. So, it’s hard. And summer is very difficult for Colin because of the lack of structure. When school starts in August, we all get excited.

I’m so grateful for Laura because we can have typical family experiences together. I feel like I get a little bit of a break, and I get a little taste of the other world. I wonder what it must be like to have no children with special needs. I can’t even imagine what it’s like. Although it makes me a little jealous sometimes, too. I can’t understand, but I also wish it were me. And then when I get down, I try to bargain with God. I say, I’ll trade PWS for diabetes. I know it is silly, but I know others also do this under stress. It makes me so sad that food, which is life giving, is so dangerous for Colin. I wish I could trade the food issues for something else.

**Public Life**
Moms who don’t have kids with special needs have no idea of the additional burden it creates.
Sometimes, I’m jealous of them. Other times, I don’t think about it. Most of the time, I don’t think about it because I’m so used to having it. I have friends who now have kids that are old enough to have more freedoms. And as the kids are get more freedom, so do their parents. But we will always need a babysitter when we go out. I’m jealous of that. We miss out on some of the “growing older” experiences, such as going out and sleeping in.

I also realize that even good friends don’t understand exactly what it’s like to have Colin. Even though they think they might understand, they don’t really get it. Because how could they? They don’t have to live it. I get depressed that I have this burden that they don’t have. I’m worried that I will never have any freedom. That I’ll always have to be here with Colin. Our friends are beginning to go out of the house on a whim. Jeff and I can’t do that. And I feel isolated and left out.

This might sound horrible, but if Colin were more disabled, I would have much more help. And then I would have more freedom. He’s so functional, which is great, but the fact that he kind of knows what’s happening and missing, makes it harder as well. He sees his sibling doing typical teenage stuff. And he can rebel. It makes it hard.

When you first look at Colin, he seems normal. But when he talks, he has a little bit of garbled speech because of low tone, and he acts a little differently. So, I think it’s pretty clear that he’s not necessarily like other kids. Colin has a habit of asking too many questions, which is part of the syndrome. They are very curious and often ask things that are not important or not appropriate due of anxiety that PWS causes. He will ask a waiter too many questions, or stop to talk to every police officer we meet, or pet every dog we see, which is cute, actually. He can just overdo it. We have to limit him on the questions. And sometimes we have to play interference or do a little filtering so that his behavior doesn’t become inappropriate.

**Transformation**
I had no experience with the world of special needs prior to Colin. None of my friends had siblings who had special needs. I didn’t know anything about the world of therapists and special education teachers. I feel a lot more tolerant. Now, if I see a kid acting up or looking a bit different, I am far less judgmental.
I’ve learned about other people in the world and all those different experiences are valid and worthwhile.
There’s this whole other parallel world that I didn’t know about.
Before Colin, I never knew how to act around people with special needs. And now I feel much more comfortable.
I feel like you should get a little hidden badge, a sign among families so when your kid is having a tantrum, or is just different, you can say, don’t worry I understand.
This experience has made me grateful for all of the children who are born healthy.
Considering how many things can go wrong with a child’s development . . .
It is a miracle when things go right.
I also realize that Colin’s life is fulfilling and worthwhile.
He may face difficulties and frustrations, but he is happy and loves life.

Marriage
Things can get stressful, but we’re a pretty good team.
Jeff handles the research, and I always handle the day-to-day management.
In the beginning, I couldn’t bear to read anything. Jeff would give me a little bit, and I just couldn’t deal with it.
Now, I can read stuff without falling apart and talk about it easily. And now we’re even more of a team.
An added strain between me and Jeff is the fact that Colin prefers me.
Jeff doesn’t understand why he always prefers me. And I wonder why I always have to manage Colin.

Future
This is a chronic situation. But there are solutions out there.
I don’t really expect a cure for Colin that will stop him from feeling hungry.
I am hoping for a better understanding so that there could be better interventions to make their lives easier.

Our kids will have very different futures.
For Laura, we have the typical dreams.
She will go to high school, study hard, get good grades, go to college, find a partner, and have a life that makes her happy.
And then on the downside for her, be prepared because someday she will be the guardian.
I hope we raise her with enough love, guidance, patience, and tolerance to undertake this task.
For Colin, it’s not going to college. Can we find an adult living situation that will be stimulating for him?
But I hope he will live with other disabled adults.
It sounds terrible, but I don’t want him to live with me for the rest of his life. I’m going to need a break.
I don’t know if that sounds selfish or not.
The Colorado PWS group is working on trying to get a group home for Prader-Willi syndrome in Colorado. This is necessary because it’s very hard to take an adult with Prader-Willi syndrome and put them in an existing mixed group home. There can’t be any open access to food. It must be this way in order for them to be safe.

I can think about the future now. I couldn’t go there initially when Colin was a baby. This is my reality now. It doesn’t upset me anymore. I’m not hoping Colin will go to college and be a lawyer or a doctor. I just want him to find some type of sheltered work environment, so he can be stimulated and fulfilled, be interested, and have a safe place to live.

**Advice**

Take one day at a time. You’ve got to mourn when you get the diagnosis. Whatever dreams you had, are not going to be the dreams that you are going to acquire. And you have to give yourself some time to feel sad—and that’s perfectly normal. There will be times throughout your life where it comes back, and you have to mourn anew.

For me, I had to just take a little bit at a time. I didn’t want to know what life would be like at 25, when Colin was 6 weeks old. I only wanted to know what I had to expect when he was 3 months old.

Also reach out to other people in the same situation and find other families who have your exact syndrome. Get support through doctors, therapists, friends or religious organizations.

Don’t suffer in silence. I don’t immediately introduce myself and say my kid has Prader-Willi syndrome, but when it’s clear that something unusual is going on, I explain. I think this is a good opportunity to educate the world. You don’t have to advertise it, but you need to tell people so they can help and understand what you are dealing with. I want people to know that Colin has a syndrome and that accounts for differences, and that they should understand. I hope they understand and are tolerant.

People in Colin’s school knew that he was different and that he had special needs, but they didn’t really know what it was. I find that as people get to know us a little bit better, they’re grateful if I tell them about PWS. I recommend writing a letter to all of the parents in your child’s class. Tell them about your kid. It is helpful. Families really want to be helpful and supportive. I wrote a letter to the class asking them to forego birthday treats, and everyone was thrilled to help.
If you have information, you have less to be fearful of. And differences do not seem as bad when you’re educated. You don’t have to walk around with a big sign on your shirt . . . but don’t withhold information.

Sandra

This semi-retired nurse, age 47 and married, now works as a stay-at-home mother to Audrey, age 16, and Nate, age 14, diagnosed with intractable seizures. Here is Sandra’s story in her own words:

Diagnosis
We didn’t know anything was wrong with Nate until he was six months old. He seized for over an hour before they could stop them. We were in shock. The first five years were truly horrible. He was so fragile. It was so scary. He has had eight seizures lasting about an hour. Life Flight knew us well. We didn’t dare go more than 15 miles from a hospital. Our stomachs were in constant knots. The stress was overwhelming. Always scared. How do you live like that? Is this what it feels like to live in a war zone? Always on alert? Never sleeping well so you don’t miss anything?

Nate was always on a ton of drugs. I would determine the size of my purse by the amount of Valium I needed to carry with me. He had brain surgery at Mayo to decrease the seizures. It’s a hard thing to do to say, yes please, take out part of my son’s brain. But now the seizures only last one minute or so.

Family Life
Only in the last few years have we felt like we can go out and do things. Anything that stresses out Nate can make the seizures worse . . . hot weather, hunger, noise, excitement. So, I never want to go and do anything. He has seized in grocery stores, furniture stores, and McDonald’s play yards. But we want to go out. We want Audrey’s life to be as normal as possible. Of course, there’s no way for it to be completely normal because we’re so restricted.

While he was in school, I used to fear the phone ringing because it always meant something was wrong with Nate. I dreaded ambulance sirens. And always watched if it was headed toward school. I still need to have my phone with me at all times when he is not with me.
I realize that this is the only life that my daughter knows, but how will she handle all of this?
Does she feel the stress?
Does she feel that something isn’t right?
Are we stressing her unintentionally?
We try to give her a good life but is a normal life possible in our situation?
Will she be a better person growing up with a disabled brother?
Be a kinder, gentler, and more tolerant person?
Or will she be unhappy about the life she lived?
Will she be intolerant and impatient, wishing for the opportunities she never had?
I guess time will tell.
I feel a lot of guilt that Audrey can’t have a different kind of childhood, but what can I do about it?
Let’s have guilt over things I can do something about.
We have tried hard to give her a lot of normalcy, as much as we possibly can.
But no household is perfect. Everybody has a different set of problems.
You grow from what you get.

We try to get Audrey involved.
However, she is affected because there are lots of things we can’t do.
I hope she will be a lot more patient and understanding of people.
You know, it’s a character building thing since we have no control.
She used to get angry and mad because Nate wouldn’t go fast enough and he doesn’t play and interact.
But in the last year or so, she has kind of accepted him.
She’s nicer to him, a little more patient with him, and really helps him do things he can’t do.
We never talk about it, but I don’t think she’s embarrassed by his seizures.
She’s probably more embarrassed about how delayed he is and how different he is from other kids.
He looks like other kids, but he’s very different.

Audrey has come to us with her negative feelings.
We try to make it a frank discussion and try to problem solve.
We don’t say just live with it; rather, we try to figure out how to make the situation better for her.
We try to be open and troubleshoot. Knowing Nate’s limitations, we do what we can.
When Audrey comes home from school, I try to spend time with her.

Listening to her, hearing about her day, asking about what’s going on. Staying connected.

**Transformation**
I’m more patient now.
I have lost some of my daring.  
I used to be the type of person who would shoot from the hip. I didn’t need to be organized or routine driven.  
But I’ve had to change that. I have to be on top of everything.  
I used to be a little resentful, a little angry, and a little hopeless that I was stuck here.  
Because Nate is 24/7.  
But now I feel that this is the way life is, so let’s just do what we can do and move on.  

The truth is, I don’t know what normal is, so this is our norm.  
I have no idea what we would be like if we had only typical kids.  
They would probably both be running to soccer games and going like crazy.  
Maybe we would have had more kids. But it was too intense after Nate.  
We look back now and say that we should have had one more.  
I do not know if we could have handled it because Nate was so fragile, but I think it would have been great.  
For all of us.  

Motherhood  
I grew up thinking you have kids and they play sports and become involved in school.  
But that didn’t happen.  
It used to be hard to watch my brothers and sisters with their kids because they were having a normal life.  
A life I never had.  
But this is my normal, and I am not normal compared to them.  
I have always been a positive person, so I try to focus on being optimistic.  

This is not the life I thought I’d have.  
I never thought I’d have such a medically fragile child . . . that my life would be spent in the medical community.  
Other moms think they have it so hard. In their mind, they have big issues. They think they have so much to worry about.  
But I have to deal with seizures seven times a week. Try that.  
But could they even handle a kid like Nate? Probably not.  
Some people can’t relate to me. They almost feel sorry for me or pity me. I can’t stand that because this is just the way life is.  
Everyone has something.  

Growing up, there was a girl in my town who had seizures. Lots of them.  
I remember thinking, please not that, anything but seizures.  
And look what I end up with.  
I tried to stay away from that girl, so I totally understand why people stay away from my kid.  
I felt the same way. I don’t expect others to try and be fake.
You do what you have to do.
When Nate has a seizure in public, I focus on getting him someplace safe.
I am not embarrassed. I can’t do anything about it.
He has seized in the grocery, next to the cheese.
He has seized at a reservoir, in the water. He was heavy, cold, and rigid. I had to get him out of the water.
I know everybody was staring at us. But if I panic, they will panic.
Once, he seized at church next to this lady. Later, I called her to ask her if she was okay and answer any of her questions.
I remember watching that girl in my town seize. I remember needing to talk, so I wanted to give this lady the same opportunity.

Public Life
I do feel socially isolated with Nate because I have to watch him constantly.
You can’t socialize because your eyes have to be on him all of the time.
What he’s doing, how he’s looking, is it too hot, is it too cold, are we doing too much?
I try not to stress about it because I have enough stress to deal with.
I still consider my quality of life to be good because family is the most important thing.
Stuff does not matter, only memories and family.

But I truly wish Nate could be more involved in social events.
How I wish that he could have the same opportunities that Audrey has.
To be able to go fun places and meet new people. To be able to go to a party and have fun with other kids.
To have a good friend base. To be able to have more in his life than just two parents and a sister.

Marriage
When Nate was very young, we talked about how this could be a deal breaker for our marriage.
How the stress could end up splitting us up if we weren’t careful.
And Bill’s job is stressful and has a high rate of divorce anyway.
So we have really tried to communicate constantly.
We know that Nate will be with us forever and there’s already a high rate of divorce with disabled kids.
He thinks that my job is Nate, and he is back-up. Sometimes, I think his back-up role needs to be stronger.
So we talk it out. This communication is extremely important.
If I am angry all of the time or he’s angry, pretty soon the marriage will fail.
And do you think it is going to be any easier when you are by yourself?
It seems hard when you have two parents and almost impossible when you have only one.

Future
We are very focused on making sure Nate is taken care of in the future.
Financially and emotionally, he will probably be with us forever. He could never live by himself, ever, ever, ever. It’s not like in our retirement years we will be playing shuffle board. We will have a kid with us, so we need to think in terms of three, and not just two. I hope that Audrey goes to college, has a career, and a family. I truly don’t want her to think she has to take care of her brother when we die. We want it to be her choice, not her responsibility.

**Advice**
Try to develop a bond with people who have disabilities, so you can communicate with them. They will totally understand where you are coming from. At the same time, try and spend time with “normal” people with “normal” kids. Do not isolate yourself and say it’s because my kid is disabled. Both sides have great advice. Live in the real world.

Find a friend you can vent to. Everybody needs someone like this in their life. My sister is great for this. She has typical kids, but she understands me. And my husband is great, too. We will vent back and forth and problem solve. We bounce ideas off each other.

Do your research. If you are prepared, it either won’t happen or you’ll be able to better handle it. Knowledge is power. I am not the only one out there dealing with this stuff. There’s a ton of stuff online. Find it. Nate can’t button, snap, or zip. Where do we go to get clothes for him? I go out there and try to find out.

Be realistic. Don’t overestimate your kid’s abilities. Don’t push them into something they are not ready for. I see moms with typical kids who are trying to turn their kids into the next Mia Hamm. They pay for endless lessons, they push them, and they get burnt out. And then I see moms with kids with disabilities who are trying to make their kid into an Einstein. But he can’t even read! They are not teaching him to read because he doesn’t have the mental capacity to read. Face it. I also see moms who stop having kids after their disabled kid. I feel bad for them because this kid becomes their entire life. It is sad.
Sharon

Sharon, age 39 and married, wears a variety of hats. Not only does she spend her time as a music teacher, graduate student, board member, and community activist, but Sharon is also raising 8-year-old Amanda, 6-year-old Zachary, and 3-year-old Megan. Zachary has Down syndrome. Here, in her own words, is Sharon’s story:

Diagnosis
I had a wonderful, natural childbirth. It was a beautiful experience. Apparently, the doctors were highly suspicious when Zachary was born. But they didn’t tell us anything right away. We went to the mom and baby room and had some nice bonding time with him. We called everyone, and told them that we had our perfect, little son. Then they took him away for his bath, and we got some sleep. At midnight, the pediatrician came in and woke us up. She had a huge list of things that were wrong with Zachary. She said he’s on oxygen, he’s under a warmer, and he may have pneumonia. Then she said Zachary had Down syndrome. It was like a ton of bricks hit us. We spent the next 24 hours in shock. So then we had to call back all of our people. At 5 a.m., I called my mom. I don’t even remember what I said to her. How do you tell your mother?

It was horrible. It was a really terrible time. The first time I looked at pictures of us in the delivery room, Zachary was probably 4 weeks old. My mom brought them over, and I had a hard time looking at them. I just cried because they were taken before “we knew.” And I thought I would never be able to look at those again. But now I can look at those pictures with nothing but love. Because he is perfect. He’s just a different kind of perfect.

Family Life
I’m not sure that having a kid with Down syndrome really makes it much harder. I think having three kids is just hard. We wanted three kids. We thought it would be nice for all of them to have each other. And for Amanda to have a typical sibling. And it has been great for Zachary to have Megan because they are wonderful friends. I think it’s just hard to have three kids. It’s a different one that has special needs at different times. And I don’t know if that’s because Zachary is high functioning or because this is just what our life looks like. I don’t know if it would be easier if I had three typical kids.
And I don’t know how much of his challenges are the Down syndrome and how much are just being a little kid.

I think it’s great that Zachary is in the middle. He benefits from having an older sister who’s very motherly and having a little sister who is a pal. Megan constantly leads him down the road of trouble. I think having him second most likely helped us be more mellow about things. Having a disability and being in the middle allows you to stand out a little more. And that helps Zachary because they always say the middle child is the one who gets lost.

If Zachary were the oldest, I wonder if he would be our focus. But we are all very accepting of him and his disability. He has blue eyes, brown hair and Down syndrome. I think we’ve been lucky because he has not had a huge number of health issues, and he’s only had three surgeries. You know you’re a mom of a kid with special needs when you can happily say my son has only had three surgeries in his six years. His behavior can be challenging, which is the most difficult aspect of him, especially right now. But then you look at the other two kids, and they are all difficult.

We all just look at Zachary as another kid in the family. As they get older, I’m looking forward to seeing what the girls think of having a brother with a disability. Amanda knows he has Down syndrome, and she knows other kids with Down syndrome. Zachary is in a fully inclusive classroom, but the school also has a center program for kids with behavioral disabilities. Amanda refers to these kids as the “special ed kids.” One day, I told her that Zachary is considered a special ed kid, even though he is in a typical classroom. She couldn’t believe it. She knows what Down syndrome is, and she knows it takes him longer to learn. But she just sees him as another kid.

I remember being on the playground during Girl Scouts and a little girl came up to Amanda and asked her why Zachary looked funny. Amanda just looked at her and said, “He has Down syndrome.” Like, are you stupid? He has Down syndrome and that’s how he looks. It was so great because she didn’t feel embarrassed, rather that’s the way it is. I can see that junior high may be a hard time. She might be embarrassed by him, but that’s life. I was embarrassed by my sister in junior high, and she was perfectly typical.
There will probably be times when both girls ask why we spend a lot of time with Zachary. But we try to spend equal time with each kid. We make sure they all get their mommy and daddy dates. Zachary is part of the family, and we do things around special needs issues. But we don’t let it take over our lives. It is a lot of hard work, but we have a great amount of love in our family. We laugh a lot. We make enough money, so I can mostly stay home and we can go on vacations. We are happy.

**Motherhood**
I thought I would be much more fun and creative as a mother. Because I was as a teacher. And when I babysit, I’d do all sorts of fun things. But you get so tired. I feel disappointed in myself that I’m not more creative and energetic. I really am trying to just play with the kids more.
I feel so grateful to have Zachary... just because he’s really expanded my view of the world.
Motherhood is really hard. It’s harder than I thought. I thought I would be more gracious as a mother than I am. Just because my mom really seemed like she was. There is a complete lack of privacy and time for your own self.
I feel that conflict between really wanting to stay home because I think it’s the right thing to do and feeling like it’s just so boring. How many times can I make a snack for you? Just the constant asking... mommy, mommy, mommy.
So I guess it’s trying to balance everything.

I think I’m certainly more open minded about other people’s problems. Some moms think their tiny issues are a huge deal. But I don’t think it’s fair of me as a mom with a special needs kid to feel that way about someone.
Because you can never walk in anyone else’s shoes. I’ve learned that from this experience.
I try not to compare myself to other moms.
I started doing that when Zachary was really little, and it’s not worth it. It’s depressing. You look at the baby book and at nine months, they’re supposed to be doing this and that. But Zachary wasn’t doing any of it. I had to throw away the book.

There certainly are huge challenges, like getting him potty trained, but it’s so worth it. And he’s just such a wonderful human being. He has so many great qualities. I can handle the challenges because the rewards are so huge. However, there definitely are times when his disability makes life difficult. Every time I go down that road, I try to think positively.
Zachary really has made me appreciate life . . . just in a different way.
He has shown me that there’s more to life than what you thought. You need to appreciate
the little things.
Zachary got into trouble at school for poking another kid in the forehead, and he had to
go to the principal’s office.
When I asked him what happened, he described the entire exchange.
It was so great. I know I was supposed to react negatively to what happened, but I was
happy.
We had been working so long on remembering events, and he told me everything that
happened.
It was a beautiful moment.

Public Life
Sometimes, I feel like I have to explain Zachary a little bit more.
But overall, people have been amazingly supportive and accepting of him.
I just keep waiting for negative things to happen, but I haven’t seen them yet. I’m sure
that I will when he’s older.
At times, I do feel like we’re the “one black family” in the school.
I worry about what I should do to make sure everyone understands Zachary and is not
afraid of him.
I guess it’s a little bit of isolation.
But it’s also just this feeling . . . like I have to do more to talk about him.
Or if his behavior is bad, I feel more self-conscious than with the other kids.
The kids in his class have totally accepted him, and the parents, too.
But I guess I don’t really know what they’re saying behind my back.
Zachary hasn’t been invited to any birthday parties or on any play dates, but I think these
will come.
Socially, he’s not quite at the same level as his peers, so he’s not initiating a lot of social
behavior. Yet.
I want him to have friends, typical friends. I really want that for him.
I’m trying not to be upset about it now because there’s nothing I can do except to try and
facilitate some friendships.
But he plays by himself so much that I’m scared to have a play date because I am afraid
he’ll just go off and do something else.
I see the acceptance at school. The kids always say hi to him and talk to him.
He’s just part of the class. He may not be their best buddy, but they don’t shun him.
I worry about the friendship thing, but he always exceeds my expectations.
So I’m trying not to be too worried about it yet.

We are starting to get more stares now. Little kids will just look at him.
And that doesn’t really bother me because I decided early on that people do that out of
curiosity.
It’s not like they’re trying to be mean or anything. I just have a big smile for people.
I feel like this is our normal, and I don’t even think about it most of the time anymore.
At first I would tell everyone he had Down syndrome, and I’d look for other people with Down syndrome every minute. If I saw one, I’d be so happy because we were not the only people. And now I don’t. We are a normal family and this is what’s normal. There’s really no such thing as normal. But there are some times when he can have some challenging behaviors, and it is a little embarrassing. I feel like I am held to a different standard with Zachary. If Megan were throwing a fit, I wouldn’t be embarrassed. But it’s different for Zachary because of his disability. I feel that he should be perfect all the time because otherwise, people will look at me like, oh, that kid has Down syndrome. I always try to make sure he is well dressed in clean, matching clothes. Because I often see kids with disabilities in terrible clothes. I don’t want that to be Zachary. I do worry about people’s perceptions because I want them to think that Zachary is great and cute, even though he has Down syndrome.

I remember being at the zoo when I was pregnant with Zachary. I saw a family with three kids. The middle child had Down syndrome. And I clearly remember looking at them and feeling so sad for them. I thought how do they even deal with that? There was no behavior problem at all, but I felt so sorry for that family. I just don’t want people to feel sorry for me because there is absolutely nothing to be sorry about. Yes there are more challenges; yes it’s scary thinking about school and jobs. But I am in no way sorry that I have him, so I don’t want people to feel that about me. I think that’s the biggest reason why I feel more worried when he acts up in public.

Transformation
I love the changes that I’ve seen in myself as a result of having Zachary. I really do because I always thought of myself as a very open and accepting person. We were raised to appreciate different cultures, so I thought I was so well adjusted. But when I had Zachary, I had to confront some terrible stereotypes I had about people, especially with cognitive disabilities. I had to go through a grief period when he was first born. He taught me that a person with a disability really is a person. And I think so many times in our culture, we think of them as not quite people. I still remember when Zachary was a baby, I put a cute outfit on him and I thought, it’s so sad, we have all these cute clothes for him and they’re just going to go to waste. Even though he was wearing them and he looked perfectly cute in them, it was like I thought he’s not really a person. One friend told me that after their child’s diagnosis, her husband said, I guess we won’t need the baby car seat now.
People have so many weird reactions.
I think it is partly denial, but I think it’s also the fact that most people with disabilities are not considered to be true, full humans.
The biggest change I’ve seen in myself is opening up to a world full of people who have so much to offer.
And seeing the value in them and finding value in ways other than intellectually.
I was always very good at school and really valued intellectual development, but it is neat to see that there are other ways you can shine in the world.
It has made me an advocate for all people with disabilities and for people who have any kind of difference.
We need to look at how we can make our culture more accepting of everybody.

Marriage
I think having kids is the biggest factor that affects marriage.
We have a great marriage because we are a very good team.
Greg loves to do lots of research, and he makes books and games and does all kinds of stuff with the kids.
And we love to go to the inclusion conference together. We stay overnight in a hotel and it’s like our date night.
So, I’m not sure Zachary’s disability was a significant factor because we’re really close anyway.
I know for some people, it can be extremely hard, but just having kids in general is hard.
We constantly work on our marriage.
We go on a date once a week, take at least one trip, and have weekends away.
We make time to be together and enjoy each other.

Future
I see all of my kids going to college.
There are some great post secondary programs that are beginning to evolve for kids with disabilities.
I fully plan for Zachary to have an academic experience all the way through school.
My husband is very involved with the issue of employment for people with disabilities.
I think that as parents of young kids, we need to be working on that issue now.
Getting people to hire individuals with disabilities, so it won’t be such a rare thing.
The other problem is health care because if you have a full-time job, you will lose your Medicaid benefits.
And that’s scary to think about.

I’m fine if Zachary lives with us forever. We already have plans for our basement.
We can easily convert part of it into a little apartment if we need it.
My parents are building a house with an attached apartment. Zachary can live there.
At first, it bothered me that he might need to live with us, but that doesn’t mean that we will be caring for him every second of the day.
And because he’s really independent, I know he will have a job. We might have to support him and help him find friends. I think he will be fine all the way through school. Then it will be a little more of a challenge. As we get older, it will get scary.

We fully expect Zachary to have girlfriends, and if he wants to get married, that’s great. A lot of people with Down syndrome are getting married. The girls already talk about how he will be a great uncle. Most men with Down syndrome are sterile, so they can’t produce children, which is probably good.

But I think he will have a great future. He constantly rises above our expectations.

**Advice**
Don’t just listen to professionals, do your own research.
Don’t be afraid to stand up and ask question things.
We spend a lot of time doing the research ourselves.
Take time for yourself.
And if you’re married, take time for yourselves as a couple because that’s really important.
Don’t be afraid to ask for help when you need it. I’ve really learned that a lot.
You can’t do it all by yourself. You really can’t. I think that’s true with kids, and it is even more true with a disability.
Take the time to work with your child at home. We do a lot of work on reading, sign language, and language development.
But at the same time, don’t let it consume you. Because it really can.
The guilt isn’t worth it.

**Shelley**

This 47-year-old, married, mother of two is raising Zachary, age 12, and Caroline, age 10, who has Tetrasomy 18P, a rare chromosomal disorder. Here, in her own words, is Shelley’s story:

**Diagnosis**
When Caroline failed to meet her milestones, we began months of testing. A geneticist found Tetrasomy 18P when Caroline was 11 months old. It was horrifying.
The doctor’s office called to make an appointment to discuss the results. We knew something was up because they refused to tell us anything over the phone. The geneticist told us Caroline had four copies of the P segment on the 18th chromosome, and she should only have two.
I had no idea what to do with that information.
And then the doctor took out a huge genetic encyclopedia. It had one page dedicated to each anomaly with horrifying pictures on every page.

We got home from the appointment, but my husband and I couldn’t stay with the kids. We were just too upset.
So my uncle stayed with them.
Jay and I walked into town.
We ended up walking into an open church and sitting down.
We both sat there and cried and cried.
Then we settled down and decided we had to move to Denver to be near my family.
We had no other choice. We needed the help.

I have this lovely black and white photo of Caroline.
My dad, who loved to shoot in black and white, took it before he died.
Caroline is about 5 months old in the photo.
It is October, and we are happily playing in the leaves as I give my daughter Eskimo kisses.

A month after this photo was taken, I remember starting to worry that she wasn’t rolling over.
By December, we were referred for testing.
We were on our path to having our daughter identified as developmentally disabled.
But that beautiful photo doesn’t show she’s disabled.
It just shows a loving relationship with a mother and her baby girl.

**Family Life**
I’m glad Zachary is older.
It would be so hard to have younger kids who would developmentally pass their sibling.
You would have that constant comparison thrown in your face.

It gets easier as they get older.
The differences between your child and other kids with the same chronological age become so pronounced.
At that point, you stop comparing them.
It’s reality.
You get to the point where they are just so different, it’s like apples and oranges.
Then you can let go and let them be who they are.

If Caroline had been an older sibling that would have been a longer process.
Sometimes, I think about Zachary and Caroline.
It’s so hard to imagine life without Zachary.
But in some ways, it would be easier because we would not feel so bad about burdening him or neglecting him.
There would be a whole set of worries that wouldn’t be there.
But on the other hand, if we completely focused our attention on Caroline, there might be the temptation to become even more isolated. Zachary is a nice reality check for us. We can’t make disability our entire world.

I do worry about Zachary. I worry that we give him too much responsibility. He is asked to help with Caroline, but we need to remember he is still only 12. It is hard to know what’s reasonable as far as expecting him to take responsibility. Also, Zachary is much more a part of our marriage than he would be if Caroline were typical. We end up sharing quite a bit of our time with him. He’s very close to us. We must establish boundaries because of that. In some ways, he is growing up more quickly than he would. He also has a lot of independence. My sister has a son Zachary’s age, and she doesn’t let him ride his bike or skateboard alone. Instead, he has to go with a sibling. But that’s not an option for Zachary, so he gets to do a lot on his own. While it is risky, it makes me too sad to think of him not being able to do these things.

I also worry about the pressure Zachary puts upon himself. He stresses a lot about achievement. A while back, he got so upset about getting a B. I asked him why a B was so awful. He told me he felt like he had to get perfect grades because Caroline wasn’t going to be able to. It goes back to him feeling like he has to earn our love. Caroline is certainly not earning our love through achievement.

I really want both of my children to understand this is an unconditional relationship. And sometimes I might get mad and sometimes I might get disappointed, but the basic thing is completely a given. And I think in some ways having Caroline makes me more confident that Zachary is going to get that. Because he can see that she doesn’t have to earn it. That’s one of the ways in which I think, one of the many ways, in which she’s really helping us to have a better family than we might have had without her.

Last summer was the first time that we ever went on a trip as a complete family. We usually take separate vacations involving extended family. One of us takes Zachary somewhere. The one-on-one time is really nice. But it means the other two have to stay home.
I like to spend alone time with Zachary.
It feels like I’m taking a break from my real life. This time together feels so natural.
We love to go to the movies, just the two of us.
What that means is you leave at a certain time. And no disaster happens that makes it so
you can’t get out the door.
And you get there on time and you buy the tickets.
And you don’t have to worry that anything is going to call attention to us that’s going to
make us embarrassed or mad.
It’s easy and uninterrupted.
And I think it’s really important for us to interact in ways that Caroline is not directly
impacting because so much of the time she is.
I no longer feel guilty about not including Caroline, because Zachary and I need this time
together.
This is our time.
I want him to have some sense of his own childhood and his own relationship with me, as
well as the communal thing.
And I really encourage my husband to do things—just the two of them—for the same
reason.

We recently hosted a dinner party.
I had the most fun in the last hour when Caroline parked herself in front of the TV, and I
was sitting talking with our guests.
I didn’t feel guilty about it—just sad that the most fun for me is the part that she’s least
present for.
But then I can also see the blessing in her being happily and safely occupied for an hour,
giving me the opportunity to relax.
I just wish her isolation was not part of the equation.
It makes me feel blue.
I don’t think it makes her unhappy.
Maybe I am just projecting how I would feel about it onto her.

I think that having a typical sibling for Zachary would have been a huge gift to him.
But we just can’t give him that.
We give him a bunch of cousins instead.

Having Caroline is like having a baby all the time.
In a typical situation, the child would mature and in a couple of years, it would be really
different.
Whereas for Zachary, it’s never going to change.
She’s been demanding from day one.
It’s interesting. This is all he has ever known.

**Public Life**
When we are out in public, Caroline will sometimes start yelling with pleasure.
But people don’t know that it’s pleasure. Zachary gets uncomfortable and says it’s just too loud. I try to tell him that it’s also hard for me when she’s loud, so he knows that it makes me a little bit uncomfortable. But we have to put up with it, and we won’t stay in the situation any longer than we need to. I don’t want him to feel guilty because it’s a real feeling. I don’t want it to turn into resentment.
So, I just want to acknowledge that it makes me feel really uncomfortable, too. I always try to affirm in some way that I do get it . . . that she does embarrassing things at times. I remember telling him once about how people shoot me looks like, can’t you control your kid? And even though I know it is their problem, and not mine, it is still really hard. He was like, wow, you feel that way? It was important to share that with him. It makes him feel less alone in his feelings and lets him know it’s okay to talk to me about those difficult feelings.

Then, we need to take it to the next level. This is parsing out how much of it makes us uncomfortable. And how much of it is investing too much importance in what other people think. Navigating the challenges of being a teenager come into play. Especially when it comes to caring what other people think.

I tend to feel isolated in family situations. I am one of 5 kids and there are many cousins. Everybody else’s kids just run through somebody’s house, but Jay and I have to take turns watching Caroline. Where is she? What’s she doing? Is she safe? It’s just normal for our life, just our little bubble.

Even my mother doesn’t get it. She refuses to put baby gates in her house to keep Caroline safe. Going to my own mother’s house is difficult for us. It’s isolating.

We have these friends who are great. They are so accommodating, making their house safe for Caroline. And they love her. They have taken it upon themselves to try and understand. They don’t pity us, but get our struggles. I really feel like we can just be who we are around them because they get it. And that’s so wonderful.
When we are out in public and people are looking at us, I’m much more likely to worry when Zachary is there. I just don’t want to put him in too many uncomfortable situations because life gives you enough of those. You do not need to go out and look for them. I had a stressful childhood without having a disabled sibling, and I don’t want Zachary to have to contend with similar stress. I am very alert to not causing social stress by unnecessarily being in those situations. Unfortunately, this translates into limiting the situations that we are all in together as a family. But when it’s just me and Caroline, or the three of us, it’s fine. Jay has never been too worried about what other people think. He’s a very good role model for that.

Transformation
Having a child with disabilities definitely rocks your world, but it shouldn’t be the hub that everything feeds off of. Caroline is my gift; she’s taught me so much. But it’s important not to let the disability control you. It should not define your life or what you enjoy. There’s a nakedness and authenticity to Caroline’s experience. This has changed me. The repertoire of who I am has been expanded. I am a better mom, teacher, and wife. I can relate better to my family and my students. I am much more present to my students and more effective. It’s also changed my relationship with God. How I look at my faith.

Caroline’s personhood just shines. She is this very complete person in a way that we may never understand. We are all still tied up in our fears and expectations, but Caroline doesn’t have these things holding her down.

When she was 4 or 5, I realized that she had a very specific vocation. She is here to teach us some very specific things about what it means to be human. That humanity isn’t something you earn. All of us should be able to respond to each other with the kind of openness and love that Caroline has. Really, in a lot of ways, it’s the rest of us who are disabled. Caroline is not participating in the “fallenness” of the world. She has a kind of purity that we all really need. The life she is living is very meaningful and worthwhile, but it is very different. And the world doesn’t have a category to be able to respect that. There’s so much noise in our lives and so many distractions.
Some of the skills that Caroline is missing mean that she doesn’t have those distractions. If you could live a life free of fears, what would that look like? It would look like Caroline.

Having a child with disabilities gives you more patience. It makes you better, less clueless.

Jay once told me that he was in the waiting room of a hospital developmental unit with Caroline. And this little boy sat next to him. The boy was completely nonverbal and nonresponsive. But Jay began interacting with him, telling the boy all about Caroline and their visit. He said that before Caroline, he would have been scared to death of this boy. Scared to do the wrong thing or offend him. But instead, he felt very comfortable. And he was reproaching himself for how oblivious he must have been before.

**Motherhood**

When we found out about the diagnosis, I was absolutely devastated. I went into an emotional tailspin and became very depressed. I started seeing a counselor, who helped me deal with the reality of Caroline’s diagnosis. What I had never realized before was how much I had constituted parenthood as an intellectual relationship. Being a college professor with a Ph.D., I had always thought about motherhood in terms of the books I would read with my kids and the in-depth conversations we would have. Because I knew I could never have any of these encounters with Caroline, I could not picture how I would be her mother.

But my counselor told me that you can relate to people on four different levels: intellectually, physically, emotionally, and spiritually. She told me—and I will never forget this—that there was no reason I couldn’t relate to Caroline on the other three levels. I could still connect with her physically, emotionally, and spiritually, which made sense. It was just that the intellectual piece had been so important to me that I couldn’t get past it, so I couldn’t process it.

I wasn’t equipped to think of our relationship without the intellectual piece, but I had to find a way.

I needed to focus on the other three levels if I were going to be able to mother her. I needed to change the perspective that I had on what it means to mother. I was forced to recognize that there was more to me than just a brain, that I have more to offer people than my intellect. This was an important life lesson for me.

It also helped me mother Zachary.

Looking back, I realize I had these ideas about what our relationship would be like.
When I realized these things weren’t going to happen, it was like a death of that anticipated child.  
And so I had that weird feeling of grieving somebody who was not actually dead.  
You’re grieving who your child is not and you are feeling disloyal, but you have to sort of get through that process.  
And realizing you didn’t even now you had these expectations.  
But part of what I realized is that my own conception of my self was so narrow that it was hard for me to imagine a mother-child relationship that wasn’t primarily intellectual.

Physically, Caroline has needed so much attention.  
I think our physical relationship has been more intense than with my son.  
Just because Caroline is still in diapers, I pay close attention to her bodily processes—and she is 10.  
I know when she’s got a rash on her bottom, and she needs a bath.  
Whereas Zachary could walk around for 3 days before suddenly realizing that his hair is sticking up in weird angles.  
Go take a shower. He’s 12.

I really appreciate Zachary’s typical development.  
I’m like, wow, you are doing what you need to do.  
Then I decide that I’m not going to be proud of him because of what he can do.  
I just want to be proud of Zachary because he is who he is.  
But then the loyalty thing plays in, too.  
If I can be proud of him because of what he can do, then that means I’m not proud of the disabled child.  
So it’s very interesting.  
And one of my main goals as a mother is to never let Zachary feel like he has to earn my affection.  
So, I’ve always been really conscious of that with him.

I am frequently struck by how each individual human being is directly and knowingly created by God.  
That God knew precisely what the genetic makeup of Caroline’s first cell was.  
And deliberately called her into existence knowing that.  
He loved her into being, not in spite of her differences and also not because of her differences.  
He just wanted her as herself.

It’s amazing how “grounding” parenthood is.  
Even more than marriage.  
It’s very clear what parenting is . . . nurturing this new person as their particular life unfolds.  
A life very connected with mine, but not identical.
I think some of the trouble I had with processing Caroline’s diagnosis was because I hadn’t constituted her as a separate person. “This can’t be true for her” was all mashed together with “this can’t be happening to me” in a way that felt unbearable.
Over the past 10 years, I’ve come to see myself and Caroline as entirely separate people, very different from each other, but very good for each other.

Marriage
Jay and I have been married for 15 years. We recently went out and drank champagne to celebrate. We clinked glasses, and Jay said, “It’s been a winding road.” And I said, “But we never have to worry about the other one veering off.” It has been a road with many twists and turns, and he is much more emotional than me. But neither one of us has ever felt like the other one might peel off at one of those turns. Our confidence in each other is huge. That’s so important. We have learned a lot about each other’s strengths and weaknesses, and we have an appreciation for both of these. We are more patient with each other’s weaknesses because of Caroline. We are much better people than we were 15 years ago. We are much gentler with each other. And with other people.

I wouldn’t wish this on anybody. But I think that the diagnosis has forced us to have a certain focus and intentionality about what we need our life to look like. Every marriage could use something that really makes people focus on what’s important. We have been forced to figure out our top priority. And forced to do it in a context where we really had to think clearly about it. Our reality would not have allowed our priority to be our golf game.

Future
The other day, Zachary began talking about going away for college. I realized that I have never envisioned a household that doesn’t include him. And I need to wrap my brain around that.

It’s scary not knowing the future implications of Caroline’s rare syndrome. I try to be realistic and focus on taking each day one at a time. The difference is that I see Zachary as having so many choices. For Caroline, it’s the opposite. She’s not going to have a whole range of choices. We have come to assume that she will live with us until we die. I don’t feel it is bad for us to envision ourselves as two old people with our middle-aged, wonderful daughter.
But maybe when she’s in her 20s, it’ll be better for her to live in another setting. I try not to picture that scenario because it is really scary for me to think of not having hour-to-hour knowledge of exactly what she is doing. At some point there is going to have to be somebody else. If that happens, I am going to have to trust somebody else or a group of other people to have this hour-to-hour awareness. And to keep her safe.

Susan

Susan, age 40, is the married mother of four boys, Dillon, age 24; Sam, age 21; Connor, age 5; and Henry, age 2 ½. Susan and her husband are still searching for a diagnosis for Henry. He is developmentally delayed and nonverbal. Here, in her own words, is Susan’s story:

Diagnosis
My pregnancy was very complicated. I was carrying identical twin boys with twin-to-twin transfusion syndrome. This is when twins share a single placenta, causing the fetuses to become connected and share blood circulation. As a result, their development was delayed. After I gave birth, Henry’s twin, Mason, was diagnosed with congenital heart disease. He died a week later. As time went on, Henry did not seem to be developing normally. At the age of four months, he still looked and acted like a newborn. He never cooed or babbled. We still have no diagnosis. We are waiting for insurance to approve a microarray genetic test. Hopefully, this will give us some answers. I am getting antsy. As a mom, you want to know what’s going on with your child so you can research and find resources to help. And just wrap your arms around what this is and what it means.

The doctors think he has some brain damage, some form of cerebral palsy. Maybe because of the pregnancy, being a twin with twin-to-twin transfusion syndrome, or being incubated at birth. Or maybe it happened when cells were forming during conception. Nobody knows. If the genetic test doesn’t show anything, we have nothing left to do. Just watch him grow.

When I was pregnant and found out about the twin-to-twin transfusion syndrome, I felt devastated. It was like I was standing beside myself in a ghost-like appearance.
I really didn’t understand what was happening.
I thought, okay, now what do we do?
It was so overwhelming. We were on a rollercoaster ride.
I thought I did something to cause all of this.
But then as time goes by, the feeling that I did something wrong went away.
And then Mason was diagnosed.
What if Henry had it? Would they both die? Could they survive the heart surgery?
What would their lives look like?
Then Mason died and our hearts were torn to shreds.
We had to be thankful that Henry survived.

Family Life
Things between Connor and Henry are difficult because they can’t communicate.
And Henry is so much smaller.
Connor wants to treat him like a regular brother and doesn’t comprehend that he just can’t.
He does not understand his brother’s boundaries.

It is getting harder now because Henry’s communication skills are not keeping up with his development.
He just can’t express himself.
He gets frustrated. He has lots of tantrums.
My husband and I get frustrated.
We have no idea what to do.

I try to tell myself that it’s not his fault.
I try not to get upset.
Connor tries to help and fix things.
It is what it is.

I worry that Connor is suffering because he is not getting enough attention.
He tries to get our attention by acting out or doing something he knows is wrong.
I probably don’t help by being overprotective of Henry.

Marriage
This has made our marriage stronger.
We have been together for nine years, and our communication skills are very strong.
Being able to communicate about Henry has improved our bond.
Of course, things are not perfect.
As a mom, I am compassionate and understanding.
As a dad and husband, his male ego can get in the way.
But we work through it. He is very supportive.
We try to work together to resolve issues and find some type of answer.
Motherhood
I see myself as a mom who is attentive, listens, and observes everything.
I feel like I am a huge umbrella.
I just want to shield my kids and keep them safe.
My older boys tell me what a great mom I have been.
My friends tell me I was insane to start another family.

I don’t know many other moms who have kids without some type of special need.
But I feel that these moms have it better.
They have the luck of the draw, having healthy, non-special needs kids.

I can’t help but feel left out when other moms talk about their typical 9-month-old children saying momma and dada.
It’s hard to deal with because I so want my 2 ½ year old to say these words.
Sometimes, I wish I were in their shoes.
Then I think back, and I was in their shoes about 20 years ago.
As a mom, you don’t want to compare your kid to others.
But you always do it because you want your child to be as normal as the next child.

Transformation
I do not think I have changed. I have been refined.
I have had to become more compassionate and patient with my son.
Becoming more flexible has been important. Becoming more giving with my time for his needs and his appointments.

This experience has made me more aware of myself and those around me.
I am more aware of my emotions and my actions.

It also has made me more sensitive and opened up my thought process about having a child with a developmental delay.
My oldest son had problems with his hearing when he was a baby.
But he was still along the same lines as everybody else, just a little behind.
Henry’s disability has made me more aware of the differences in developmental needs.

Future
I worry that things will only become harder.
The communication piece with family, friends, and school will cause more problems for him.
He will wonder why he can’t talk like everyone else.
I think that as he gets older, he’s going to figure out that he is not like everybody else.
This will inevitably cause challenges, especially in the teenage years.
All of the hormones will make it worse.
Advice

Be open to communication. Whether it is your husband, sister, mom, dad, or therapist. As hard as it was for me to talk about Henry and Mason when I went back to work, it helped.

It was so hard. I cried whenever I talked about it. But talking helped.

The pain never goes away, but it does subside.

Search out local resources. These are great for information, funding, and support.

Give yourself time to breathe and grieve.

I grieved over Mason and Henry.

I still do.

I look at Henry and feel a thud in my heart.

The thud is a combination of what could have been and what I wanted it to be.

It also comes from seeing Mason in Henry. And wondering how things might have turned out differently.

And then the feeling is over, and I move on.

But feeling those feelings helps me to cope.

Tessa

This 39-year-old, married, part-time environmental consultant is raising three children with her husband. Ellie is 9, Maggie is 6, and Jack is 4. Jack is undiagnosed. He has endured numerous medical tests, but all have come back negative. His current diagnosis is global developmental delays. Here is Tessa’s story in her own words:

Diagnosis

At 6 months, Jack was missing major milestones.

Three months later, we began testing. We haven’t stopped.

I think we took a lot for granted because he interacted with us so typically, just like his sisters, and because his tests were negative.

We just figured therapy would make him catch up.

My older girls were energetic, happy, and rambunctious. I figured Jack would become the same way.

Jack’s challenges have unfolded very slowly for us.

With all the tests we have done, Jack is still undiagnosed.

We have never had that “aha moment” to tell us what is going on.

In a way, being undiagnosed is both a blessing and a curse.

It is a blessing because the sky is the limit.

Maybe just around the corner, Jack will make the turn and catch up to his peers.

It’s a curse because we don’t know if the road ends.

Is it today, is it tomorrow . . . or was it yesterday?

Although we still wonder, we are beginning to accept that we may never know why Jack is the way he is.

Jack is the baby of the family and has always been, so it has taken us longer to understand his
delays. Jack as a baby is not out of context in our family. There’s a lot of babying that goes on. I am glad Jack is the youngest child. Psychologically, I feel like I was able to have healthy children. If Jack had been first, I would have felt more responsible. But having two older healthy children takes the pressure off. Experiencing motherhood before Jack has allowed me to be a better mother to him.

**Family Life**

At moments, our house has so much anger, stress, and resentment. Feeding Jack is very difficult because it is hard for him to eat independently. Our family dinners are not always a time to unwind and chat. He’s unhappy a lot during this time. But we need to accept him and decrease the negative energy focused on him. We need to build better circles of support. We need to accept the fact that sometimes leaving him at home with a sitter is better for the entire family.

Being out in public with Jack causes anxiety for me. We do not go out to eat a lot. We avoid quiet places because I am very uncomfortable with his noises. I just want him to be calm and follow social norms. Ellie doesn’t like going to the library with her brother. When I ask her how she feels about being there with Jack, she says that she feels embarrassed. She says sometimes she just pretends he is not her brother. I am very happy to hear that she can verbalize this to me as I expect her to be embarrassed and want her to be able to talk about her feelings about Jack.

I want people to know he has a disability. That way, they won’t think he has discipline issues. It’s an ego thing. They won’t look at me as a mother who can’t discipline her kid. If they knew, maybe they would have more compassion and not judge us.

Sometimes, I think I spend way too much time thinking and talking about Jack. Other times, I feel guilty about not doing enough for him. I am often explaining why he attends a special school, why he can’t talk, why he’s different. I have to work hard not to feel pressure to make his older sisters behave perfectly to compensate for his behavior. In public, I want them to be perfect to “make up” for Jack. Maybe if they are perfect, I will be judged less because of Jack. I know that is not fair to any of them.
The girls know he’s different, but they seem unaffected so far.
Their friends seem to notice and ask questions.
I struggle with how to explain Jack to children.
I try to be aware of how I word things to the girls because I don’t want them to resent Jack.
If I do not want to go to the library because of Jack’s screaming, I try hard not to say we cannot go because of Jack.
What makes it more difficult is the fact that there are few activities they can all participate in together.
They can’t go to the same school. There are more divisions.

I try to think of the good things about having Jack as a brother.
I hope it makes the girls more compassionate and understanding of differences.
I want them to appreciate things more and not take things for granted.
I hope we can all truly love and accept him for who he is.
I hope I can always see the good things about him.
I try to focus on him, his smiles, his sense of humor, his love.
I feel very blessed that he adds so much love and laughter to our lives and that he touches so many people with his bright smile.

Public Life
We recently attended a local carnival.
The girls were running around together having fun. Jack stayed with me and watched.
It made me so sad that he couldn’t join in with his sisters.
It is very difficult to include him. Every activity is just so hard for him.
It seems like everyone is moving on and we are still stuck in time in the baby phase.
He’s a 2-year-old boy living in a 4-year-old body.
It’s like we are living in a different world from everyone else. A parallel universe.

Jack’s disability is a big part of our lives.
I spend a lot of time taking Jack to doctor appointments, therapies, and doing research.
It is difficult to explain our world to people who don’t live it.
While I don’t want our friends to feel like we are always talking about Jack, I want them to understand our difficulties.

Motherhood
I had no concept of how challenging motherhood could be.
Mothering Jack is not only more difficult, but it will be long term.
The duties of motherhood pass as your kids get older, but that won’t happen with Jack.
As Jack gets older, I worry that he will not catch up enough to enjoy some family activities and that we won’t be able to do many activities as a family.
Already, my husband and I split up. One of us takes the girls to a movie or ballet and the other takes Jack.
Even though I would not take a typically developing 4-year old boy to these events, it is so sad and disappointing to me to think this could happen even more in the future. Sometimes, we get a sitter so we can both take the girls. This is our reality, but it makes me sad.

We were in church on mother’s day and sat behind a family of five. Two older boys and a girl.
I watched them and thought that was my life, my life with three typical kids.
But it’s not that way. My life will never look like that.
Jack’s disability is always in the background. It creeps into all situations.

I was on the fence when it came to having a third child.
Our family did not feel complete, so we decided to go ahead and have a third.
It was Jack.
Now, 4 years later, I still have a baby.

**Transformation**
Jack has taught me so much about myself.
I am now more aware of people with disabilities. I never knew anyone with disabilities before.
I have always thought one of the great challenges of parenting is loving and accepting your children for who they are, their uniqueness, and not trying to mold them into something different.
Jack demands this in a different way.
And I hope that makes me a better parent to all of my children.
I think it has opened up my world to a better understanding of disabilities in general.
It has created more awareness of the struggles some people go through.
It has created a different lens through which to see things.
When I see a man walking down the street with a limp, I think he was once a little boy with a disability. I think about his mother.

I believe Jack’s life has value. Even if he stays a 2-year-old cognitively for the rest of his life.
He adds so much love and laughter to our lives.
I would never choose this life for him. I would change this in a second.
But—for self preservation—I must see the positives in his disability.
I must see him as a gift.

**Future**
I feel a lot of hope and optimism about the future.
I don’t think it will be easy.
We will have to work hard to maintain balance in our lives and a positive attitude about Jack’s challenges.
But I think it will help us to have perspective in life.
I hope we are better able to discern the positive in what at first seems like a negative situation and be happy and grateful even in difficult times. And if Jack’s sisters learn these lessons earlier in life, even better.

**Advice**
Don’t be afraid to ask for help. For small and big things. Sometimes, you just need to talk to someone who will listen. Be kind to yourself and don’t feel all of the guilt. Let some of it go. Don’t waste time feeling sorry for yourself. Trust yourself and your gut . . . you know what’s best for your family. Love yourself.

**Tiffany**

This 33-year-old, married, deaf educator/early interventionist has now become a stay-at-home mother to Rebecca, age 5, and Abby, age 3, diagnosed with Rett Syndrome. Here is Tiffany’s story in her own words:

**Diagnosis**
Abby began missing milestone after milestone. She didn’t sit up, crawl, or walk. And she wasn’t communicating. We began hoping that she was just a slow learner and would catch up. But she didn’t. Her doctors first thought she had autism, and then they suggested it might be Rett Syndrome. My husband couldn’t deal with it. He became depressed and fell into a funk. My parents were in denial. They said there was nothing wrong with Abby. She was “just perfect.” But I knew something was wrong. I researched Rett and it scared the crap out of me. The description fit Abby to a T. I knew she had it. A blood test confirmed it. She was 2 years old.

We were devasted. We cried our eyes out when we found out. We felt like it was a death sentence for Abby. What did this mean for her and our family?

**Motherhood**
I have wanted to be a mom since I was a little girl. I was sad that I was the youngest because I wanted my mom to have more kids. But I never realized how hard it would be. It’s way harder than I ever imagined. The challenge has been eye opening. There are times where it is enjoyable.
However, at times, I feel like it is more of a chore than a joy. This sounds terrible, but that’s how I feel sometimes. I imagined it would be all fun and games, just go and play. But I am a chauffeur, always running someone somewhere. The house is always a mess, dishes are on the table, and we are always late. I can never relax and enjoy. There’s so much responsibility . . . always making sure Abby is safe, getting fed, not freaking out, and trying to keep her happy. And I also need to keep Rebecca happy. There’s so much stress around us, so I feel this is critical for her.

Right now, I am feeling overwhelmed and stressed out. I am happy a lot, but I don’t feel like I am as happy as I used to be. I have always been a positive person, but I am not as optimistic about things. I am frustrated a lot. I am tired constantly. I never get a break. Sometimes, I wonder what things would be like if Abby were normal. Things are just not as enjoyable as they could be. If Abby did not have a disability, I would still be working. That would make things better for me because I never wanted to be a stay-at-home mother.

Guilt. I feel it all of the time. It is the story of my life. I always feel guilty about something. Maybe it would be better if I was not so tired. I wish I had more energy to give to Rebecca. She needs a lot of energy and attention. I feel like I focus too much on Abby. The balancing is hard. It makes me feel sad that sometimes I do not get to enjoy Rebecca because I have to mess with Abby. I am sure it bothers Rebecca, but she can’t seem to express it.

I feel guilty when I don’t force Abby to do her therapy at home. I just hate “therapizing” my child all of the time. I just want to love her and play with her in my own way. When the guilt comes up, I try to tell myself that just because I don’t always work with her at home, doesn’t mean she won’t be happy.

I wish I had five arms because it is so difficult. Abby is dependent on me for everything. She needs help eating, diapering, bathing, and doing everything. It is quite challenging. And Rebecca is left on her own. It is a never ending cycle. Rebecca does not get the attention that she needs, so she acts out.
And we snap at her because we are so worn out.

I spend so much time driving my kids back and forth to different schools. 
I don’t get any time to myself.
I feel a little selfish for really wanting my time and space.
It makes me feel bad because I have never really been that selfish in my life.
I have always put others’ happiness before my own, but I am just so tired. It’s constant.

I spend so much energy cleaning. It is endless.
I need to teach Rebecca more responsibility. I need to teach her how to help me clean.
But it does not feel right to make Rebecca do things that Abby does not do.
Can I expect Rebecca to do chores and not Abby? I feel so guilty about it.
It’s a catch-22 sort of thing.

There are days when I feel like the world’s worst mom.
Today, Abby was having a major fit. She wouldn’t stop crying and was biting herself.
She was inconsolable.
I could feel my blood pressure rising. I was trying to stay calm, but she would not stop.
I lost it and screamed at her to stop. That made her cry even harder, and I started to cry.
How horrible of me to scream at my poor disabled child who can’t control her crying fits.
I was so upset with myself for losing it.

We recently went to get a family portrait. Abby was unhappy and not cooperating.
The photographer asked me if she was a “special child.”
I felt ashamed and embarrassed that he could tell.
It was weird that I had those emotions because I usually want to tell people about Abby.
But the fact that he noticed made me feel strange.
It was a hard emotion to experience.

**Marriage**
Abby went through a horrible period of rages. It was so hard for us.
Joe and I yelled at each other constantly because we could not figure out how to calm her down.
But we got through it.
Joe has been my rock and has helped me get through Abby’s fits.
We have grown closer now that we have a child with a disability.
The disability has made us a lot stronger.
As high school sweethearts, we have been together a long time.
I think it has been great for us to work together as a team.

**Family Life**
What has made this experience much better is the fact that Rebecca is so amazing with her little sister.
I think she is going to be a more sympathetic and caring person because she has a sibling with a disability.
Abby loves Rebecca.
She loves to be carried around by her. She loves to nibble on her head. It is so cute.
Rebecca constantly tells her that she loves her and wants to cuddle.
We are so happy for that because we don’t want Rebecca to feel jealous because of the attention that Abby gets.

Rebecca’s class went to the circus recently.
Abby didn’t have school, but I opted not to take her because I was worried about her behavior.
I feel so guilty leaving her out, but I also feel it is important to have special times with Rebecca.
I need to focus on Rebecca without always being concerned with Abby.
Some of the other parents are bringing their other children.
It makes me sad that I don’t feel I can bring Abby.
I know she is unaware that she is being left out, but I get frustrated that she can’t be part of an outing like other siblings.

Last week, I took Rebecca to her class picnic.
My dad spent the morning with Abby and planned to drop her at the picnic late.
I couldn’t stop thinking that I had one hour to enjoy the picnic before Abby arrived.
That’s terrible, I know.
But I had a small window to relax and enjoy my time before Abby showed up.
Then the work began.

Tonight, Rebecca told me she loved her family, but she loved Abby the most.
Hearing this melted my heart.
I feel so relieved and happy that Rebecca does not feel jealous or resentful of Abby and her differences.
She knows that Abby is special, but she loves her in the same way as any other sister.

**Public Life**
Abby doesn’t communicate, but she squeaks and squeals with delight.
She doesn’t understand that she needs to be quiet, so it’s hard to get her to settle down.
The library is a tough place to go.
A while back, we were at the library and Abby was squealing loudly.
Because her disability is invisible, you can’t tell she has any issues by just looking at her.
The librarian approached me and told me we would have to leave if Abby didn’t quiet down.
“‘This is a library and it needs to be quiet,’” she told me.
I was so offended. I told her Abby had a disability and did not understand how to be quiet.
Then, we stormed out.
It was the first time I really felt different in society. I felt so sad and angry.

When I take the girls to the park, I have to give all of my attention to Abby because she wanders. I never get to enjoy spending time with Rebecca. Sometimes, I get jealous of other parents. They are lucky that they do not have to constantly worry. They can get their kids up, dress them, feed them, and get them off to school. No problems. They don’t have to worry about them falling down the stairs or running into the road or taking over an hour to finish one meal. They go to the park and can sit in the shade, chill, and talk to their friends while their kids play on their own. Instead, I have to constantly chase after Abby and be on guard. I cannot relax for a second. I used to love the park, but now I dread it. It is hard for me, and I feel bad for Rebecca. Luckily, Rebecca is outgoing and meets friends easily. But the guilty feelings always come back.

Recently, we all went to a play date at McDonald’s. All of the kids ate for five minutes and then ran to the playground. But Abby takes an hour to eat. So, the other moms chatted while I had to focus on Abby’s feeding. I had to concentrate on her not choking. The moms were inquisitive about Rett and asked me a lot of questions about Abby. I like to inform them, but I get sad sometimes when I think that Abby would be playing with her peers if she were typical. I know I should not think like that. But at times, it hits me like a ton of bricks.

I enjoy when people ask about Abby. I like to educate. I think it’s important. I almost wish people would ask. Then I could spread the word about Rett. I also want them to know, so they are not questioning and wondering and staring. She constantly wrings her hands now, so people stare. While I am so proud of my beautiful daughter, sometimes I get that feeling of embarrassment. There are some days that I don’t care that people stare. Other days, it really hits me hard.

**Transformation**

My older sister had mild CP, so I experienced disability at a young age. I have always been a compassionate person, but I think my sister and Abby have made me more compassionate towards other families of people with disabilities.
I still remember how tough it was on my sister. Kids always made fun of her. I hope Rebecca becomes more compassionate.
I talk to her about people making fun of Abby. I tell her that I would want her to stand up for her sister.
Not in a mean way, but I want her to protect Abby and to educate others in the process.
Because I remember kids making fun of my sister. I felt embarrassed for her and for me. It was terrible.

So far, we have been lucky that Rebecca is compassionate and is so proud of her sister. Another Rett mom told me that her son asked her not to bring his sister with Rett to his soccer games because she was embarrassing.
She told me she was initially angry with her son, but then thought more about it.
She didn’t feel like she should be angry with him because she could understand his feelings of embarrassment.
It’s difficult because it can be awkward and uncomfortable, but it’s also your sibling.

We try to look on the bright side. It is what it is.
We are hoping for a cure someday.
We need to try and enjoy our family without letting the Rett invade our lives.
It has changed my view on the world.
It changed my view on how I have to help Abby work through everything.
But at the same time, I enjoy Abby as a person.
Sometimes, I try to forget she has a disability. She’s just my little baby.

**Future**
I may still be in a little denial about just how hard it will be when Abby is older.
She can’t feed herself, bathe herself, dress herself, or do anything independently.
But I rejoice in the fact that she is so happy.
That’s all that matters to me at this point.

I thought motherhood would be fun and easy, and then my kids would grow up and we’d have our alone time.
I know this won’t be the case.
Abby will be reliant on us for the rest of her life and the rest of our lives.
My husband says we are in the honeymoon stage now because Abby is so cute and little.
But it is going to get tougher when she gets older and people start wondering more about her.
And what about the teenage years? What do we do when she starts menstruating?
It sounds so terrible, I know, but I’ve thought about a hysterectomy.
It will be so much more challenging down the road . . . dealing with other adults and other kids.
However, right now we try to focus on today.
Otherwise, it is too upsetting to think what might lie ahead.
Advice
You must rejoice in the fact that things could always be worse.
You need to look on the bright side.
It’s sad to say, but there are always other people that have it worse than you.

Stay positive.
Enjoy your child because time goes by so fast.
Don’t spend all of your days worrying.
Enjoy today.
Love your child.
Have as much fun as you can.

Tracey

This 39-year-old, married, holistic nutrition consultant and knitting/crocheting teacher has endured the painful process of learning that not one, not two, but all three of her children had some type of special needs. Her 10-year-old son, Conner, has autism; her 8-year-old daughter, Cecilia, was diagnosed with a variety of issues, including reflux, severe anxiety, auditory processing disorder, and failure to thrive; and her 7-year-old son, Bradley, has asthma and global developmental delays. Today, Cecilia has outgrown most of her issues, and Tracey no longer considers her daughter to have any special needs. Here is Tracey’s story in her own words:

Diagnosis
Conner was born six and a half years into a solid marriage.
He breastfed, wore cloth diapers, ate organic food, never watched television, and was never sick.
At age two, everything changed.
He stopped talking, stopped looking around, stopped eating, and stopped sleeping.
One year later, he was diagnosed with autism.
We were not given much hope for our son.
We were told to start looking at institutions because back then, that’s what parents did.

Cecilia had issues from birth . . . reflux, anxiety, sensory processing.
And Bradley’s problems emerged at age one.
The Children’s Hospital had no idea what to do with him.
Doctors just labeled him with developmental delays.
Soon, my family began to disappear. We went from talking every week for an hour to once a month for five minutes.
We were trying to come to terms with what is, while still clinging to was supposed to be and everyone was disappearing.

I felt so isolated.
My mother used to work as a special education teaching assistant for years.
She used to say how happy she was that her students were not her kids. I just don’t think she could handle having any kind of disability in her family. My dad and brother just couldn’t handle any kind of crisis. I remember thinking that I did everything “right” when I was pregnant. But my brother and sister-in-law didn’t even give up smoking while they were pregnant! And they had healthy kids. It wasn’t fair.

With my third child, I went into labor five weeks early. We were in crisis mode. We called my family for help. Nobody answered. We had to take our 3 year old and 16 month old to the labor and delivery room with us. We were all alone.

**Family Life**
The five of us are very connected. Because Bradley has difficulty understanding body language and signals, he’s a target on the playground. So, we agreed as a family that it is dangerous to stay on the playground. We no longer spend any time after school on the playground because we need to keep Bradley safe. Cecilia understands that there are limitations, and she handles these well. She understands that Conner is her big brother with autism, and the autism will never go away. In fact, as he enters puberty, his behaviors will get worse. She understands that her brothers are not like her. When we have to leave someplace early because someone is struggling, we leave as a family. When we see a movie, we pick one near a bookstore, so we can exit early with Conner. My husband and I decide beforehand who will leave with Conner. This is just our reality.

**Public Life**
I used to be the mom on the playground with no friends. I couldn’t sit and chat with a Starbucks in hand. Instead, I had to shadow my kids, preventing hitting episodes and runaways. I just played guard the entire time. I used to go back and forth between wishing I could be part of the “normal” mom’s world and thinking all of those moms could just go fuck themselves because I didn’t care about them.

But the truth is, my negative emotions were putting words into their mouths. It was never them against me.

At that time, I was so wrapped up in my loss.
I’d cry for hours because my kids’ lives were not what I wanted them to be. This was not the life I wanted for them. I remember cleaning closets all day because it was the only way I could feel in control of my life. I had some great looking closets. But I learned that grief was a cycle . . . and it would hit at different times. In order to function, I couldn’t let myself cry all day. I could not let it take over my life.

Today, I bounce back faster. I have more experience. I have more hope. I know setbacks are just temporary. I do not let myself feel depressed for more than one day. As I get to know my children better, letting depression go on for more than one day dishonors them. I have also learned to place fewer expectations on others. And now the playground is easier for the most part because my kids have better social skills. I have a bit more freedom when we are out and don’t have to worry so much about my kids.

**Motherhood**
If I had an accurate picture of what motherhood would be like, I would not have started this. I wouldn’t have believed I’d only get four hours of sleep a night for years. Who would ever want to take that on? Everything has been so hard. I would not repeat it. We were married for more than six years and so ready for kids. I did everything right. But look what happened. Three kids with needs. The special needs took me to a different place. The facts of my life are not pretty. They are scary. But unless you are inside my world, you can’t understand it. Things could be a lot worse. Really.

I turned to my faith. I try not to ask why, but rather figure out what. I believe that “these children are sent to us, so we have the opportunity to become better people.” This world is a better place because of them. My kids are fabulous people. A classmate recently hit Conner, and he told me it happened because the boy simply forgot that we don’t hit others.

**Marriage**
This has been a good thing for our marriage.
When my family bailed on us, we realized that we needed to depend on each other. We were in this together and had to take care of each other. Stick together or you will fall. It brought us closer. We try to nurture each other and make it grow, not just work.

Transformation

I am a stronger person today. I used to avoid conflict, but it no longer bothers me. I now stand up and say something when enough is enough. I have become more confident. When I interview doctors, I ask them up front what they have to offer. I am less tolerant of parents acting badly and more tolerant of kids. I do feel empathy for parents going through hard times.

I do my best to educate others. Everyone has their own problems, so it is hard to expect all people to understand. A lot of our friends faded away when our kids came along. There was a certain fear of “catching” what our kids had. Some people bailed on us because their realities were just so different from our own. We couldn’t identify with their life and then you have nothing to talk about. They would complain that their 4-year-old child did not stop talking, and I would wish for that to happen. We had nothing in common. It became a waste of energy.

Future

I want my kids to have a future. I want them to have the life that makes them happy. The life they want. I need to step back and understand that sometimes. It is my worry and not theirs. I want them to be happy. College is a reality for all three. They will probably be able to live independently, but the boys will need assistance. Conner will definitely need help handling money and simple housekeeping tasks. I will need to make sure there’s no mold growing in his fridge!

Advice

Find the things that will help you cope. My faith plays a main role for me. I pray a lot when I start to lose it. Catholicism does a bad job with special needs. They don’t serve any kids with special needs in any of their schools. However, I see this as a gap that I can fill. I can create awareness and make a difference.

I have become a resilient person.
When I feel depressed, I make a list of what makes me happy. I force myself to do at least one thing on the list.
Depression is soul sucking, so it’s important to put this list in writing. So it is permanent. I do something just for me at least once a day.
I try to focus on my motherhood duties and put one foot in front of the other. I continue on with life.
I play my happy songs over and over again. I read books that make me laugh out loud.
You can be depressed for a day, but then get back to life.
Don’t give into the depression.
Support groups help some people, but not me.
It actually brings me down to hear other peoples’ problems.

Yvonne

Yvonne is a 34-year-old, married, stay-at-home mother raising Robbie, age 8, and Brandon, age 19 months. Robbie is diagnosed with autism, optic nerve hypoplasia (underdevelopment), asthma, food allergies, and sensory integration difficulties. Here, in her own words, is Yvonne’s story:

Diagnosis
At 6 weeks old, we learned that Robbie was visually impaired.
He had an MRI, which showed a partial absence of his corpus callosum, the white matter connecting the left and right parts of the brain.
At 18 months, we learned that he was growth hormone deficient.
At 4, we received his diagnosis of autism.
He had been showing signs of autism early on, but the doctor kept insisting the spinning and learning difficulties were caused by his bad vision.
Finally, I got him tested.

It was so hard to get one diagnosis after another.
But learning that he was visually impaired was the most difficult.
Being a first-time mother, you have so many expectations of what it’s going to be like and how life will be with your new baby.
This was the first time I learned those expectations were not real.
I had to quit my job to be there for my son.
I had no interaction with disability before Robbie. It was all new to me.

Motherhood
Being a first-time mom with Robbie, I didn’t know what to expect.
I just wanted to be like my own mom, who was so loving and patient.
But this is not what I thought it would be like. It is so much more of a hardship.
I feel so guilty for resenting Robbie. But he takes so much out of me.
At night, I think about what I can do to make him happy. Then he wakes up and tells me he hates me and wants to kill me.
I know he doesn’t mean it . . . it is the autism talking.
I just can’t take it anymore.

When Robbie is at school and I have only Brandon, I feel normal.
We get to go to the park or the store, and we don’t have to deal with somebody screaming.
It’s nice to be part of something that is not a group for special needs.
I look forward to the times when it is just us.
It’s so easy, and we don’t stand out in a crowd.
Since Robbie was born, he has felt like work.
But Brandon is undemanding and fun to be with.

I think motherhood is about caring, loving, and accepting your kids. Loving them unconditionally.
I try to do that every day.

I think if I would have had Robbie later in life, it would have been easier for me to cope.
I think being in my 20s, it was hard.
I felt like I was not ready to be a mom or ready to cope with having a special needs child.
I feel I am more patient with Brandon than I ever was with Robbie.
I feel lucky to have Brandon.
Now, I know that I will get to be a grandmother.
Brandon will go to prom, drive, and do typical kid stuff.

I feel like I am missing out on things with Brandon because we are always in the car going to some appointment for Robbie.
I feel like I can’t enjoy Brandon and see the new things he is learning.
I feel guilty that Brandon does not get the attention he needs.
But this is my life.
I am used to the fact that this is never going to change. I need to deal with it.
Some days are better than others.
When Robbie is having a hard day, telling me he hates me, I wonder why this is happening to me.
Last year was a very hard year. We tried an inclusive classroom and it did not work.
They were constantly suspending him, and his behavior was out of control.

**Family Life**
We thought about having only one child.
But then we thought what if something happened to us? Who would take care of Robbie?
It’s an awful thing to say . . .
We waited 7 years to get pregnant again.
I was really nervous about having a second child.
First, we were worried about him being visually impaired. Then after he was born, and we knew his vision was fine, the worry about autism started in. I don’t think that fear will go away until after he turns 4. We are constantly watching him for any signs of autism. I have one special needs son; I am scared to have another. I do not need or want another one!

For so many years, we only knew what it was like to have a child with so many needs. Then Brandon came along. And he’s all over the place, into everything, on the go, interacting with other kids. It’s just so new and exciting.

Getting through the day is hard. I cannot leave my neighborhood because if Robbie’s school calls me, I have to be close so I can pick him up immediately. I feel like a hostage in my house.

My side of the family does not understand Robbie, but they are very compassionate toward him and try to help with him. My husband’s family does not handle it well at all. They don’t interact with him.

**Public Life**
I feel isolated. I lost a lot of friends because they just didn’t understand my situation. When my son is having behavioral problems, they think it is just him being a bad kid. He can say some pretty mean things. I don’t like going to social events, like family gatherings, because I never know what to expect from him. It makes me mad because I feel like we can’t participate in things and be around other people. Other moms don’t know how easy they have it.

It is so hard going to the park with both boys. Robbie has so many needs. Being visually impaired, I have to watch his every move to make sure he doesn’t fall. At the same time, I have to watch the baby. I can’t enjoy it at all. Even my own backyard is a juggling act.

**Transformation**
The disability has humbled me. I’m more compassionate toward other people who have children with special needs. I am more grateful for things.
I appreciate the things that I have.

**Marriage**
I feel like we are closer because of Robbie. We need to stay strong for him.
But it is also stressful.
My husband doesn’t really get it because he doesn’t have to deal with most things.
It all lies on me.
Robbie has tons of therapies and doctor’s appointments.
It’s harder with a baby because he has to come with me.

**Future**
I think the future will get easier.
I think I will have matured, and we will have things under control.
When I look into the future, I hope I will be happy and my husband and I will still be together.
I have this expectation that both boys can go to college.
I don’t know if Robbie will ever be able to live on his own.
I would like it, but I don’t think it will be possible.

**Advice**
Never give up.
Be patient.
Follow your gut.
Appendix B: Interview Question Outline

Introduction

Hi. My name is Lucie, and I am a doctoral student at the University of Denver. Thank you for taking the time to talk with me today and for agreeing to be involved in this study, which examines the unique journey of parenting a child with and without special needs.

I am going to ask you some questions about your mothering experience. My questions are about YOU and YOUR journey—a subject most mothers are not used to discussing. The focus is often on our children, and we are used to relating to life through their eyes. But—for the next hour or so—I want you to be open with your reflections, your thoughts, and your experiences.

Let’s start with some routine information: Please tell me your name, your age, your ethnicity, and your occupation. Please give me a brief description of your child with special needs, including his/her medical diagnosis. Please supply additional sibling information (name, sex, age).

Interview Questions

Main question:
What is the lived experience of raising a child with and without disabilities?

Probes:
Please tell me about your family. What type of disability does your son/daughter have? When and how did you learn about his/her diagnosis?

Please tell me about your typically developing child/ren.

What is it like living with this disability and raising a nontypical child? How do you cope and come to terms with mothering a disabled child?

Does having another child who is typical make things easier—or harder—for you? How has the disability altered your relationship with this typical child?

Is this what you thought motherhood would be like? Please explain.

How has this experience changed you as a person? How does the disability affect you—the mother—and the rest of the family? How has this changed your marriage? How has it changed your outlook on life?

Tell me about how you learned to be a mother. How do you see yourself as a mother? How do you think others see you as a mother?

What does motherhood mean to you? How has this meaning changed since the birth/diagnosis of your child with disabilities?

Do you ever find yourself trying to live up to society’s image of a “normal” family? Please explain.
What is most important to you in life?

How would you describe your quality of life?

How have you changed over time? How has your family changed over time?

Receiving your child’s diagnosis can be disorienting and life changing. Would you agree? Why or why not? Have you experienced other life changing events?

Would you please describe your feelings when given the information that your child was not going to be what you expected? Do you still carry those feelings? When did you notice a change in your feelings? What, in your opinion, help to change your feelings?

Did this child add to or take away from your growth as a woman? How so?

How would you compare yourself to other mothers you know who do not have a child with special needs?

What were your expectations of the motherhood experience going into this journey? Where did those expectations come from? And what is the reality of the experience?

Do you think there are certain conditions or elements that help you work through difficult times? Conditions or elements may be parental help, financial stability, support groups, God, religion, belief in a higher entity, personal characteristics, personal power, etc.? Do you think timing is important? Would you have reacted to this role differently if you experienced it five or 10 years earlier or five or 10 years later?

As a child, what did you think mothering was? As an adult without children, what did you think mothering was?

When your special needs child first entered your life, what did you think mothering was? Today, what do you think mothering is?

Please describe yourself and your family in 10-20 years. What advice would you give to other mothers in the same situation?
Appendix C: Diary Entry Description and Guidelines

Thank you for agreeing to participate in this study of mothers raising children with and without disabilities. This four-week diary will help the researcher to understand your everyday experiences through your own written words. Because individuals sometimes have difficulty expressing their emotions orally, diaries offer a more comfortable and secure way to articulate these feelings.

Please keep this diary for four weeks, making a minimum of three entries per week. I will be giving you a blank, bound notebook to use as a diary. However, feel free to type your entries and print out or submit to me through electronic mail—if you would rather not handwrite your diary.

Listed below are some thoughts to consider for your diary entries, but these are by no means the definitive guidelines for your entries. Please feel free to elaborate or include additional information regarding your experiences and perceptions. Also, please feel free to write about any meaningful previous experiences you may have encountered prior to the start of this diary.

During the next four weeks, please consider writing about any episodes or anecdotes associated with your children that may have caused you to experience any heartache, loneliness, anger, disorientation, frustration, yearning, somberness, regret, joy, happiness, or laughter.

* What were your overall perceptions and/or feelings about these experiences?

* Have there been any particular difficulties and/or benefits in raising both a child with and without a disability?

* Have you had any experiences with your children that you would consider stigmatizing or difficult?

* Can you recall any stories that made you feel lucky or unhappy to be a mother?

* What do you think is difficult about your mothering journey?

* How has this experience changed you?

* Is this how you imagined motherhood—and your life?
Appendix D: Informed Consent

“Stuck between Two Worlds”: Mothers Raising Children with and without Disabilities

You are invited to participate in an in-depth interview as part of a study on mothers raising both a child with disabilities and a typically developing child. The purpose of this research is to learn more about these mothers’ experiences and personal responses to raising both a child with disabilities and one without. The benefits of being involved in this study include gaining valuable insight into what it means to raise a nontypical child and a typically developing child in the same family. You also may enjoy the ability to share information about your own experiences.

The study is being conducted by Lucie Lawrence, a Ph.D. candidate in the Department of Human Communication Studies, University of Denver, (303) 345-3346, lucie.lawrence@du.edu, under the supervision of Elizabeth Suter, Ph.D., Department of Human Communication Studies, University of Denver, (303) 871-4492, esuter@du.edu.

Participation in this study will involve keeping a diary for four weeks and taking part in three separate interviews, with each lasting about one to two hours. The diary entries and interviews will involve describing the challenges and experiences of raising a child with disabilities and one without, specifically views on motherhood and identity. Your involvement is completely voluntary. You may choose not to answer any of the questions and are free to withdraw from the study at any time.

The researcher will treat all information gathered for this study as confidential; only the researcher will have access to the information you provide. Interviews will be audiotaped and transcribed. Upon transcription, all participant names will be changed to pseudonyms to maintain confidentiality, and each diarist will be given a pseudonym. The information obtained in this study may be published in scientific journals or presented at scientific meetings, but the research report will never reveal your identity.

I am required to inform you that there are two exceptions to the promise of confidentiality. Any information you reveal concerning suicide, homicide, or child abuse and neglect is required by law to be reported to the proper authorities. In addition, should any information in this study be the subject of a court order, the University of Denver might not be able to avoid compliance with the order or subpoena.

If you have any concerns or complaints about how you were treated during the interview, please contact Susan Sadler, Chair, Institutional Review Board for the Protection of Human Subjects, at (303) 871-3454, or Sylk Sotto-Santiago, Office of Research and Sponsored Programs at (303) 871-4052, or write to either at the University of Denver, Office of Research and Sponsored Programs, 2199 S. University Blvd., Denver, CO 80208-2121.
You may keep this page for your records. Please sign this page if you understand and agree to the above. If you do not understand any part of the above statement, please ask the researcher about any questions you have.

I have read and understood the foregoing descriptions of the study, “‘Stuck between Two Worlds’: Mothers Raising Children with Disabilities and Without.” I agree to participate in this study, and I understand that I may withdraw my consent at any time without penalty. I have received a copy of the consent form.

___________________________________________________  ________
Signature         Date

☐ I agree to be audio taped
☐ I do not agree to be audio taped

___________________________________________________  ________
Signature         Date
Appendix E: Research Study Description:

“Stuck between Two Worlds”: Mothers Raising Children with and without Disabilities

Hello. My name is Lucie Lawrence. I am a doctoral student at the University of Denver, as well as a mother raising a 5-year-old child with special needs and two typically developing children.

You are invited to participate in my research study (dissertation) on mothers raising both a child with disabilities and a typically developing child. The purpose of this research is to learn more about mothers’ experiences and personal responses to raising both a child with disabilities and one without. The benefits of being involved in this study include gaining valuable insight into what it means to raise a nontypical child and a typically developing child in the same family. You also may enjoy the ability to share information about your own experiences.

To participate in the study, you must be raising at least two children between the ages of 1 and 21 years. One child must be typically developing, and the other child must have some kind of developmental and/or physical disability. Mothers need to have given birth to their children. Adopted or foster care children will not be included. The study will consist of both mothers who knew and did not know about their child’s disability during pregnancy.

Participation in this study will involve keeping a diary for several weeks and taking part in three separate interviews, each lasting about one to two hours. The diary entries and interviews will involve describing the challenges and experiences of raising a child with disabilities and one without, specifically views on motherhood and identity. Your involvement is completely voluntary.

I will treat all information gathered for this study as confidential; only the researcher will have access to the information you provide. All participant names will be changed to pseudonyms to maintain confidentiality. If you are interested in participating (over the next 3 to 6 months) or have any questions about the study, please contact me at lucie.lawrence@du.edu or cell, 303/345-3346.

Thank you for your time and consideration.

Sincerely,
Lucie Lawrence
Appendix F: Advice/Recommendations

At the conclusion of each interview, I asked the mothers to reflect on their experience and suggest advice and recommendations to other mothers of children with disabilities. Because most of the mothers say they participated in the study primarily to help others, they were eager to comply. They reached out and shared what they have learned in the process of raising typical and nontypical children. Their suggestions are straightforward and simple.

Motherhood truths

- Love yourself.
- Know when to let go. Realize that we do not control things in life.
- Any little thing that can help you get perspective is important.
- Selflessness is the definition of motherhood.
- Women have an unlimited capacity to mother. We do things we never thought we could do.
- You will get through this. Believe it. It will get easier to cope.
- Don’t lose yourself in this experience because it is hard to recover that loss of identity.
- Find balance in what must be done.
- It is your responsibility to help siblings remember they are siblings and not parents.
- It’s important to just love your child.
• In order to raise a family, handle the business of disability, and maintain a marriage, you must have a sense of self.
• You can’t lose yourself in your kids.
• Cry, get angry, and then move on.
• Trust yourself and your gut . . . you know what’s best for your family.
• Do not make your child your entire life.
• It is important to become a resilient person. Don’t give in to the depression.
• Throw out the non-essentials. Focus on what’s important.
• Be a family. Take care of each other. Do things together as a family. Don’t sit at home.
• Don’t give yourself unachievable realities. Do not set the bar so high that you’re just setting yourself up to fail.
• Be accepting of your mothering capabilities and the mother you are trying to be. Accept that you are doing your best.
• Acknowledge yourself and your feelings. Believe that it will be okay.
• Know what you can handle.
• Be confident in your understanding of your child with special needs.

Slowly, over the first year, I realized that I’m able to do this. It is important to believe in yourself, have faith in yourself. (Anita)

If you are not prepared to have a child with special needs, you should think hard about having kids. You can’t be selfish especially with a child with special needs. (Catherine)

I have learned as I have gone along. I have grown in the process. I am so glad I never saw into my future. Who knows what I would have done. (Kelsey)
When I talk to expectant moms or new moms with kids with Down syndrome, I always tell them the truth. I say it is hard, but that it will be okay. While they can’t possibly imagine that to be true, I assure them it will be okay. Because Down syndrome is the “Cadillac of cognitive disabilities,” our kids have a good shot at leading very fulfilling, happy lives. I tell them not to let the disability run their lives. It doesn’t mean that’s all they need to think about or talk about. Yes, the disability is overwhelming, but it cannot be allowed to take over your life. As a responsible parent, you need to make a separation between your child and yourself. (Marcia)

I am used to Olivia having OI. It has become a part of my life. Getting to know Olivia and seeing how adaptable, capable, and independent she is has helped me cope. Also seeing how independent she can be gives me a sense of relief. (Madeline)

I remember feeling so panicked in the beginning. Like I had to learn everything and do every single therapy immediately. But my pediatrician said no, just take him home. Just protect him and love him like any other child. I did. That was important for me to hear. (Mary Beth)

I had to stop going to the twins club when I could no longer hear how hard it is to raise healthy twins. (Kate)

To be the kind of mommy that you need to be, whether for your typical or disabled child, you need to come to a place of acceptance. It’s healthy for you and for your kids. (Rachel)

Sometimes, Addie wants to be a second mom to Joshua. But I remind her that it is not her job, nor her responsibility. She is his sister. (Bonnie)

Ask yourself, does the driving in rush hour outweigh the benefits of a 50-minute therapy session? (Cindy)

I see moms who deliberately stop having kids after the birth or diagnosis of their child with special needs. I feel bad for them because this kid becomes their entire life. It is sad. (Sandra)

Mothering is not about molding your children into perfect human beings. Instead, look at your children and give them what they need to grow to be the best they can be. (Jill)

It is so easy to get caught up in this world that you’re living each and every day. Owen and autism are always in my head. (Catherine)
When I feel depressed, I make a list of what makes me happy. I force myself to do at least one thing on the list. Depression is soul sucking, so it’s important to put this list in writing. It needs to be permanent. I do something just for me at least once a day. I try to focus on my motherhood duties and put one foot in front of the other. I continue on with life. I play my happy songs over and over again. I read books that make me laugh out loud. You can be depressed for a day, but then get back to life. (Tracey)

**Grieving is human**

- It is okay to grieve over the disability.
- Let yourself feel what you need to feel.
- Give yourself time to breathe and grieve.
- Take one day at a time.

I grieved over my son. I still do. I look at Henry and feel a thud in my heart. The thud is a combination of what could have been and what I wanted it to be. It also comes from wondering how things might have turned out differently. And then the feeling is over, and I move on. But feeling those feelings helps me to cope. (Susan)

You’ve got to mourn when you get the diagnosis. Whatever dreams you had, are not going to be the dreams that you are going to acquire. And you have to give yourself some time to feel sad—and that’s perfectly normal. There will be times throughout your life where it comes back, and you have to mourn anew. For me, I had to just take a little bit at a time. When Colin was 6 weeks old, I didn’t want to know what life would be like at 25. I only wanted to know what to expect when he was 3 months old. (Rebecca)

**Dump the guilt**

- You have to let go of your guilt. You need to move on.
- You must make life as good as it can be.
- Be kind to yourself and don’t feel all of the guilt.
- Don’t waste time feeling sorry for yourself.
I have a lot of guilt. I will never find out why Joshua has this and how he got it. But I need to set aside my guilt because I will never know why this happened. (Bonnie)

**Knowledge is power**

- Arm yourself with information.
- Don’t rely on other people to give you information about your child. You need to be the expert because you know your child best.
- Search out local resources. These are great for information, funding, and support.
- Seek out support because nobody will come knocking on your door.
- Nobody throws you answers. You need to seek them out.
- Do your research. If you are prepared, it either won’t happen or you’ll be able to better handle it.

I am not the only one out there dealing with this stuff. There’s a ton of stuff online. Find it. Nate can’t button, snap, or zip. Where do we go to get clothes for him? I go out there and try to find out. I seek out answers. (Sandra)

**Focus on the positives**

- Highlight all of the positive things that you can because it will be easy to find the negatives. You’ve got to hunt down the positives and hang on to them.
- If you’re looking for the good stuff, you’ll find it. But you may have to make an extra effort to hunt it down.
- You must rejoice in the fact that things could always be worse.
- It’s sad to say, but there are always other people who have it worse than you.
- There is always someone else who is going through something more difficult.
- You need to look on the bright side.
• Enjoy your child because time goes by so fast. Don’t spend all of your days worrying.

• Enjoy today. Love your child. Have as much fun as you can.

When I feel like I have nothing left, I fill my head with positive sayings: Adapt and overcome; dig down deep and find it; God doesn’t give you more than you can handle; and I was chosen for her. I pride myself in my ability to pick myself up and dust myself off. You have to be selfless, so suck it up. Reach in and pull it out from somewhere deep down. There’s no time for self-pity. Do the best you can. Know there is so much love in the end. I feel like there are two types of people: optimists and pessimists. There’s no room for pessimism. You must be constantly optimistic. Denial is natural, but optimism and hope are key. I choose to be positive. I try to view obstacles as learning experiences. Always retain hope. (Jessica)

Recently, I had a lady tell me that Patrick is doing a great job in choir, and he’s really valuable. I was in shock. I didn’t know what to say to her. He’s never been treasured in those kinds of situations. So often, when we venture out in public, his behavior is not treasured, but merely tolerated. Perhaps that’s why this comment was hard for me to take in. It is a big shift from our usual experience. He is desired at choir, and not “put up” with. And I am afraid it will not last. But it was so nice for someone to cherish him. (Alexandra)

Think outside the box

• Being creative is important.

Daniel is in a wheelchair, which means we need to figure out other ways to do things. We need to figure out a vacation that works or a sport in which he can participate. Daniel plays adaptive baseball, and it’s a great experience. (Anita)

Connect and share with others

• Don’t suffer in silence.

• It is important to connect with others.

• Share your life and experiences with others who understand.

• Be open to communication. Whether it is your husband, sister, mom, dad, or therapist.
• Don’t be afraid to ask for help. You might be amazed at how nice and giving people in your life can be.

• Find a friend you can vent to. Everybody needs someone like this in their life.

As hard as it was for me to talk about my child when I returned to work, it helped. I cried whenever I talked about it. The pain never goes away, but it does subside. (Susan)

Other moms raising children with disabilities have helped to give me perspective. They show me that I can live with this. I can see the funny side of things, however trying and absurd they may be. I think it is important to know that even though you may feel desperately alone and lonely, there are others out there who really do get it. Finding other parents and resources has been so important. Connect with these parents as fast as possible. (Bonnie)

My sister is great for venting. She has typical kids, but she completely understands me. And my husband is great, too. We will vent back and forth and problem solve. We bounce ideas off each other. (Gabrielle)

Beware of self-pity

• Don’t get mired in self-pity.

• People don’t want to hear your story. Everyone has a story.

• Live your life the best way you can.

Every once in a while, I have a pity party but I don’t involve anyone else in this party. It is a party for only one. After my short pity party, I am okay and the weepiness goes away. Just ride the wave and it will be okay. Bridget gives me permission to have a pity party. Everyone has their issues . . . ours seem to be very visible. (Brenda)
**Have faith**

I’m a praying person. I ask for God’s help. (Brenda)

Faith is so important to me. I would be sunk without it. There are no answers to why this kind of thing happens, so you have to be okay with it. Faith helps you accept. You don’t have to understand. Faith will help you get through it. (Georgia)

Find the things that will help you cope. My faith plays a main role for me. I pray a lot when I start to lose it. Catholicism does a bad job with special needs. They don’t serve any kids with special needs in any of their schools. However, I see this as a gap that I can fill. I can create awareness and make a difference. (Tracey)

**Focus on self-care**

- Take care of yourself and take time for yourself. Take breaks.
- It doesn’t matter what it is, just do something. It helps you stay healthy.
- Without a healthy mom, nobody is any good.
- Exercise for your sanity.
- Search for your spirituality because this can help you deal with emotions.
- Get help to clean, cook or watch your children, so you can have a break.
- If you do not take the time you need, you will have nothing left for yourself or your kids.
- Yoga, meditation, alone time, and time with friends can help keep things in perspective.
- See a psychiatrist.
- It is important to find people who can give you the alone time and couple time that you need.
• You need time to be a person—and not just a mom.

Face your reality

• This will never go away.

I am not sure if I have ever or will ever come to terms with the disability. It might get better, but it never goes away. There are constant challenges that I face every day. Simple things have become very challenging and a lot of planning is needed for everything. This is my reality. (Denise)

The best revelation that I ever had was that I’m not going to ever be able to coast free. We are never going to solve Joseph’s CP. There will always be more problems to solve. I used to think, I just need to get over this one issue, and then all will be good. But as soon as I stopped thinking that way, things seemed much better. The truth is that there will always be another battle to fight. We might have a bit of a breather from time to time, but that’s just a short period to recharge our batteries before some issue hits us again. (Maureen)

Believe in your child

• Always assume that your child will be able to do anything that you work toward.

• Never give up. Think long term.

• Your child with delays is just another child. Treat him or her like your other kids.

People told me this when I was pregnant, but it just went right over my head. Now I get it. While you need to be optimistic about your child, you also have to be realistic. There are so many people out there setting boundaries for your child. You can’t be one of those people. Sometimes I treat my son like a typical kid when I should not. But I do not want to limit him. (Emma)

Make marriage a priority

• Make your relationship a priority and take time for each other and yourself.

• If you don’t, you will have nothing left to give your children or spouse.

• Recognize that you and your partner may handle things differently, and that’s okay.
• Stay positive and hopeful.

• Take time for yourselves as a couple because that’s really important.

You can’t do it all by yourself. Don’t be afraid to ask for help when you need it. That’s true with kids, and it is even truer with a disability. (Sharon)

**Be a true advocate**

• Be an advocate for your child and especially your child with special needs.

• Take advantage of all of the services available to you.

• Get your child tested as soon as possible to take advantage of early intervention services.

• Focus on getting a good preschool placement because it is so important.

• The independence piece is critical. Start thinking about this early. This is your goal.

• Don’t give up on your child.

**Seek support**

• Seek out support because nobody will come knocking on your door.

• Disability is traumatic and life changing, so don’t expect to bounce back quickly after learning about the diagnosis.

• Do not expect to get over it quickly and run out and seek information.

• Find a local or online support group.

My support group of other moms has been very helpful. I feel like the experience of being with other moms is important. Their experiences are distinct, but also comparable. Everyone is feeling the same feelings . . . anxiety, guilt, and sadness. This has been so helpful. Even just the knowledge that there are people out there like me. I had no exposure to the world of special needs kids. But realizing I am not alone has been great. (Gabrielle)
It took me a full year to work up the courage to seek help. I did not want to admit it was real. It was just so scary for me. I’d see pictures of other kids with OI, and it would freak me out. I was so horrified. (Madeline)

Everyone copes at a different pace, so be merciful to yourself. It is okay if you need lots of time to sit with it. Take it at your own pace. Friends who have kids with disabilities are a great source of support for me. (Jill)

**Live in the real world**

- It’s so important to get out and get involved. Do not let yourself or your kids get isolated.
- These children need what all children do.
- Do not isolate yourself and say it’s because my kid is disabled.
- Don’t overestimate your kid’s abilities. Don’t push them into something they are not ready for.

I see moms with typical kids who are trying to turn their kids into the next Mia Hamm. They pay for endless lessons, they push them, and they get burnt out. And then I see moms with kids with disabilities who are trying to make their kid into an Einstein. But he can’t even read! They are not teaching him to read because he doesn’t have the mental capacity to read. Face it. (Sandra)

As Ben gets older, it gets harder . . . but I work to keep him involved. This is good for siblings, friends, and family. And it helps society understand that these kids enjoy what other kids enjoy. And should not be feared or stared at. (Mary Beth)

**Don’t fret the future**

- Try not to worry about the future.
- Plan for the future, but focus on what you need to do today and six months ahead.
Education is key

- Educating others is vital.

I go through cycles where I do not mind teaching others about autism. Other times, I hate it. I feel a bit of both. It is nice to educate others, but sometimes I do not have the energy. (Bonnie)

I don’t immediately introduce myself and say my kid has Prader-Willi syndrome, but when it’s clear that something unusual is going on, I explain. I think this is a good opportunity to educate the world. You don’t have to advertise it, but you need to tell people so they can help and understand what you are dealing with. I want people to know that Colin has a syndrome and that accounts for differences, and that they should understand. I hope they understand and are tolerant. People in Colin’s school knew that he was different and that he had special needs, but they didn’t really know what it was. I find that as people get to know us a little better, they’re grateful if I tell them about PWS. I recommend writing a letter to all of the parents in your child’s class. Tell them about your kid. If you have information, you have less to be fearful of. And differences do not seem as bad when you’re educated. You don’t have to walk around with a big sign on your shirt but don’t withhold information. (Rebecca)
Appendix G: A Roadmap Of Arvay’s Steps

STEP 1: I recruited participants through playgroups, schools, friends, support groups, and social service agencies.

STEP 2: I conducted an introductory interview to introduce the project, set expectations, sign consent form, and hand out the diary.

STEP 3: I conducted face-to-face interviews and recorded them. I collected diaries (or in some cases, I collected them several weeks later, if not completed at time of the interview).

STEP 4: I hired a professional transcriber to transcribe the 32 interviews.

STEP 5: I conducted four interpretive readings of the written transcripts (reading for content, self, research question, and relations of power/culture).

STEP 6: I read and analyzed volumes of interview transcripts and diary entries, extracting the data into a meaningful and manageable form. Using this data, together with my analysis of the four readings, I crafted poetic representations for each narrative.

STEP 7: I conducted an interpretive interview to elicit feedback from participants on the poetic representations. I provided participants with their narratives and asked them to review and comment on content and structure. I considered this to be a form of member checking.