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Different Challenges and Different Blessings: Life Experiences of Young Mothers of Children with Down Syndrome

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DIFFERENT CHALLENGES AND DIFFERENT BLESSINGS:

LIFE EXPERIENCES OF YOUNG MOTHERS OF CHILDREN WITH DOWN SYNDROME

By

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Abstract: Different Challenges and Different Blessing: Young Mothers of Children with Down Syndrome

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Life experiences of young mothers of preschool aged children with Down syndrome were explored in this qualitative narrative study. Intensive interviews of four purposefully chosen young women were conducted. The findings of this study illustrate the impact of a preschool aged child with Down syndrome on the life of a young woman.

A variety of themes were identified. The primary themes were background of the woman, including her public school experience, learning of the diagnosis of Down syndrome, supports, the child’s medical complications; learning to cope, and the impact of that disability on their day-to-day lives.

Child care and career were both impacted by the fact of the child’s Down syndrome. Medical complications and behavior strongly affected day to day life. None of the participants recall positive inclusion experiences with other students with disabilities. The participants told of confronting bias in their immediate social circles and local communities. They also mentioned gathering support, and beginning to grow into advocates for their children. Expert knowledge and law are different from actual practices and widespread beliefs about the value of persons with disabilities in our society.

The shared experiences provide insights into what it really is like to be a young mother of a child with Down syndrome; Suggestions for future research and lessons learned by the researcher were presented.

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my brother, Steve Driscoll

and to the memory of my wonderful parents

Maurice and Margie Driscoll

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Dr. Gail McGregor

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Chapter One: Introduction

Turbulence, constant change, vast amounts of easily accessed information: these terms help describe the early years of the twenty-first century. The economy of the United States continues to be weak, with resulting economic pressures on many people. This fast paced, uncertain young century is the background for today’s young families.

Although many very young women continue to have children, a large group of parents have waited to start a family until they are settled in their lives, perhaps seeing their baby as a culmination of all their dreams. Babies often become the center of the parents’ lives, energy, money and socialization. It can be, as Landsman (2009) said, “an age in which infants are commodified and technology seems to hold out the promise of ‘perfect babies’” (p. 3).

Many families in today’s society almost idolize their children, the children who carry their parents’ hopes and dreams. Donahoo (2007) noted: “Of course, creating the perfect child or perfect childhood is impossible, but that has not stopped us from expending tremendous amounts of energy trying” (p. 34). He described the phenomenon as arising from social and economic factors, such as more money and more competition, to the point where children have become the latest status symbol for some parents. Within this context, life with a child with disabilities gives parents unique experiences, with unique joys and difficulties.

Prenatal Testing

Perhaps as part of the quest for perfect babies, the American College of Obstetricians and Gynecologists issued a press release in 2009 recommending prenatal testing be offered to all women, not just to older women. Typically these tests include amniocentesis or chorionic villus sampling (CVS). Mansfield, Hopfer and Marteau (1999) noted that termination rates after a prenatal diagnosis of Down syndrome are estimated at between 90 % and 93%.

Place (2008) discussed the scope and ramifications of prenatal testing and related it to the current focus on choice and proactive prenatal care:

> According to the medical profession the direction and scope of reproductive services such as IVF and pre-natal screening… are usually presented to the wider community in a positive light with images of ‘successful’ birth outcomes showcasing the importance of their work. Unsurprisingly this has led to women being expected to take control—from timing a pregnancy to choosing one particular pregnancy over another… Is it safe to assume the push to achieve better birth outcomes and the concomitant use of prenatal testing automatically improves lives? Could it be the issues raised are causing some lives to become harder? How meaningful, for example, are tests such as amniocentesis and CVS? As the mother of a child with Down… I believe it is important for me and other women in similar situations to share their lived experience. Perhaps we can illuminate some of the more complex and troubling issues these technological advances have the capacity to create—not only for ourselves—but for all women. (p. 118)

Women who decide to continue their pregnancy even with a prenatal diagnosis of a disabling condition, or women who discover their child’s disability later have embarked on a very different journey of parenting as they raise their children alongside the *perfect* babies.

Disabilities within Families

Many researchers have tried to quantify the impact a child with disabilities has on a family. One researcher gathered data before and after personally experiencing disability in his family. In 1963, Roos described and quantified common patterns of reaction to having a child with a disability. The patterns he described include (a) loss of self esteem, (b) shame, (c) ambivalence, (d) depression, (e) self sacrifice and (f) defensiveness. In 1985, after he became a parent of such a child he noted further “critical conflict areas which are likely to be reactivated by the realization of having a retarded child” (p. 251). Roos’ additional conflict areas include (a) disillusionment, (b) aloneness, (c) vulnerability, (d) inequity, (e) insignificance, (f) past orientation because the future is uncertain and (g) loss of symbolic immortality: not having a child in your image to continue your lineage. Roos’ insightful work after the diagnosis of his child clearly illustrated a turning point in his life and sheds more light on the lives of other parents in similar situations. His personal insights illustrate the importance of lived experiences in addition to empirical research.

Mothers. Using personal narratives, Landsman (2009) told of many women in the current century who are mothers of children with disabilities. Her research is rich with the detail of feelings, emotions and insights that are difficult to capture in quantitative studies. She wrote of the focus placed in this era on having and raising children. In contrast to some earlier studies which focused on grief, guilt and blame, she wrote that “‘parental adjustment’ may not be a matter of being resigned to one’s 'misfortune' but rather of being challenged by and redefining through experience, preexisting cultural understandings of what constitutes normality, perfection and personhood" (p. 10-11). In the midst of this era of the perfect child, she guided her readers to get to know other mothers of children with disabilities. She stated that mothers believe that the telling of and listening to their stories matters:

> Mothers thus express in their narratives both the boundless hope and the ever present, exhausting burdens inherent in a child's open ended prognosis. Relentless determination and everyday acts of nurturance, intervention and advocacy by mothers of young disabled children—children who in other times and places might be abandoned or segregated in institutions—are carried out within the meaning-laden context of 'overcoming disability' whose ending mothers hope to realize. (p. 142)

Some researchers used narrative studies to tell personal stories relating to disabilities. Green (2002), a mother of a child with cerebral palsy, explored the narratives of six other women who had children with either cerebral palsy or autism. Levine (2009) studied lived experiences of 15 single mothers of children with a disability. None of the participants' children had Down syndrome.

Lawrence (2008) wrote of her experience mothering a child with a disability along with narratives of four other women, including one with a child who had Down syndrome. "This study takes the reader on a journey of exploration into how mothers of disabled children navigate public spaces that presume normalcy, manage the emotions of raising a non-typical child in a typical world…" (p. 528).

Personal Perspective

The causes of Down syndrome, the difficulties and illnesses that often accompany Down syndrome, the life and life style of young women: these were all important factors of my choice of an area of research for this dissertation. My life experience has been shaped by having a sibling with Down syndrome. These elements don't completely explain why this topic is relevant to society and to me. I will try to explain my choice.

While advancing maternal age is a risk factor for Down syndrome, more children with Down syndrome are actually born to mothers who are 35 or younger. Like others in their age group, these women are often involved in their own education, developing careers and may be active in youth-oriented social life. I wondered how a child with Down syndrome fit into the life of young mothers.

I have known many young mothers of children with disabilities. Some act as if they had been in training all their lives for just such a challenge. Some parents are bewildered. Some mothers are angry and resentful. Some mothers of children with disabilities are not able to handle the extra layer of work and worry that comes as part of the package. Some parents have adopted their children, making a conscious choice to include a child with a disability in their family.

As a preschool educator, I have a close link with the parents of my students. It was important for me to be able to better understand the experience of a young parent. By understanding more about the life of a few young women with children with disabilities, I learned of some of the joys and difficulties, feelings and experiences that could be in play with many other families.

The disability of Down syndrome has a type cast, a public face of a sunny, smiling person, who is often a joy to be with. While that is very often true, it is not always the case. As described on the website of National Down Syndrome Society (2011), *About Down Syndrome: Myths and Truths*, these individuals experience a wide range of moods, feelings, needs and expressions. I know Down syndrome goes far deeper than the smiling image. I wanted to explore some of that depth and learn what the parents have experienced before their child ever comes to school.

Research Questions

I wanted to learn about the lives of some young mothers. I wanted to learn about the intersection between living as a young woman in the early twenty-first century and having a child with Down syndrome. I interviewed at length four young women who each had a preschool age child with Down syndrome. I began with these questions:

- How has having children, and in particular, a child with Down syndrome impacted their lives?
- What were the participants' perceptions of their long term plans? Did these plans change after the birth of their child with Down syndrome?
- Have they come to terms with the diagnosis of lifelong disability for their children? How have they accepted this?
- What has facilitated or inhibited this process?
- How are they coping?

- New questions became evident through my study and interaction with the participants. I realized that learning that their baby had Down syndrome was a shocking and emotion filled time for all the participants. I also learned of the health and medical issues that had major impact on these young families.

These questions and the desire to investigate and share some of the lived experiences of these young mothers led me to pursue answers using a narrative approach to my investigation.

Narrative Research

Simply put, a narrative is a life story. Smith and Sparkes (2008) discussed narrative research in the field of disabilities. They stated: “We organize our experiences into narratives and assign meaning to them through storytelling” (p. 17). They also wrote, “in order to understand ourselves and others we need to explore the meanings that make up our worlds” (p. 28).

Several authors described narrative research as a process through which a person describes an experience and, in doing that, learns or creates its meaning. Hollingsworth and Dybdahl (2007) described their philosophy of narrative research: “Personally meaningful knowledge is socially constructed through shared understandings” (p. 149). To me the key element in narrative research is telling important stories. Stahl (1983) defined a storyteller as someone who:

> Not only acts or experiences, but thinks about his action, evaluates it, learns from it and tells the story—not to express his values but to build them, to create them, to remake them each time he tells his stories. (p. 269)

Four mothers welcomed me into their homes and freely shared their stories. The remaining chapters of this work place the four stories in historical and cultural context, and illuminate the stories shared by these mothers.

Chapter Two: Review of Literature

Information shared in this chapter to set the stage for stories of young mothers, for stories of children with disabilities, and for stories of the experience of disabilities, especially Down syndrome. A brief look back at the history of disabilities provides some perspective to my study of women who nurture children with disabilities today. In addition, I give a sense of the evolving culture, illustrating changing societal perceptions and current interpretations of disabilities. I include information about advocacy and legal supports as well as educational issues such as inclusion and early intervention. I present research concerning how children with a disability affected their families as well as the parents' reactions and attitudes. I try to paint a picture of what Down syndrome is for a young mother in 2011, what she may experience and what she may anticipate in a future with new possibilities.

Down Syndrome

Down syndrome is a genetic disorder that causes, in addition to other symptoms, mild to moderate intellectual disability. John Langdon Down (1866) was the first to describe the condition that now bears his name. It is considered the most common genetic cause of severe learning difficulties, with as many as 6,000 babies born every year in the United States (National Down Syndrome Society, 2009). Recent estimates indicate that Down syndrome occurs once in every 732 live births, with some evidence suggesting possible variability among racial/ethnic groups (Sherman, Allen, Bean, & Freeman, 2007). Demographic information from the National Institutes of Health (2011) is consistent in the findings that mothers above age 35 are at higher risk for having a child with Down syndrome. The child born with Down syndrome will have an impact on the child's family, school, medical community, social networks and larger community.

Types. Human cells have 23 pairs of chromosomes. Down syndrome results from one of three types of abnormal cell division. These abnormal cell divisions create extra genetic material from chromosome 21, resulting in one of three distinct types of Down syndrome: Trisomy 21, Mosaic Down Syndrome and Translocation Down Syndrome.

Sherman, et al. (2007) stated that more than 90 percent of children with Down syndrome have Trisomy 21. These children have three copies of chromosome 21 in all their cells, rather than the usual two. This is caused by abnormal cell division during the very early development of the embryo.

Mosaic Down syndrome is a rare form. As described by the National Down Syndrome Society (2009), it occurs in only one to two percent of children born with Down syndrome. Abnormal cell division after fertilization results in some, but not all, cells having an extra copy of chromosome 21.

Translocation Down syndrome occurs in about four percent of the children born with Down syndrome. It results when part of chromosome 21 becomes attached or translocated onto another chromosome before or at conception. In addition to this translocated chromosome, these children still have the usual two copies of chromosome 21. This is the only form of Down syndrome that can be passed from parent to child, although only about half of these children have a mother or father who is a carrier. In these cases, the mother or father is a balanced carrier of the translocation, with no signs or symptoms, having some rearranged genetic material, but no extra genetic material

(Sherman et al., 2007). The recurrence risk in these cases, if one parent is the carrier of a translocation is between 10-25% (Bansal, et al., 2010).

Ranweiler (2009), writing from a nursing perspective, presents guidelines for dealing with families who have children with Down syndrome:

> Genetic counseling should be offered to all parents of a child with Down syndrome for review of the chromosomal cause of their specific recurrence risks. The genetic counselor can also determine whether any other family members may also be at increased risk for having a child with Down syndrome or for miscarriage due to the possibility of an inherited translocation (p. 23).

Risk factors. There are three key factors associated with increased risk of Down syndrome recognized by the National Down Syndrome Society (2009). These are:

- Advancing maternal age. By age 35, a woman’s chance of conceiving a child with Down syndrome is 1 in 385. By age 40, the incidence is 1 in 106 and by age 45, Down syndrome occurs in 1 of 30 conceptions.
- Previous birth of a child with Down syndrome. Mothers with a child with Down syndrome have about a 1% increased chance of having another.
- Genetic factors. As mentioned above, parents who are carriers of translocation have some increase of incidence of Down syndrome in future conceptions.

Although older mothers have a greater chance of having a child with Down syndrome, younger mothers as an age group have more children. Therefore mothers thirty five and under have the majority of babies with Down syndrome.

Complications. In addition to intellectual disabilities, children with Down syndrome are at risk for many complications (National Down Syndrome Society, 2009).

About half the children with Down syndrome are born with some level of heart defect. Children with Down syndrome are more likely to develop leukemia than other children. Because of abnormalities in their immune systems, these children are much more likely to develop infectious diseases, especially pneumonia.

Gastrointestinal blockage may occur. In one form, a membrane or web in the duodenum may be fully blocked resulting in duodenal atresia, or partially blocked, resulting in duodenal stenosis. Approximately one-thirds of infants diagnosed with duodenal atresia also have Trisomy 21 Down syndrome.

Freeman et al. (2009) found congenital gastrointestinal defects in 6.7% of the 1892 infants with Down syndrome they studied. “Defects included esophageal atresia/tracheo esophageal fistula (0.4%), pyloric stenosis (0.3%), duodenal stenosis/atresia (3.9%), Hirschsprung disease (0.8%), and anal stenosis/atresia (1.0%)” (p. 180).

Ranweiler (2009) presented data that quantify the health risks of children with Down syndrome. She wrote that:

> …three-fourths of fetuses known to have Down syndrome are spontaneously aborted or stillborn and 40% of those born with Down syndrome and a congenital heart disease die in less than 5 years from infection. Survivors at 5 years have a mean survival of 45 years, 20% of infants born with Down syndrome die during their first 10 years of life. (p. 22)

Other health issues associated with Down syndrome are thyroid problems, hearing loss and vision difficulties. Persons with Down syndrome have a greater than average risk for developing dementia and at an earlier age, sometimes before 40.

Referring to practice guidelines established by the American Academy of Pediatrics in 2001, So, Urbano and Hodapp, (2007) stated:

> These guidelines recommend early evaluations for cardiac, hearing and vision conditions, and routine screening for thyroid disease. The guidelines also note that appropriate care involves increased awareness of the risk of gastrointestinal symptoms and respiratory illnesses, vigilance for the development of other specific problems throughout childhood, and periodic review of the availability and use of supports. (p. 1031)

They also noted that 49.8% of children with Down syndrome were hospitalized during their first three years (So et al.2007). “Down syndrome, in and of itself, carries significant risks of hospitalization, at least during the early years” (p. 1036). They found a median number of two hospitalizations for each child. In their research sample, a child with a congenital heart defect was 2.9 times as likely to be hospitalized. They closed with this statement:

> …it is clear that Down syndrome involves more than developmental delays, and that systems of care for children with Down syndrome and their families should reflect the age- and hospitalization-sensitive nature of these physical health-related issues. If, over the past 50 years, we have mostly ensured these infants’ survival beyond their earliest years, we must now help to care for the many severe and early health problems experienced by young children with Down syndrome. (p. 1037)

Ranweiler (2009) had recommendations for care of the newborn child with Down syndrome as well as the mother. “Most importantly, nursing care should emphasize that children with Down syndrome are children and, therefore, like other children, they deserve state-of-the-art science and technology as well as family-centered care" (p. 23).

Current research about Down syndrome. This is an era of important research about Down syndrome. People with this condition attend school, work; participate in decisions that affect them and contribute to society in many ways. Life expectancy for people with Down syndrome, but has increased dramatically in recent decades—from age 25 in 1983 to near age 50 and beyond today (Eunice Kennedy Shriver National Institute of Child Health and Human Development, 2010).

Researchers are making great strides in identifying the genes on Chromosome 21 that cause the characteristics of Down syndrome. As stated on the National Down Syndrome Society (NDSS) website (2010), many feel strongly that it will be possible to improve, correct or prevent many of the problems associated with Down syndrome in the future. For example, NDSS presented the information that Duke University is looking for participants in a clinical trial evaluating an investigational study drug to see if it can improve communication, understanding and the performance of daily living skills in children with Down syndrome.

Researchers are creating safer and better prenatal testing to determine the presence of Down syndrome in the fetus. The NDSS (2010) has a current position statement on prenatal testing that sheds light on a developing dilemma of potential parents terminating pregnancies because they don't have an up to date image of Down syndrome. The position statement describes the progress in blood testing by the company Sequenom and by Stanford University, and then continues:

> However, when it comes to explaining the results of prenatal testing for Down syndrome, nearly 25% of physicians admit to emphasizing negative information or actively urging parents to terminate their pregnancies... As such, the NDSS urges policymakers, health care professionals, and the Down syndrome community to work together to ensure that expectant parents are not pressured to terminate a pregnancy after receiving a prenatal diagnosis of Down syndrome. Instead, they should be given balanced and accurate information so that they can make informed decisions. (NDSS Position Statement: Prenatal Blood Test, para.2)

The NDSS has arranged for publication of a new booklet, *Understanding a Down Syndrome Diagnosis* (2011) that contains balanced, accurate and up-to-date information about Down syndrome to be provided to expectant parents at the time of diagnosis. It is a booklet for expectant parents, covering health and education services, genetics and common medical conditions for babies with Down syndrome. It is designed to offer balanced, up to date information to families who have received this diagnosis. This current information evolved from and is part of a long history of growing enlightenment about disabilities.

Disabilities in American History

The Down Syndrome Association of Northeast Indiana (2009) features this quotation on their website: “We stand on the shoulders of those who came before us. We provide the shoulders of those who follow.” In this section, I provide some information about “those who came before us.” Caldwell identified three major periods in the history of disabilities in our nation. She labeled them, chronologically, as “*Forget and Hide,*” “*Screen and Segregate*” and finally, “*Identify and Help*…”(as cited in Karnes, 1973, p.5)

Forget and hide. For most of history, birth and childhood were treacherous times of life. Winzer (1993) described a time in which there was virtually no prenatal care. Few births were attended by physicians and infection was rampant. There was no system of care for premature infants. Infectious diseases such as measles and small pox, with their potential for long-term disabling effects, had taken a firm hold. No viable means of preventing pregnancy left many women weakened by multiple pregnancies.

Many mothers did not survive childbirth. Children who couldn't nurse or children with mothers who died or were too ill to produce milk faced death unless they were lucky or wealthy enough for a wet nurse. The weak or fragile child did not survive (Thulier, 2009).

This scenario resulted in relatively fewer children with disabilities than are seen in the world of 2011. In addition, the concept of learning disabilities or language learning disabilities had no place in a world where few children were taught to read. Conversely, an agrarian society that required work from all members, including children, would have a place for people who couldn't read or make decisions, but who could follow directions. As Winzer (1993) wrote:

> Before the advent of widespread literacy, when pushing the plow was more important than pushing the pen, mildly intellectually disabled — those labeled today as learning disabled and those at the upper end of the spectrum of mental retardation, for example, would simply have merged into the general populace. (p. 12)

Thus, both the concept of disability and the relative number of persons with disabilities was different in earlier centuries.

Puritans in colonial America often believed that disability was a sign of God's displeasure. Increase Mather, an early Harvard president, wrote of the birth of a child with disability as evidence of divine retribution (Albrecht, Seelman, & Bury, 2001). Increase was the father of Cotton Mather, an influential eighteenth century minister, scientist and author of the posthumously published *The Angel of Bethesda* (1972), one of the first medical texts in America. Cotton Mather addressed intellectual disability (referred to at that time as "idiocy") in this book, implying that he considered it a theological rather than a medical issue. In 1720, Mather used terms for disability as an apparent insult when he called his political foes "idiots and fuddle caps" (Wickham 2002, p. 945).

By the mid nineteenth century, there were some attempts purported to improve the situation of persons with disabilities. This often took the form of placing them in a colony or institution. Trent and Trent (1995) presented the following excerpt from a letter written by Charles T. Wilbur in 1884, years after he had served as an institution founder and superintendent. It illustrates both some positive intentions at the outset of the movement as well as flaws in a system that was to continue, in some form, to the present day.

> The developing or ennobling influences of the institution, with the inmates kept in large classes of their own kind or worse are not for their own good. My views are decidedly changed since I learn that society desires only to get rid of them and be protected from them, when the older ideas were to uplift them by every means that could be used. (p. 96)

Screen and segregate. The phenomenon of a child with a disability as a family member grew in the second half of the twentieth century. As medical science evolved and more children survived birth (McNabb & Blackman, 1998), families began to need information and support concerning their children with disabilities. In the early decades of the last century, more rational and scientific interpretations of the concept of disabilities led to a beginning effort to develop methods of education and suggestions for the care of children with a disability. At this time, the concept of intellectual disabilities, in general, began to be studied.

Modern research concerning children with disabilities has its roots in the early decades of the last century. Researchers (Gesell & Gesell, 1912, Watson, 1928) were interested in determining if heredity or environment had a stronger role in the development of children with disabling conditions. This is often called the nature-nurture debate. It was also at this time that Binet and Simon (1916) as well as Gesell and Gesell (1912) began to study, measure and describe sequential skill development of children. The trend at that time, which had started almost a century earlier, continued to be placement of children with disabilities in institutions.

Information written for parents lagged behind the professional literature. Dybwad (1966) presented some of the earliest suggestions for education of parents of children with disabilities:

> First comes parent education, because parents have got to know: What are some of the needs of these children, and above all, in what ways are they like other children (rather than unlike other children)? Thus parent

> education is the first step—straight-forward, good sound education on the new principles we have developed about learning, exactly the kind of methods which we are using now in business and the professions to convey new information to people. (p. 6)

He specifically addressed Down syndrome in his booklet, although the information that he gave is simplistic and inaccurate from the twenty-first century perspective:

> Let me come back as an example to the child with Down's [*sic*] syndrome. It is most distressing to see how many of them are inadequately nourished by being kept on a soft (baby food) diet, and therefore are not exercising their jaw and mouth muscles which are crucial to the development of language. Thus the basic language deficiency which all these children show is further complicated by this faulty dietary management, simply because the mother does not have the benefit of continual adequate health supervision for the child. (p. 12)

Identify and help. The second half of the twentieth century produced the beginnings of awareness, understanding and acceptance of persons with disabilities. Parents, professionals and persons with disabilities helped create this and advocated strenuously for their education and legal rights.

Trent and Trent (1995) describe three groundbreaking books written by parents of children with disabilities that told of their personal experiences. All three parents wrote of being encouraged to institutionalize their child with an intellectual disability. These books were all written by celebrities or well respected professionals, and included *My Son's Story* (Frank, 1952), *The Child Who Never Grew*, (Buck, 1950), and *Angel*

Unaware (Rogers, 1953). In keeping with the trends of the time, the children of Buck and Frank were placed in private institutions; Roy and Dale Evans Rogers' child passed away before her third birthday.

Dybwad (1990) noted that Pearl Buck was "the first person of international renown to make it public knowledge that she had a retarded child" (p. 162). Carol Grace Buck was born with phenylketonuria in 1921. She was placed in the Vineland Training School in New Jersey. At first, her family concealed her existence from the public. Sometime after Carol's birth, Buck wrote to a friend. Finger and Christ (2004) present a portion of this undated letter:

> It is not a shame at all, but something private and sacred as sorrow must be. I am sore to the touch there and I cannot endure even the touch of sympathy. Silence is best and far the easiest for me. I suppose this is because I am not resigned and never can be. I endure it because I must, but I am not resigned. So spare me and so make no mention of her. (p. 45)

In 1950, Buck did share the story of her daughter, publishing her narrative entitled *The Child Who Never Grew*, first as a magazine article, and later as a book. Buck donated the earnings from her book to the Vineland School and became an advocate for persons with disabilities.

John P. Frank was an aspiring writer and former clerk to Supreme Court Justice Hugo Black. In *My Son's Story* (Frank, 1952) he wrote of his family's struggle with finding a diagnosis for his son with Down syndrome, and of his worry that his wife couldn't handle the extra work. He quoted the advice he was given by his family doctor when he and his wife were facing another expected child, suggesting that his son be placed in an institution. "'I've seen home care for badly retarded children tried every way there is to try it…and it always fails…and think of your child about to be born…'" (p. 145-146).

Angel Unaware (Rogers, 1953) was a best seller and introduced many in the general public to Down syndrome. Roy Rogers and Dale Evans used royalties from this book, in part, to help form the National Association for Retarded Children, a group that continues to be viable in 2010 as the ARC.

Collectively, these stories served to personalize the situations faced by many parents of children with disabilities in early and mid twentieth century America. They helped open the public consciousness to children with disabilities.

Advocacy. Gunnar Dybwad (1909-2001) and Rosemary Dybwad (1910-1992) were pioneers in advocacy for parents and their children with disabilities. Gunnar began his work in the field of juvenile delinquency in 1934 and noted that many of the offenders had some type of disability. This led to a sixty year career in disability rights and awareness.

Rosemary Dybwad earned a doctorate in sociology and emerged as an advocate for children with disabilities. Dybwad (1990) published a retrospective collection of her papers including a presentation in which she wrote that World War II fostered a greater acceptance of disabilities and a "fight against discrimination and intolerance against other human beings who are different on account of their religion, the color of their skin or their physical disability" (p. 156). It was against this background that the parents' movement developed, seemingly spontaneously and internationally, "to gain for their children a measure of the new social justice, the new benefits of rehabilitation and also the new scientific endeavor" (p. 156).

While progress has been uneven in our society, much of the progress that has been made is due to parent advocacy. The parent groups that evolved and coalesced in the 1950s and 1960s were instrumental in pushing litigation and, ultimately, legislation that helped ensure education for all children and inclusion of children with disabilities into the school community and fabric of American life.

President John F. Kennedy created The President's Committee on Mental Retardation at the behest of his sister Eunice Kennedy Shriver, who spearheaded much of the work. Kennedy and Shriver had a sister, Rose, who had a disability. The Committee's landmark publication was *The Mentally Retarded Child…Their New Hope* (1970). The Advertising Council, INC was a key collaborating agency in production of the pamphlet. It was published in the mainstream press rather than scientific or medical channels and was another important factor in raising the awareness of the society as a whole of persons with a disability.

Wolf Wolfensberger, educated as a philosopher and psychologist, played a key role in developing and putting into modern culture the idea that persons with disabilities have the same rights and liberties as other citizens. In 2007, the editors of *The Exceptional Parent* chose seven "wonders of the world of disabilities" (p. 50). One of their *wonders* was the work of Dr. Wolfensberger. Writing on behalf of the editorial staff, Hollingsworth and Apel wrote:

> In today's world the concept that ALL people should have the same rights and civil liberties and the same access to everyday living conditions and

> circumstances as everyone else, regardless of disabilities either physical or cognitive, seems a forgone conclusion. Of course, they should. But when the young Dr. Wolf Wolfensberger, now 74, was first advancing and expanding the principle of Normalization, first devised by Scandinavian Bengt Nirje in the 1960s, and formulating the concept of Social Role Valorization (SRV) in the 1970s and 1980s, it was far from a forgone conclusion. (p. 54)

Ferguson and Ferguson (2000), credit Wolfensberger with “raising our awareness of the symbolic dimensions of discrimination and stigma in the lives of people with severe disabilities” (p. 638). Treating adults as children because of their intellectual challenges deprives them of the symbols of adult independence and can limit expectations and accomplishments.

Des Jardins (1980) opened the door to parent advocacy for new generations of families with her book *How to Organize an Effective Parent/Advocacy Group and Move Bureaucracies.* Using a strong, commanding tone she told parents that they must stop feeling guilty and insignificant.

> You must stop apologizing for asking a bureaucrat to do a job you are paying him to do. You must stop begging for what you are entitled to by law. You must not accept these old excuses: ‘There isn't enough money;’ ‘We need more time.’ You must stop whispering when everyone else is shouting. Don't be afraid to complain. You must use mass action. (p. 18)

Law. Some laws are so important that the nation is forever changed by their passage. Some laws have become so iconic in our society that they have well known names, such as the Civil Rights Act, or Women’s Suffrage. The law now known as IDEA is one such law, of paradigm shifting importance. Strong parent advocacy led to awareness, a call to action, litigation and, finally, change. After years of tireless lobbying and advocacy by parents and other advocates, Public Law 94-142 was originally passed in 1975 as the Education for All Handicapped Children Act (EHA). It required the public schools to educate all children with disabilities. The centerpiece of this education was to be an Individual Education Plan, based on the needs and abilities of the child. Later revisions of the law led to renaming it the Individuals with Disabilities Education Act (IDEA, 1990) and to a shifting emphasis to provide education and support services as much as possible in the school environment the child would normally attend. The concept of least restrictive environment, requiring that the child be educated as much as possible in general education, both in placement and curriculum, has received increased emphasis in subsequent iterations of this law.

The passage of EHA did not immediately change the culture and habits of a society and its schools. The struggle to gain access for all students to general education environments continues today.

Education of students with disabilities should produce outcomes akin to those expected for students in general education. Students with disabilities should be educated with their peers without disabilities. These are two major principles of the reauthorized IDEA (2004) relating to the experiences of community belongingness for all students. Arne Duncan, Secretary of Education referred to this in an August 3, 2010 speech to special education leaders:

> In our proposal to reauthorize the Elementary and Secondary Education Act, we're working hard to ensure that we have the right policies and incentives to help

> states and districts accelerate achievement for all students, including those with disabilities. We want to make sure that students with disabilities are included in all aspects of ESEA, and to continue to measure achievement gaps and work to close them. We want to align ESEA with IDEA so that we create one seamless system that addresses the needs of each child (para.4).

The concept of inclusion, educating students with disabilities in the general education arena as much as possible, was part of the letter and spirit of all iterations of this law, and methods for facilitating its success continue to be an important area of professional development. For example, Lipsky and Gartner (1998) studied 1,000 school districts which implemented inclusive education programs. They identified factors for the successful implementation of inclusive education including leadership, collaboration, support, funding, effective curriculum and parent involvement.

Words from the 2004 Individuals with Disabilities Education Act, one of several revisions to the 1975 landmark Public Law 95-142, provide insight into an official philosophy that is not yet perfected, but shows progress:

> The law states that disability is a natural part of the human experience and in no way diminishes the right of individuals to live independently; enjoy self-determination; make choices; contribute to society; pursue meaningful careers; and enjoy full inclusion and integration in the economic, political, social, cultural, and educational mainstream of American society. (29 USC Sec. 701)

Public schools have been charged with educating all children with disabilities for over 35 years. As a result, at the outset of my study, I assumed that the young mother of today would have grown up with students with disabilities as their classmates and fellow students. Yet, almost 35 five years after Public Law 94-142 went into effect, inclusion is variable across districts and states and varies widely based on disability types. For example, in 2009 only 14% of the students with cognitive disabilities spent 80% of their day in general education classes (National Center for Education Statistics 2011).

Independence, Respect and Self-Determination. I used Caldwell's (1973) descriptions of eras in the history of disabilities in America through the late twentieth century. Future scholars putting our current work into a historical context might use the terms independence, respect and self-determination to characterize the current era.

The concept of self-determination is an important factor in current policy and practice in the education and career planning for individuals with disabilities (Wehmeyer, 1996). Self determination is a belief that persons with disabilities should be the primary decision makers in their own lives. They should be encouraged and supported to make choices free from undue external influence or interference.

Bailey and Agosta (2007) published results of the Robert Wood Johnson foundation sponsored research concerning self determination. The key results indicated that a shift in decision making from professionals to individuals is occurring, with an improvement in some, but not all quality indicators of self determination. They also found that the key factors in successful self determination were flexibility, a system wide approach and the availability of direct support workers.

Ward (2006), addressing comments to the membership of TASH, an organization focused on the needs of individuals with the most severe disabilities, wrote of future directions in special education and self determination. He described a need for a systems shift in general education and adult service systems to ensure that self-determination skills are taught to all students, not just to students with disabilities and that persons with disabilities are seen as independent, respected and valuable citizens with much to contribute to their communities.

> Self-determination is interplay between the individual and society. Individuals with disabilities must have the abilities and opportunities to be self-determined. Society must give individuals with disabilities, including those with severe and developmental disabilities the skills, opportunities, and the support to do so. My challenge to TASH and others working with individuals with severe disabilities is to address the dichotomy of self-advocacy and well-meaning, but often overprotective parents and professionals. TASH must ensure that true self-determination is promoted. (p.5)

Current approaches to education. This is the era of standards-based reform, embodied in the current *No Child Left Behind* policies. The reauthorized Elementary and Secondary Education Act, passed in 2002, is a law and movement that has sparked much controversy. One intended outcome of this act is that special and general education has become more of a shared endeavor with high expectations for all, and access to the general education curriculum for all students.

Reporting her research concerning the impact of NCLB on inclusion of students with disabilities, Cole (2006) stated “The best and most positive effect that NCLB has had on special education is that students with disabilities now count as part of the assessment system.”(p. 2). Increased attention has led to documented benefits for both general education students and students with disabilities.

A key feature of NCLB is annual, statewide, testing of students to determine their rate and amount of progress. These scores are used to determine whether a school has made Annual Yearly Progress (AYP) targets relative to the proportion of students who are educationally successful. There are significant consequences for schools that do not make AYP. Testing may have the potential to cast students with disabilities into a causative role in terms of a school reaching AYP.

Early intervention. IDEA evolved over the years and revisions were made in 1990, when states were required to provide educational services from birth. The societal change from institutionalization to membership in home and family and the impact these children with disabilities had on their families led to questions about how families cope with and teach their children. The development and funding of services to support families in these settings and help with interventions to optimize developmental outcomes has been a significant. Early intervention services are important in the lives of many families with young children with disabilities.

Families with children who meet eligibility criteria for disability are entitled to early intervention and support services from birth through 36 months. This service model was developed through parent and professional advocacy based on the demonstrated fact that children with disabilities make the most progress with focused intervention from a very early age. Fewell and Oelwein (1991) extensively evaluated 92 children with Down syndrome. They found measurable, positive gains in the rate of development of the children with Down syndrome receiving early intervention. Hines and Bennett (1996) evaluated over 50 studies published between 1960 and 1994. They stated that “the conclusion that children with Down syndrome and their families are likely to benefit from early intervention is generally a consistent finding" (p.100). Connolly, Morgan, Russell, and Fullton (1993) found that the positive effects of early intervention could still be measured in the teen age years.

Over 600 families access these services on any given day in Montana, with 1297 infants and toddlers and their families being served in fiscal year 2008. The website of the Montana Department of Health and Human Services described a program of early intervention services for children with disabilities ages 0-36 months. Families with children who meet the eligibility criteria established by the state are entitled to a range of services defined under federal law. Services are provided as part of an Individual Family Service Plan (IFSP) developed with the family.

The lead decision making role in early intervention services belongs to the family and services are provided in the context of the family. The purpose of the intervention is to help parents learn skills to teach their child, to support families and to assist in identifying and locating resources.

This delivery model seems appropriate to family based services, but the very nature of these services gives parents additional responsibilities and challenges to learn the skills and serve as their child's primary educator. In her extensive study of the experiences of mothers of children with disabilities, Landsman (2009) looked at this from an interesting perspective:

> Thus, women who themselves grew up with few if any role models [regarding care of persons with disabilities], little exposure to disabled people and no expectations that they would ever be in the position of mothering such individuals

> paradoxically find that they are now bearing primary responsibility for caring for their disabled young children. (p. 89)

As young children turn three they are eligible for public school based services. These services are developing and best practices lead to functional, developmental and standards based preschool special education services. The guarantee of a publicly funded education with birth-22 year old services changes the trajectory and potentially improves the outcomes for these children.

New possibilities. Persons with Down syndrome today have a wide variety of lifestyles. They range from adults cared for in activity centers to adults with jobs and apartments, from people who rarely leave the family circle to students taking courses on college campuses and in a few cases, appearing on TV shows.

A mother of a young child with Down syndrome can envision a variety of career possibilities for her child’s future. McCabe (2005), a parent of a four-year-old boy with Down syndrome, described her experiences at a National Down Syndrome Society conference. She wrote of a dynamic 26-year-old speaker, Craig Blackburn, who described his keys to success as believing in your dreams and potential. Craig has Down syndrome, as does another presenter, Bridget Brown, a recent high school graduate and advocate for persons with disabilities. She credits self-determination and person centered planning with her success. She was about to start her postsecondary education at the Des Plaines Technical Center and expressed gratitude to the heroes in her life who” didn’t clip her wings”.

This is an era of entrepreneurship and new careers. Some publications and events help illustrate the world of persons with disabilities today in relation to the world of work. The National Council on Disabilities (2007) published a wide range of suggestions and recommendations for including and incorporating persons with disabilities into a wide spectrum of modern life. These progressive policies provide a luster of optimism for the future. Yet, they must be viewed from the current reality that continues to include multiple barriers and hurdles.

While persons with Down syndrome and their parents and friends can and should take inspiration from the positive experiences of others, there is still need for advocacy. In today's society, most adults with Down syndrome have limited employment and independence. The Bureau of Labor Statistics (2010) reported that only 19.2 % of persons with disabilities were employed. This compares with 64.5% of the general population. Eight of ten persons with a disability are not in the workforce at all.

There is a wide variability in life outcomes for persons with Down syndrome. The new possibilities are not yet the norm, with still much work to be done. While a young mother wonders, worries about and tries to prepare for her child's future, life with a young child with Down syndrome takes place in the family and shapes that family.

Disabilities and Families

Services for persons with disabilities will continue to evolve, with some future researcher most likely decrying the naïveté of the work we do today. My brief presentation of the history of disabilities can give some hints about the experiences of individual families as they lived through those times. By mid twentieth century, researchers began to study the interaction between the disability and the family.

The studies mentioned in this section represent a brief sample of many that relate the effects of parenting a child with a disability. These studies provide the professional community with insights into the varied situations facing these families. The research can also help provide inspiration and guidance to parents facing similar situations.

It has been long established that caring for a child with a disability has a major effect on parents. Seltzer and Greenberg (2001) studied many factors concerning parents of children with disabilities. They state that:

> In life course theory, a turning point is conceptualized as a point when a person's life takes a sharply different direction. Having a child diagnosed with a disability is an example of such a turning point because parents' lives may be forever altered. (p. 266)

Seltzer and Greenberg found several factors illustrating some possible effects, or possibly, co-occurring factors of that turning point when comparing parents of a child with a developmental disability with parents of children who were typically developing. These factors include lower rates of employment, larger families, and lower rates of social participation. They found parents of a child with a developmental disability similar to parents with typically developing children in health, and well-being, educational and marital status.

The wide range of disabling conditions that affect children presents a wide variety of symptoms and intensities. The condition and level of disability affect parents differently. The structure, strength, health and maturity of the parents, among other factors can cause the same type of disability to have a different effect on families.

Challenges. Reichman, Corman and Noonan (2007) discuss the factors of stress, guilt, blame, reduced self esteem, and tolls on mental and physical health. They also found difficulty in finding child care, diversion of attention from other aspects of family functioning and high expenses for medical care, education or treatments. These factors impact future decisions regarding work, education/training, having additional children, and relying on public support. In addition these factors are likely to affect parent's allocation of time and resources to other children, their parenting practices, expectations of healthy siblings in terms of achievement, responsibility and short or long term contributions to the household. Reichman et al. (2007) conclude that all these factors can also influence grandparents and other extended family members.

The behavior problems of the child with a disability appear to be an element that is often reported along with family stress. In a study of 116 mothers and 120 fathers of children ages 1-10 with disabilities, Saloviita, Itaalinna, and Leinonen (2003) found that the main explanation of maternal stress was child behavior difficulties. Difficulty in coping with children with behavior problems is noted by Eisenhower, Baker, and Blacher (2005). "Interestingly, greater stress and negative interactions appear to be more attributable to the increased levels of behavior problems among children with developmental delay than to the presence of developmental delay itself" (p. 659).

Baker et al. (2003) also studied parent stress in families of children with developmental delays. Their findings were similar to those of the Eisenhower (2005) study, with an interesting additional interpretation. They noted that a transactional relationship between parenting stress and behavior problems developed over time so that high behavior problems contributed to stress and high parental stress contributed to high behavior problems.

Skinner and Weisner (2002) discussed another difficulty faced by families of children with developmental delays. The high level of care needed by some children with disabilities can be a major negative factor in terms of the stress involved in getting adequate child care and workplace flexibility. “Even if the child is in a school setting, caregivers are still ‘on call’ for medical and behavioral emergencies.**”** (p.310)

Why me? Whatever the effect on a family of having a child with disability, many parents continue to look for an answer to “Why me?” A brief discussion of some mothers’ philosophies gives further background to the experiences of the participants.

As families touched by Down syndrome and other disabilities became more common in communities, the public culture developed several rationales for the birth of a child with the condition. One philosophy seemed to see the child with disability as a means of personal growth for parents. Venestra, as cited in Thomas, Dowling, and Nicoll (2004) said, “These special children transform them into different people, stronger people, dare I say it? ...deeper people!”(p. 173). Groneberg (2008) wrote of how a fable written by Emily Perl Kingsley comforted her after she had heard the diagnosis of Down syndrome for one of her twins. Emily Perl Kingsley’s story describes a pregnancy as a time of planning a wonderful trip to Italy, but getting there and finding yourself in Holland. As Groneberg stated: “She continues the metaphor, allowing for the disappointment of missing Italy, like everyone else. But still, once you get acclimated there you might find that there is much that is good about Holland” (p.47).

Cornfield (2005) expressed dissatisfaction and anger at the Kingsley story, saying:

> ‘Holland’ makes it seem as though disability is a one size-fits-all package tour, when disabilities and their effects on families are as finely shaded as the differences among pensiones, hostels, and four-star hotels… It feels like

> "Holland" is telling us not only not to feel sad, but to feel happy in a specific way... Kingsley seems to believe that emotional responses can be generated consciously, and that a little positive thinking is all that's needed to smooth some ruffled travel plans.

Smith (as cited in Thomas, Dowling, & Nicoll, 2004), also provides a voice of strong disagreement with the Kinsley story and expressed his frustration with the idea that parents of children with disabilities are chosen by God, saying:

> ‘God never gave us more than we could cope with,’ or so the saying goes. I have grave doubts. I believe in religious tradition and I like the warm feeling of being in a place of religious devoutness. But the act of participation in a church service seems to trigger off an emotional war within me. Who wrote these fairytales? I find myself thinking. I recite the words. But they don’t mean anything to me. I couldn’t care less. Why are ‘things sent to try us?’ Why would God, if there is one, allow so much madness in the world? Enough is enough. I don’t want to be tried anymore. (p. 65)

The concept of a parent honored by God when given a child with a disability carries with it a certain paradox, when recalling the commonly accepted idea in the eighteenth century and earlier, of disability as a punishment from God.

Families and Down syndrome. The birth of a child with Down syndrome is a unique event in the life of a mother. In addition to coping with the diagnosis, families often face additional medical complications. Many aspects of the lives of these women, including scheduling, prioritizing, amount and quality of relaxed family time, career or education, to name a few, take on increased complexity. These young mothers are in the midst of a journey that is both joyous and difficult. They balance the sometimes complex needs of caring for a child with Down syndrome with their own developing personal and professional lives.

Hodapp, Ly, Fidler and Ricci (2001), reporting studies of outcomes of families of children with disabilities, coined the phrase *Down syndrome advantage*. They found that families of children with Down syndrome report less stress and more rewards than other families with children with disabilities.

Other research confirmed this advantage. Parents of children with Down syndrome had less depression and pessimism than parents of children with other intellectual and developmental disabilities (Lewis et al., 2006; Stoneman, 2007). Similarly, divorce rates have been found to be lower for families of children with Down syndrome than families of children with other disabilities or no disabilities (Urbano & Hodapp, 1995).

Despite the positive findings noted above, the negative consequences of having a child with Down syndrome are described more often. Reporting on family adjustment to a child with Down syndrome, Abery (2006) wrote:

> To understand a family's response to rearing a child with Down syndrome, one must consider not only the demands of stressors and strains placed on individuals within the family but also the demands placed on the family unit as a whole (p. 5).

These studies represent a brief sample of many that relate the effects of parenting a child with a disability. This field of research can provide the professional community with insights into the possible situations facing these families. The research can also help provide insight, inspiration and guidance to parents facing similar situations.

The Experience of Young Mothers

Studies have reflected on the importance of economic status, family size, age of child, marital status, type of disabilities and other factors. However, there appears to be a lack of research focusing on young mothers and more specifically, young mothers of children with Down syndrome.

As mentioned earlier, while advancing maternal age is a risk factor for Down syndrome, more children with Down syndrome are actually born to mothers who are 35 or younger, when they are likely to be completing education, building careers, families and lifestyles.

Research focusing on young mothers of children with Down syndrome is needed. Lott, Patterson, & Seltzer (2007) state that "Demographically represented populations will also extend our abilities to understand not only the impact on the family of having a child with DS but also how families can be positioned to improve the environment for individuals with the disorder" (p. 288).

Several researchers have tried to learn how different factors affect families of children with a disability. The age of the parents does not appear to be studied often as one of their factors. For example, Eisenhower et al. (2005) compared the following demographic factors: sex of child, IQ of child, race of family, marital status of parents, education of parents, and income of families. They did not include parental age as a factor in their study about families of children with disabilities.

Patterson (1998) examined information from mothers of 500 children with Down syndrome. He considered effects of the child's age, place of birth, number of siblings. He also noted effects of maternal education and employment, mother's income and marital status. Like Eisenhower et al., while studying a wide variety of factors, they did not evaluate the data in the context of the age of the mother.

These studies support the need for this research. I found the narrative approach to be most useful in my search for information about the reality of their lives. Telling the experiences of some young mothers may open a dialogue concerning the effect of maternal age on families experiencing disability and may raise awareness of some of the young mothers' experiences and unique needs.

Summary

I presented the literature in this chapter to prepare the reader for the stories of young mothers and their experiences of Down syndrome. The historical discussion helped describe changing attitudes and current interpretations of disabilities. I considered research concerning the studies on the general impact of disabilities on the family to provide a frame of reference for the stories of individual mothers. The childrearing atmosphere of the current time set the scene for stories of young mothers in 2010. I closed this chapter with information about the impact and authenticity of narrative research on understanding personal experiences of families. What these percentages and projections, history and impact studies cannot tell is how the birth of a child with Down syndrome affects specific women. The stories of some women living this experience will help in understanding the lived reality represented by the statistics.

Chapter Three: Methods of Inquiry

The presence of a child with Down syndrome in a family creates some unique situations. Young women below age thirty five are in a life phase that may include completing education, planning for or developing a career, developing and enhancing relationships, and making financial decisions. The mother of a child with Down syndrome works to prioritize and balance time between her own needs, the needs of her family and the needs of her child with Down syndrome. I was interested in learning about the intersection between living as a young woman in the early twenty-first century and having a child with Down syndrome.

Plan of Inquiry

This study explored the lived experiences of a handful of women aged thirty five and under who have preschool-aged children with Down syndrome. Through extensive interviews with four women, I gained information and insight into their experiences. I studied a small group of women so that I could explore in depth the information they shared.

In one sense the information shared by each woman was complete unto itself. Using various lenses and analysis techniques within and across their stories helped me to discover what is unique and what is shared between them, and also suggested new ways of sharing the information.

Qualitative narrative approach. “Qualitative inquiry is predicated on the belief that reality is socially constructed, complex, and ever-changing. One comes to know those realities through interactions and subjectivist explorations with participants about their perceptions” (Glesne, 2006 p. 7). Glesne’s description helps explain why this approach is an effective fit for my study.

My research questions asked about the intersection between living as a young women and having a child with Down syndrome. My questions lent themselves to a narrative approach. I asked about long term plans, and if they have changed since the birth of their child with Down syndrome. I asked them about coming to terms with the diagnosis of Down syndrome

Some things cannot be measured as much as described. The well-done narrative approach attempts to provide an authentic record of a lived experience. In my experience, almost anything involving small children is messy, uneven, illogical, emotional and values-based. The aspects of life that can be so described are important to a whole picture and can only be true with first person telling. As Connelly and Clandinin (1990) write: “The study of narrative... is the study of the ways humans experience the world” (p. 2).

Narrative inquiry, the study of individual’s stories, provides an orderly method to learn about the distinctly disorderly world of that individual’s life. Maykut and Morehouse (1994) described this genre of research as “gaining deep understanding of some phenomenon experienced by a carefully selected group of people” (p. 55). The interview is the primary tool of narrative research.

Interview. The interview at its most essential is a verbal exchange of information; as simple as a friend asking a friend what she had for lunch, or as dramatic as David Frost grilling Richard Nixon (Frost, 2008). The essence of the interview goes far beyond mere questions and answers. A good interview results in a deeper exchange which touches and ultimately changes both interviewer and interviewee.

Josselson, Lieblich and McAdams (2003) described the *ways of knowing* (WOK) interview. *Received knowing*, implies an authority that can judge information as absolutely right or wrong. *Subjective knowing* implies that truth lies within a person as an inner voice. *Procedural knowing* includes testing, proving, disproving, convincing and being convinced, understanding and being understood. With *constructed knowing*, the goal is “to understand contexts out of which ideas arise, and take responsibility for examining, evaluating, and developing systems of thought” (p. 37). I utilized the constructed way of knowing in my approach to exploring my participants’ perspectives and experiences.

Hollingsworth and Dybdahl (2007) studied the purpose of conversation in narrative inquiry, highlighting key principles of the interview. I utilized their principles by developing trust, listening non-judgmentally and helping to scaffold conversations. By being vulnerable myself and sharing my own stories, I encouraged talk about controversial or difficult issues and allowed space for unexpected topics and turns in my conversations with participants. I tried to value styles of discourse that differed from my own and examine my assumptions. I was attentive to issues of power in relationship—specifically, my entrance as researcher or expert, and attempted to deconstruct this consciously. I was happy to explicitly articulate the learning that I gained in the conversation. The participants became my teachers.

“It is through the living out of these kinds of principles,” Hollingsworth and Dybdahl (2007) wrote, “that conversational narrative inquiry has impacted policy and practice across the professional fields of education, medicine, social work, business and law" (p. 79).

Participants

In a narrative study the researcher selects a few participants who genuinely represent a specific group. The four participants in this study represent a purposive sample. I kept the number of participants relatively small because I wanted to take the time to have in-depth interviews and conversations and to find meaning in the stories these women told me. Discussing the choice of breadth or depth in a study, Patton (2002) wrote:

> The design issue is how much time and effort we are willing to invest in tying to increase our understanding of another person. So, for example, we could look at a narrow range of experiences for a larger group of people or a broader range of experiences for a smaller group of people. (p. 227)

All participants were mothers, below the age of 35, with children who have Down syndrome. The children were between the ages of two and five. I chose this age range because in my experience, I have noted that families have a deep knowledge of their child by age two, care needs are typically less intense than in infancy, and the children's entrance into their preschool years adds a community involvement aspect.

My participants also represent something akin to a convenience sample as it was difficult to find many young mothers of children with Down syndrome. I recruited participants through preschool and kindergarten teachers in Missoula County Public Schools in Missoula, Montana; School District Number One in Butte, Montana; as well as the Missoula, Montana Area Special Education Cooperative. I contacted specific teachers and therapists in Lolo, Hamilton, Stevensville, Arlee and St. Ignatius, Montana. I also contacted several other organizations to request that they inform the parents of their clients of the study. These organizations included Western Montana Child Development Center, Family Outreach of Helena, Montana, Parents Let's Unite for Kids (PLUK), the Montana Speech Hearing and Language Association, the Missoula Buddy Walk group, the *Community Page* of the National Down Syndrome Society website and *DREAM.com*, the website of Down syndrome Research and Education Montana, based in Bozeman, Montana.

In the case of the schools, I requested permission from the director of curriculum, the director of special education or the special education cooperative director to send a letter of introduction and a description of the proposed study to parents of specific preschool and kindergarten students. The students were chosen at the discretion of their teachers or speech - language pathologists, who had been informed of the study criteria. The letter instructed the parents to contact the researcher if interested. All participants self-referred after being informed of the study. The other organizations were asked to tell potential participant about the proposed study and have the parents contact the researcher if interested. Over the course of three months, four mothers committed to participate.

Kelly. At 34, Kelly was the oldest participant. After a difficult pregnancy and premature birth, she had her first child at age 20, interrupting her college education. The baby needed intensive care for two months, but developed normally and is now a busy teenager who lives with her father in another city, visiting her mother on alternate weekends and for vacations. Kelly had her second child while in a later relationship. Kyle, a five-year-old kindergartner, has Down syndrome. Since Kyle's birth, Kelly completed her education and training as a paralegal and works for a busy law firm. She is no longer together with Kyle's father, but they share his care. They work together to address Kyle's persistent health problems and his difficult-to-control behavior.

Anne. A 24-year-old single mother of two children, Anne, has plans to attend college. She is mother of six-year-old, Leon, a healthy, active kindergartner and four-year-old, Sonny, who has Down syndrome. All her children were from separate relationships. Anne had her first child at age 15. The little girl, Brianna, died in crisis shortly before her birth. In addition to medical complications, the infant had Down syndrome. Today, Anne is busy, optimistic and determined. She and Sonny's father have recently been divorced.

Liz. With a private practice as a chiropractor and two young children, Liz 32, still finds time to help other new mothers adjust to life with a baby who has Down syndrome. Her children are Avery, a five-year-old girl and two-year-old Tate, who has Down syndrome. Liz's husband Josh is a teacher in their local public school district. She and Josh moved to her hometown just before Tate was born and enjoy strong extended family support.

Candace. Family and faith are key factors in 29-year-old Candace's philosophy and daily life. She has three children. Ariel, age nine, is from her first marriage. With her husband Dallas, she had Max, age three and Cecile, almost one year old. Candace is a trained photographer, maintains a business website, and keeps in practice photographing family and friends. Her daily life is almost totally filled by her children, with priority given to teaching and therapy for Max, who has Down syndrome.

Data Collection Procedures

I conducted in-depth conversations with each participant, gaining information from their responses to my open-ended interview questions. With one exception, the interviews took place in the subject's home or another quiet location of their choice at a time of mutual convenience. One participant lived out of state. Her interviews took place by telephone. The formal interview conversations occurred after several emails and a long introductory telephone conversation. I followed the lead of each mother in the interview setting. I realized that it was difficult for them to find time to talk without the presence of their children. With the exception of the out of state participant, at least one interview with each participant took place in their home. There were interruptions and delays with little children present, but I felt that there also might have been more authenticity in some of the conversations. The interviews were recorded digitally and personally transcribed. I feel that I learned much about the women as I transcribed the interviews.

I documented my impressions during the interviews, noting emotions represented pauses, the flow of the conversation and recollection of further detail. The subject matter included motherhood, the participants' experiences with Down syndrome, their families and support systems, their relationships, the services their child receives, whether or not the participants are employed outside their homes, information about their jobs, family life and education, personal difficulties and successes maintaining job, family and school, factors that increase or decrease stress and other information that emerged through the relational process of interviewing. A list of initial interview questions may be found in Appendix B.

I used my first interview with each participant to establish rapport, begin to build trust through more neutral social exchanges and by sharing some of my background with the mothers. After establishing mutual comfort and rapport, I started with my planned interview questions and then went where the conversations lead, asking new questions as needed to allow for a full expression of ideas. Following each interview, I found a quiet location and spent about 30 minutes to an hour reflecting on the exchange that just took place, making field notes about my impressions, connections to other conversations or ideas, information to look up, questions to follow up on, and things left unsaid. This allowed me a critical opportunity to process the exchange while it was still fresh. These field notes then served as a data source for next sessions and for analysis, as I looked for patterns with which to interpret emerging themes.

The participants were told that they could stop an interview at any time and were given an informed consent form which was explained to them in detail. The informed consent form is included in Appendix C. The form reminded the participants that they could possibly have been exposed to personal discomfort through self disclosure, but assured them that this would be handled sensitively. Questions were presented in a manner that allowed participants to choose not to answer a particular question. If a participant expressed discomfort or appeared embarrassed or uncomfortable, I waited for some time, and acknowledged my own response to the pause in conversation. Participants were asked if they wished to discontinue that line of questioning or reschedule remaining questions for another time. None of the participants stopped an interview.

The participants were interviewed at least three times. I continued the interview process until the participant shared all the information she chose to give. In several instances, I clarified information or followed up with emails or phone calls. Several interviews allowed for more true to life narrative as different life events were occurring at the time of interview. A series of interviews allowed me or the participant to revisit a topic from an earlier interview. One participant had been the subject of a feature article in her hometown newspaper. With her permission I also gained information from that source. I performed a member check by sending each participant a copy of her story (Appendix E). I asked each participant to read it and tell me of any inconsistencies. All four participants stated that the stories were accurate in depicting their respective experiences.

Participant Safeguards

This proposal was submitted to and approved by the Institutional Research Board (IRB) of the University of Montana for approval before any research with the participants was undertaken. A copy of the IRB application is included in Appendix D.

The confidentiality of three of the participants and their children was protected through use of pseudonyms. One participant requested that I use her real name. Files containing participant’s names were destroyed. The participants chose pseudonyms for themselves and their families. While assuring confidentiality, the researcher faithfully and truthfully reported the story of the participant. The direct quotations that I used are attributable to the participant only through the pseudonyms, with the exception of the one participant who chose not to have pseudonyms, but are accurate.

Data Analysis

The voices of two qualitative researchers helped introduce my understanding and use of this form of data gathering and analysis.

Jorgensen (1989) presented a non-technical picture of the process of analysis. He described breaking the source materials into parts or units. He described the process:

> Analysis is a breaking up, separating, or disassembling of research materials into pieces, parts, elements, or units. With facts broken down into manageable pieces, the researcher sorts and sifts them, searching for types, classes, sequences, processes, patterns or wholes. The aim of this process is to assemble or reconstruct the data in a meaningful or comprehensible fashion. (p. 107)

Glesne (1992) spoke of the complexity of social interaction as a necessary facet of qualitative research:

> The openness of qualitative inquiry allows the researcher to approach the inherent complexity of social interaction and do justice to that complexity, to respect it in its own right. Qualitative researchers… assume that human interaction is complex and they will attempt to uncover some of that complexity. (p. 7)

I analyzed the information shared by the participants in as simple and orderly fashion as possible, considering the amount of data and the open ended format of the interviews. Potential themes were noted at transcription and on first reading, with patterns emerging and themes solidifying through recursive readings and member checks for accuracy. Analysis of the data that I gathered through my interviews provided me ways to turn transcriptions of interviews into ideas, concepts, and themes. I used an approach that seemed to mesh with my style of thought and organization to begin the work of data analysis. I used NVivo 8 software, developed by QSR International (2008) to organize and help analyze my data as described by the *zoom model*, the tool for my analysis.

The zoom model. Taking her inspiration from the lens of a camera, Pamphilon (1999) developed the *zoom model*, a framework for analyzing life histories. This frame encourages study of narratives from a variety of perspectives, with the premise that no one perspective can tell the whole story. Her framework includes four viewpoints.

Pamphilon called the first hypothetical lens *macro-zoom,* which examined the data from three viewpoints she described as *dominant discourses*, which refer to the cultural mores and beliefs of the time; *narrative form,* referring to the manner in which a woman tells her story, as a main or supporting character, for example; and *cohort effect,* noting how a life history will be effected by the age at in which the person lives, such as a time of economic depression. This viewpoint allowed me to analyze the participants' stories while considering such factors as raising a child with Down syndrome in an age of instant, unfiltered information or an age that is strongly focused on the child; as well as a reflection of where we are in terms of societal treatment of persons with disabilities.

When I used the perspective of the *meso-zoom* lens I studied the data from other viewpoints, looking at meaning shown by the *style of narration*. An example of this occurred in every interview, times when the story did or didn't flow freely. One such time was Kelly's story of her son's Christmas program, which was slow and filled with many long pauses and expressions of emotions. Using this lens, I also considered *narrative themes.* Looking at the whole of the story themes or personal values created by each woman may help me understand the context in which the participant places her story. For example, Candace told her story from the context of faith and joy.

I attended to *order of telling* and *what is selected, what is left out*. These are illustrated by Kelly's description of her son's current health problems. She started talking about them before I had even started asking my questions and they were clearly of paramount concern to her at that time. Another focal point was the use of *specific key phrases*. These were very helpful to me in understanding the relationship of each participant to her child and to society, showing, for example, caution or an expectation of acceptance.

The next lens of the Pamphilon (1999) analysis is *micro-zoom*, which views the data from two more viewpoints. I noted *pauses or hesitations* which suggested difficulty in finding the words to express an idea, or a reluctance to express an idea. For example, all the participants love and protect their children. At times it was difficult for them to express their frustrations with their children. I studied all the information through the lens of each participant's *emotions* which may have reflected her personal reactions to life events. Many moments arose during the interviews that were emotional for both of us.

Finally, the data were studied through what Pamphilon calls an *interactional-zoom* point of view. I considered *transaction* and reflected on the interactions between the participants and me. In the course of my interviews, I shared some personal emotion and experience with the participants. I realized that I may have helped to guide the direction of the conversation. The last viewpoint is that of *reaction*. I considered my reactions to the participant's story and studied various ways those reactions influenced or are part of the story.

Trustworthiness

I interviewed and conversed with the participants until no new information or themes were noted in the data collection process, and in fact, stories/themes began to be repeated. As Candace politely stated, "We may have talked about that last time."

In addition to this basic method, I employed some strategies to demonstrate validity of the data. Creswell (2007) presented eight frequently-used strategies for validation of qualitative data. He suggested the use of at least two of them in any given study. Several of the strategies he presented were appropriate for my work. I used the strategy Creswell described as *prolonged engagement and persistent observation,* including building trust with participants, learning the culture and checking for misinformation. I did "clarify researcher bias from the outset" (p. 208) and provided enough "rich, thick description" (p. 208) to allow the readers to make their own decision about the information. Creswell described *triangulation* as a process in which "researchers make use of multiple and different sources, methods, investigators and theories to provide corroborating evidence" (p. 208). My study relied solely on interviews and observations as the methods for gathering data. Doing the interview in several sessions and reintroducing ideas in a different context helped corroborate some of the information shared by the participants. I checked with participants as I interpreted my findings and developed themes, asking for verification and accuracy of their voices and perceptions. Finally, Creswell stated that "Peer review and debriefing provides an external check of the research process" (p. 208). I gave excerpts of the transcriptions and coding schemes to my committee co-chairs and they corroborated my coding. As I wrote up my results, I included enough of the young mothers' voices and made my coding process transparent enough that participants, committee members, and ultimately, a larger readership, will deem it accurate.

Three decades of work with children with disabilities and their parents also helped to establish my credibility and trustworthiness. I have completed hundreds of parent interviews and am skilled at helping parents share needed information. I am sensitive to the importance and emotional weight of the topic.

The Significance of the Findings

The primary value of this study lies in the information shared by the participants related to their experiences birthing and raising young children with Down syndrome. The findings have meaning first of all to these young mothers and to me, privileged to collect and study these stories. To my knowledge, stories such as these have not been explored and will have unique information that will enrich and expand current knowledge.

Current research is relatively limited in the area of families of children with Down syndrome. There is little focus specifically on young mothers. Hopefully these stories will also be important in informing early intervention professionals to better assist other young mothers. Hopefully they will help other women in similar circumstances who might identify with the voices and perspectives shared. Perhaps the best reason for pursuing this research lies in Landsman's (2009) description of mothers of children with disabilities who wanted their stories to matter.

Reflexive Statement About the Researcher in Relation to the Work My personal history touches the world of persons with Down syndrome on several levels. In the late 1950's a friend of my father, Kevin Shannon, had two sons with severe disabilities who were placed at the Boulder River School and Hospital in Boulder, Montana. My father and mother joined Kevin, and some other interested persons, in starting the Rocky Mountain Association for Retarded Children. Family legend has it that my dad wrote the check for the first donation. Ironically, that group quickly gained more personal significance for my parents. In 1961, when I was 11, my mother gave birth to the tenth child in our family. About a week after birth, Steve was diagnosed with Down syndrome. My parents took him to several doctors and to Spokane, Washington, where there was a larger medical community. The experts confirmed the diagnosis. My parents faced the choice of sending him to the state institution at Boulder or keeping him at home with us. My mother told me that she knew absolutely nothing about disability. She didn't know if he would learn to walk or talk. They made the choice to keep him with us.

He became the focus of our family and remains so today. He remains in the care of our family with two of my sisters serving as guardians since the death of my mom twelve years ago. Steve lives with my husband and me about three months of the year. He requires care, time and patience. He is slow, stubborn and much attached to his routine. He is also loving, complimentary, friendly, sympathetic, sweet and a wonderful companion. He has impeccable manners and is very willing to correct any missteps made by others. Our time together is bittersweet, as at 49, he is beginning to show signs of dementia.

I am also a speech language pathologist, having chosen my profession after watching therapists work with my little brother. I have worked in the field of public school special education for over 35 years, moving from a time when virtually all the parents of my students were older than me to a time when the parents of my students are typically in the age groups of my adult children, or younger. I have helped teach many children with Down syndrome. I asked my questions and interpreted the answers through a lens of someone who knows Downs's syndrome well: as a sibling to a darling little boy, a companion and caregiver to an adult and as a longtime therapist to three- and four-year-old children with disabilities.

I am a mother of five children, all grown. I know how important the role of mother is to a family. The participants in my study were busy women, coping with all the demands of a busy life as well as all the demands of having a preschooler with Down syndrome. I was able to relate to the pressures of life with a busy family. My two youngest children are twins, born when I was 35 and my older children ranged from four to eight. Although my twins are now 25, I have never forgotten the commotion, the stress and the fleeting sweetness of those busy years. I could see life through the lens a very busy mom.

I feel that my perspective gave a useful, unique and hopefully empathetic slant to my research.

Chapter Four: Results and Analysis

The purpose of this study was to enhance understanding of the lives of young women in the current century who have children with Down syndrome. Data pertaining to this central purpose and the analyses of that data are reported here.

The information in this chapter is organized into six sections: (a) description of the zoom model analysis procedure, (b) biographic overview of the participants, (c) explanation of the emerging themes, (d) participant's advice for other mothers, (e) participants' long term plans for their children and (f) lessons learned by the researcher. The chapter closes with a summary of the findings of this narrative study as a foundation for discussing the research questions in chapter five.

The Zoom Model Framework for Analysis

I structured my analysis using the *Zoom Model* (Pamphilon, 1999), a framework for analyzing narratives from four different perspectives similar to different zoom lenses on cameras. When studying the interview transcripts from these perspectives, themes pertinent to one or more participants emerged.

The *meso-zoom* lens gave me the perspective to study the data from the style of narration, from times when the story did or didn't flow freely, from the order of telling, from specific key phrases, and from topics the participants included or omitted. The *micro zoom* lens allowed me to consider *emotions* which may have reflected their personal reactions to life events and *pauses or hesitations* which suggested difficulty in finding the words to express an idea, or a reluctance to express an idea.

The *macro-zoom lens* examined the data from viewpoints that Pamphilon (1999) described as *dominant discourses*, which refer to the cultural mores and beliefs of the time, and as *cohort effect,* referring to how the individuals react to the shared trends and experiences of their era. The macro-zoom lens allowed me to analyze the participants' stories while considering such factors as raising a child with Down syndrome in an age of instant and unfiltered information, and in an age that is strongly focused on the child. The broad view allows consideration of the educational experiences of the participants, as they were all educated well after the 1975 landmark federal law that changed the face of education for students with disabilities. I also used this lens to look at how these women's stories reveal where we are in terms of societal treatment of persons with disabilities.

Finally, the data were studied through Pamphilon's (1999) *interactional-zoom* lens. I considered *transaction* and reflected on the interactions between the participants and me as well as my *reaction* to their narratives. Before I present the emerging themes I will briefly reintroduce the participants.

Biographic Overview of the Participants

Anne is a 24-year-old single mother of a six-year-old, Leon, and four-year-old Sonny, who has Down syndrome. Anne lost her first child, Brianna, at age 15. In addition to medical complications, the infant had Down syndrome. All her children were from separate relationships. She and Sonny's father have recently divorced.

Candace, 29, focuses on family and faith. She has three children. Ariel, age nine, is from her first marriage. With her husband Dallas, she has three year old Max, who has

Down syndrome, and Cecile, almost one year old. Candace is a photographer and maintains a business website, but her life is almost totally filled by her children.

Kelly, 34, had her first child at age 20. The baby needed intensive care for two months, but is now a busy teenager who lives with her father in another city. While in a later relationship she had Kyle, a five-year-old who has Down syndrome. Kelly works in a busy law firm as a paralegal. She and Kyle's father, Tom, are no longer together, but share in his care and cooperate to address Kyle's persistent health problems and difficult behavior.

Liz, 32, has a private practice as a chiropractor and has two children, Avery, a five-year-old girl and a two year old who has Down syndrome. She and her husband Josh, a teacher, live in her hometown with extensive family support and are active in supporting new parents of children with Down syndrome.

Emerging Themes

As I studied the narratives, some specific ideas and experiences were repeatedly mentioned by every participant. I present them in this chapter as general themes to lead to greater understanding of the lives of the four young women who were the participants in this study. The general themes emerging from the narratives of all the women are: (a) personal *background; (b) public school experiences of the participant; (c) diagnosis;* (d) *medical complication*s; *(e) support; (f) career; (g) personal growth*; (h) *living in a child centered age and (i) living in an era of testing and choice.*

Sub themes emerged from some participants' stories as the described their struggles and successes in coping, adjusting and thriving. These included (a) *mother as* *teacher; (b) humor; (c)determination; (d) gratitude; (e) leadership, (f) concern and caution; (g) faith; and (h) behavior.*

General themes. All women in this study shared the experience of raising a preschool aged child with Down syndrome. Nine themes of importance to all participants emerged as the data were analyzed.

Personal background. Every human action and event occurs in context of the times and the prior experiences of the individual. Each woman in this study brought her own knowledge, experiences and emotions to her role as mother of a child with Down syndrome. A look at some things that had shaped each woman helps give context to her story.

Anne. Two key events in Anne's childhood seem to have played significant roles in shaping her into the woman she is. Her parents divorced when she was four. As she said, "I was not ready for it." She has unhappy memories of that time, saying that it was not healthy. "When I went through my parents divorce… it was horrible." The divorce, and a childhood spent moving between parents, appear to have been big factors in creating the life she has today.

> Anne: Yeah I think right before that I was living with my Mom and then after that, actually right after my pregnancy, I lived with my dad and actually then I started living with my mom again…Yes a lot of back and forth as a teen I think my… Actually, I don't know. I think my Dad was more stable… which was what I didn't want at that time. I just wanted to do whatever I wanted to do…and so I lived with my Mom. But when I needed... Like the whole pregnancy I needed the stable, loving... so I lived with my dad…It's interesting…my childhood.

Anne has been through more sorrow, medical crises, and challenges than many people face in a life time. Her life before the birth of Sonny has led her to the perspective that his presence is a joy and benefit in her life.

Anne wears a delicate tattoo on her left wrist. The word *Brianna* is traced there in elegant script. The story of that name will always be part of Anne's story. Pregnancy at age fifteen is a life changing event. When asked if she continued to go to school, Anne said:

> Anne: No. I couldn't actually, I was so sick. When I was pregnant, like at the beginning of the pregnancy I was so sick and tired that I just couldn't...I remember waking up in the mornings. It was time for school... I would go to my boyfriend's and just sleep. It was horrible. It was a really bad pregnancy. I was really sick and miserable and depressed…horribly depressed, just irritable.

Anne struggled through the difficult, unplanned pregnancy until the birth drew near. Her doctor must have had some concerns in the eight month. Anne told this part of her story haltingly, with many pauses:

> Anne: Yeah I was 15 and I…didn't know anything. Yeah they wanted to do a test to see...I didn't really know what the test was for so... I didn't really ask a lot of questions…Yeah they told me they wanted to do this test, amnio … amniocentesis. They did that and I really didn't know what they were doing it for or anything. But they told me a little while afterwards. They said they had good news and bad news and they told me that she was a girl, which is what I wanted and had Down syndrome…I wasn't disappointed at all because I really didn't see the big deal and they did more tests because of her size.

The medical team did an echocardiogram and found that the baby's heart had a hole and was oversized. They also found a spinal problem which Anne recalls as being spina bifida, a condition not typically connected with Down syndrome. Anne's memory is hazy about the details of ensuing events, but, during our conversation her voice shook with emotion she tried to explain them.

> Anne: And basically they told me that she was going to...That she wasn't going to make it and said that...yeah and they pretty much told us that…I hadn't accepted that…I didn't think that was going to be true… and they actually said if she did... They actually said that once she was big enough that we could intervene and deliver her and see and determine…deliver her and see if she… and you know…keep her alive... if that would have been the case she would have been a vegetable…
>
> Interviewer: At 15! I mean did they…I don't know who they might be, but did people accept your right to make those decisions?
>
> Anne: Yeah. I think pretty well…pretty well…there were a couple…there was one person in particular that said something that really bothered me. "Well…let nature take its course." And I'm like, "This is my baby. You don't need to tell me that." I mean if you were in my situation…would it be easy to hear something like that? And knowing that she was most likely going to die. It was just hard to hear that.

Anne did let nature take its course and delivered Brianna a few weeks later. The baby was dead at birth. When asked, Anne fervently agreed that it was hard for people to remember that very young mothers are still children and need to be raised and nurtured.

Asked if she felt that she grew up at age fifteen, she brought laughter into the conversation with her deadpan addition at the end of her answer. “I think I had some hard situations and some choices or whatever... Or my experiences had forced me to… had forced a maturity (long pause) *somewhat!*” (her emphasis).

Losing the child was a life altering event. The fact that the child had Down syndrome was also life altering, although at the time it was a detail of the story.

Candace. Many moves while she was growing up appear to be a key part of Candace’s background as this encouraged development of a very close family unit.

> Candace: I have lots of friends, but I am still really friends (with emphasis) with my mom and sister. It was like we always took each other with us when we had to go somewhere.

She continues to value and nurture family, both immediate and extended, as she lives her life as a wife and mother.

Candace had a difficult pregnancy at age twenty. Her little girl, Ariel, was very sick with ear infections and digestive problems, cried almost constantly and was hospitalized many times during her first year. That experience colored Candace’s expectations about caring for an infant.

***Kelly*.** Several aspects of Kelly’s life seem to have been important to the person she has become. In addition to discomfort when around people with disabilities, Kelly had a difficult pregnancy at a young age. She was twenty when she had her first child, Nicki. Her early pregnancy affected her further education and eventual career choice. It also affected her perception of difficulty and health in relation to infancy. She developed serious complications during her unplanned pregnancy. “When I had Nicki I got preeclampsia and had her two months early... I had a lot of water retention and my blood pressure skyrocketed and my liver almost ruptured." The birth was Caesarian and Nicki was hospitalized for 28 days. In a self deprecatory style I found to be typical in our conversations, Kelly described the infant's health.

> Kelly: She had to be on a monitor for quite a while. She wasn't really sick, she just hadn't matured. She wasn't really sick. She just had a hemorrhage in her brain that you wouldn't really realize unless you checked for it.

Later, when she was pregnant with Kyle, she was very concerned throughout her pregnancy about once again developing preeclampsia and delivering prematurely. "So that's where my focus was…afraid that that was going to happen again. And it didn't and everything was just fine and so I wasn't even thinking of anything, that anything remotely like that could happen."

Liz. She decided on a career as a chiropractor and attended graduate school. She and her husband went to graduate school at the same time. Liz's tendency to always plan ahead had many positive benefits when Tate entered their family. One of her ideas was to arrange her practice so that she could spend a day and a half each week with her children. "I have always worked 3 1/2 days per week so I could be home with my kids some of the time and I will always do that as long as they aren't in school full time." This came to be almost a necessity for Tate, even though she had planned it much earlier.

Public school experiences of the participants. I have had a long career in the public schools, starting before 1975, when the Educational for All Handicapped Children's Act, guaranteeing the right to education for all children with disabilities, was passed. An underlying premise of this legislation was the benefits that are possible when students with disabilities attend school alongside typically developing peers. The law uses the terms “mainstreaming” as well as “least restrictive environment”. In practice, the law requires that the regular education classroom, with supplementary aids and services, be the first placement considered for students with disabilities. All these women attended public schools in the last twenty years. Thus, attending schools with students with disabilities should have been a shared, or as Pamphilon (1981) referred to it, a *cohort* effect. I assumed that, with this exposure, young adults of today would see disability as part of everyday life. However, this was not the case with these women.

Anne. She does not remember students with disabilities in her schools, but she also does not remember many details about her own abbreviated public school experience. She moved back and forth between her parents, from California to Montana several times.

Candace. With her parents’ and aunt’s professions in special education and her experiences in peer buddies classes, she had some early awareness of disability. What she didn’t see were those children out and active in the general school environment. Because of this, her knowledge of disability was strong, but her experience was minimal. “They were there but they weren’t there.”

Kelly. In public school in the late eighties and nineties, Kelly grew up in a small Montana town. Incidence numbers may explain the lack of students with Down syndrome in her school, but incidence numbers don’t explain the situation and resulting attitude that she describes.

> Kelly: My experience with kids with disabilities was way different from what it is now in school...You know they were always separated. There was a kid my age

> who kind of interacted with people...I think he just had some kind of slowness. But he still could hang out with you, but intelligence wise he just, he was in different classes. You just did not see him much. They weren't in classrooms with you. Some of them were, but I really didn't know if there was a certain intelligence level for all of them. It's kind of like…You know I was almost afraid of saying hi to them or being around them because I didn't understand or know what they could understand and could comprehend. And I kind of equate that to older people who have dementia or something. You know…I am just afraid that I would say or do something dumb, I guess. It wasn't that I thought they were lower or anything...If I don't know what someone's understanding level is I feel a little scared to communicate with them...

Liz. Speaking of her experiences attending public school in a small Minnesota town, Liz said, "I don't recall seeing any kids with disabilities in my classes, ever! (with emphasis)…I don't know...I absolutely don't remember ever seeing them at school." She said that Josh had a little more background, as a teacher and as a special education teacher's son. "I was raised in a very accepting family. I have fourteen first cousins and six of them are adopted, and from different places with different cultural differences. But I was just never exposed to disability."

Diagnosis. Since its description as a syndrome in the nineteenth century until recently, diagnosis of Down syndrome was made by visual inspection of the child. In the current world, if the diagnosis was not made prenatally, observation is almost always supplemented or verified by a decisive laboratory analysis, often involving a wait of several days. All four participants shared very emotional recollections of learning about their child's Down syndrome.

Anne. As mentioned before, she had learned of Brianna's Down syndrome through amniocentesis a few weeks before her stillbirth. Six years later, the news of a diagnosis of Down syndrome for Sonny was somewhat blurred as part of an induced, very painful labor hurried along because of a crisis in the pregnancy. Her midwife was at her son's birth and afterwards told Anne that at the time, she had thought Sonny might have Down syndrome, but hadn't said anything. She and Pat learned of it from their pediatrician a few hours after Sonny was born.

> Anne: She came in and pretty much told us...he had Down syndrome… I had no idea, although it's funny... I had no idea. But as soon as he was born I was like Wow! He really looks just like his sister. I mean he just looked just like his sister.

There was a long pause in our conversation. Anne's brother started playing his guitar in the next room. I asked her how she remembered feeling at that time.

> Anne: In shock. In shock for sure. And I think I might have been sad too. I felt bad. I felt guilty too, real guilty. I felt guilty because it was my fault. This is weird to say, but still…I felt bad that…he had to be the way he was and that he had to suffer…all because of something that I did, or whatever. Like I know it's all irrational... (Halting) but yeah…I was very much in shock.

After another pause and some unrelated chatter Anne came back to describing their discovery of Sonny's Down syndrome, again with long pauses.

> Anne: She pretty much walked in. I was like there and Pat was sitting there. And she kind of says. She wasn't like…I think she was trying to be gentle. Like for

> sure. Because she tried to break it to us like it was a big deal. It's… to people like us it's not really a big deal. However I was really shocked because I didn't expect that at all. But yeah she tried to say it in a very concerned way...Like we were…Like it was a sad thing. I think she even said like "I'm sorry" and I was like, "What? What? Don't say you're sorry. (Gestures a baby in her arms) This is my baby. Don't say you are sorry."

I asked if she really said that.

> Anne: No…no I was like just in shock. I was like no way! He was so cute. Oh my God. He was like. He had the biggest tongue ever. The biggest tongue ever! Like it was ridiculous. And so…it was horrible…

At this point Anne got up and went to the bathroom, blew her nose and went to make her bed. She came back composed.

Candace. Candace's story of hearing the diagnosis blends a health emergency, her son Max's difficulty getting oxygen, with the delivery room statement that he might have Down syndrome.

> Candace: Like my husband was joking with me right after I had him and they were measuring him and weighing him and Dallas was watching as they wiped him off. My husband said he looked like a little Chinese baby. "Candace is there anything I should know?"

After they learned for sure of the Down syndrome, his joking words made him feel worse than he might have, as he cried for the boy he didn't have.

> Candace: My husband cried and cried. Not because he was sad, but I told him that I didn't want any more kids and he had to really talk me into that one and he

> was envisioning a little boy who would eventually play for the (local football team) or play basketball... I mean, you know, things that Max won't ever do.

Candace doesn't remember who said in the delivery room that there was a possibility of Down syndrome. Shortly after this, Max began to lose color. Candace recalls that his blood was too thick to oxygenate his lungs. He had polycythemia, sometimes known as erythrocytosis, a condition resulting from an elevated number of red blood cells resulting, in essence, in blood that is too thick. The website of the National Down Syndrome Society (2010) states that this condition is frequently seen in newborn babies with Down syndrome. Max was whisked away for treatment, with Candace urging Dallas to accompany him.

> Candace: And of course all the nurses and the doctors cleared out of the room and I was totally alone and I hated it. I couldn't get hold of... no one would answer their phone. I hated it. I was miserable.

In her telling, Candace was even more emotional about the waiting period for the testing than she was about the condition of Down syndrome.

> Candace: Even though we knew in the hospital, maybe not with absolute certainty, but pretty much, I think we had to wait three to five days for the blood test to get back which I thought was so ridiculous. Why can't they just like… You want it to be like a pregnancy test which is just like three minutes you wait and then they tell you.

Several weeks after our conversations Candace sent me this email after I had asked for clarification of the sequence of events:

> Dallas had said Max looked like he had some characteristics of Down syndrome,

> and asked if it was possible, and what they thought. They told us he only had a couple of the things they would look for, such as low muscle tone, but that the back of his neck looked okay, and so did his ears. They told us it was possible, but not to worry for now because they couldn't be sure until we did a blood test. They had the NICU doctor come in and talk to us. That's about all I remember.

Kelly. When Kyle was born, a doctor she hadn’t met before told her and Tom that their baby might have Down syndrome.

> Kelly: After he was born they immediately gave him to me to nurse and everything was fine and then they came and got him, to do all the measurements and stuff, and the doctor came and said that he suspected that he might have Down syndrome, but he wasn’t sure and he wanted to take some blood and send it... to test it. And he came in and it wasn’t my regular doctor that did all this, I guess they were on their shifts or whatever. He came in and told us when it was just me and Tom in the room. And we kind of agreed not to say anything until we knew for sure.

I found Kelly to be a reserved person, given to understatement. She presented her information in a factual way, but with pauses and with deep sighs. She described another doctor entering her hospital room sometime later, while her mother was visiting and talking about the Down syndrome in front of her mother, creating a highly emotional scene.

> Kelly: We did not want to say anything until we knew for sure...Then it was like a really weird five days...Not that it really mattered…But it was just something… It was a (long pause) a challenge, you know.

The laboratory people did not call her back. She found out by telephone, when she was by herself.

> Kelly: I had him on a Friday and they were supposed to call me Monday or something or Tuesday. And they didn't call me, the doctor didn't, and so I called her and she said, "Oh I thought someone would have called you already." And they told me that he did and (long pause)…so it kind of ...it made me mad.

Liz. Liz's introduction into motherhood of a child with Down syndrome was similar in many ways to those of the other mothers. It could have been done with more sensitivity. As she told it,

> Liz: My husband had just made a cell phone call to my daughter to tell her that she was a big sister now, and had a little brother. And the midwife came in, looked very solemn and said "Your husband has to get off the phone. I have some news for you." I get my husband off the phone and you get that feeling of dread. You know. You don't know what he is going to say and...the first question he asked me, he said, "I don't mean to be offensive, but did you drink alcohol at all during your pregnancy?" And immediately I said "No." and my heart is just pounding in my chest. I am...as a chiropractor, I am as natural as you can be. I eat all organic food. I take the supplements. I didn't drink for three months before getting pregnant with him just to be sure that everything in my body was working well.
>
> I was shocked by this statement and said "Oh my God!" Liz responded in a shaky voice, "I know." She told me that she immediately said, with her heart pounding, that she "hadn't had…absolutely not had any alcohol." She continued:

> Liz: And he said, well, your son has a lot of the characteristics of fetal alcohol syndrome, and he said… he actually… um we think he may have Down syndrome. We are not sure which one it is but he doesn't have a lot of the physical manifestations of Down syndrome and that's totally applicable to fetal alcohol syndrome.

After telling her that he was 99% sure that it was either Downs syndrome or Fetal Alcohol syndrome, the doctor left, saying that he would have the pediatrician come and check him out when he was done at his office for the day. It was about 1:15.

At first they felt that it couldn't possibly be, since Liz was healthy and they had done everything right. She and her husband said things like, "He just has wide set eyes like your family." As the day went on they came to think that he probably did have Down syndrome.

> Liz: And at 6:15 that night my midwife, who I had seen throughout my pregnancy - and the midwife who delivered Tate - and the pediatrician came in, all in their white coats, all very serious looking. And said that they were 99% sure… that they would do the chromosomal analysis but they didn't think it was fetal alcohol syndrome. When they came in we were like yeah we did realize that, yeah that's probably what it was. It wasn't a…I don't know…it was more of a shock than an emotional thing for us. We always knew that we would do what we had to do. (pause) It was definitely the shock of our lives though.

Liz did have a few other memories from the hospital. "No one really acknowledged that he had Down syndrome after that. No one talked about it. I mean the nurses would come in and they wouldn't really ask about him, just do their stuff and then just leave." She was sad and shaky when she said that no one treated her the way they had when she had her daughter. She said she understood.

> Liz: Who wants to walk into a new mom who's hormonal and everything and ask her questions and have her break down? But to me it was like "you guys are afraid to talk to me" it made me feel like I should be ashamed of it. So I knew I shouldn't but that's kind of how it made me feel.

One nurse did come in to Liz's room and talk about Down syndrome, basically seeking information relating to her own pregnancy.

> Liz: There was one nurse who came in and she was, you know, in the middle of her pregnancy somewhere and she said "I just have to ask you. Did you guys have any idea that he had Down syndrome?" And I said no and she said "Wow it just amazes me that they can't pick up on these things all the time. It's kind of scary." and I said, "It isn't scary. It is what it is."

Another troubling memory Liz has of that time was when a social worker came in to visit her.

> Liz: And she came in with a pamphlet. And that was the first social worker that we had...It had been forty eight hours and she came in with the pamphlet and she didn't say how were we doing or anything...He was born on a Monday and so its not like it was the weekend or anything...She came in and said "Here's a pamphlet about this program that they offer in the state of North Dakota with all these things." And I said, "We don't live in North Dakota. We live in Minnesota." And she said, "Oh well, then it is a different pamphlet. Let me get it and come back to talk to you." And she never came back.

While chronicling these stories, I found the descriptions of the mothers' discovery of Down syndrome very powerful. I think that Kelly, even with her reserve, may have described an often felt reaction. "I felt scared…I didn't want to feel bad about it, but I did. It didn't make me not love him…So it was just weird."

After the participants learned of the diagnosis of Down syndrome they began a transition to day-to-day survival and coping. They began to live with a child with Down syndrome as part of their family. Their children's medical complications were part of their family life.

Medical complications. In Chapter One I discussed of some of the medical complications that often accompany Down syndrome. So, Urbano and Hodapp, (2007) reported that the medical community and parents need to be aware of the possibility of cardiac, hearing and vision conditions, thyroid disease, gastrointestinal symptoms and respiratory illnesses. They report that there was a median number of two hospitalizations for each child with Down syndrome during the first year. All the participants in this study had some experiences with their children's illnesses. Three of the families experienced at least two hospitalizations.

Anne. Sonny was a very fussy baby. Anne nursed him and she was busy all the time. She opened up a home day care business, combining an income source with the opportunity to spend time with her two little boys. Sonny had the digestive problems that are often seen in children with Down syndrome, seeming to throw up everything he ate. When he was sixteen months old his health had deteriorated to the point that she had to close her business.

Anne and Pat had been in to the doctor many times, getting the answer each time that everything was normal. She did not agree and was frustrated. She was determined to find out that was wrong with her little boy, taking him to the emergency room and telling the staff staff that she wasn't leaving until they figured out what was wrong. "Basically that's when they did figure it out. It took like a whole day. She (the doctor) was still trying to say that it was not a big deal."

Sonny had a duodenal web, an intestinal blockage. His condition had been aggravated when Anne introduced solid foods, eventually reaching a point of crisis. He had surgery and ten days of hospitalization. The National Down Syndrome Society (1999) published Down Syndrome Health Care Guidelines: Neonatal (Birth-1 Month). This includes checking for gastrointestinal tract blockage.

Anne learned and grew through this experience. She came to trust herself more and more.

> Anne: The parents know. You've got to listen to the parents. And like we fired...we fired her and got a new pediatrician. It was necessary. And our pediatrician is great now...It is just that she (the first pediatrician) wouldn't listen and dropped the ball.

Sonny thrived after his surgery, although he still misses school fairly often because of colds and respiratory issues.

Candace. Shortly after birth Max started struggling to breathe and turned gray. As Candace described it his blood was too thick to go through his lungs and he needed a transfusion. She eventually learned that the blood condition was not life threatening and that it would likely heal itself, as would the hole in his heart.

Candace and Dallas were able to take Max home after two weeks, but they made three or four trips back to the hospital in that first year, with one hospitalization lasting over two weeks. He had RSV pneumonia and flu. She said it was easier than it might have been because he didn't roll over until ten months and so was able to lie quietly with an IV and oxygen tubes. It wasn't as bad as they thought it might be. They learned how to give him breathing treatments at home and have been able to discontinue these. His health issues were not as hard for Candace as her older daughter Ariel's had been.

Kelly. She said that other people with children with Down syndrome had more difficulties that she and Tom did. "Some people have a lot of problems they have to go through." This positive statement notwithstanding, Kyle did get sick a lot. He had problems with adenoids and with persistent ear infections and respiratory problems. He got sick more often when he started pre-school and had interactions with other children. In recent months Kelly has been dealing with a very difficult long term health problem as well as with a difficult, frightening new problem.

Kyle has struggled with sleep disorders for some time. His inability to sleep at night contributes to his susceptibility to colds and related illnesses. It also sometimes makes him too sick to go to school, necessitating changes in the caregiver schedule for Kyle. In addition to these annoyances, his lack of sleep often makes him irritable and hard to deal with. Kelly also lost sleep, getting up with him, or, "I'd lay awake and try to figure out and listen to him breathe and like…what's happening to keep him from breathing?" Tom and Kelly read about sleep apnea and considered that to be a possibility for Kyle. Kelly went with Kyle for a sleep study. He was bewildered and fought the procedure. Kelly, who tends to downplay most difficulties, described it:

> Kelly: It was the worst night of my life...They did not explain to me what he was going to have to go through. They have to have...forty probes stuck to him that night. If I had known, there is no way I would have…I'd be like, "I don't know if that's going to work. I don't know." It was just horrible.

Kyle has always wanted to be held and carried often. Since he is now about sixty pounds, it is growing more difficult. Recently he wanted to be carried even more often than usual. He developed a limp, was sleeping even less, and began to scream when he was picked up. In part because of Kyle's communication and behavior difficulties, Kelly had to take him to three doctors before she got a diagnosis. He has Leg Calf Perthes Disease. This involves a half moon shaped cartilage in his hip getting flattened out because of a block in blood supply. Kelly is in a holding pattern now, waiting to see if Kyle's hip heals or if surgery will be needed and waiting to see how this condition fits in with his sleep disorder. She carries him up and down her stairs. She minimizes the question of her back pain.

Liz. Tate doesn't have many of the health problems, such as heart or gastrointestinal problems that often come with Down syndrome. He has only had one ear infection. They did have to struggle with pneumonia, though. They had six incidents during his first year. He wasn't hospitalized, although they did have to make many rushed trips into the emergency room in the middle of the night. "…because we would put him to bed with no symptoms, no cough or fever or anything and then an hour and a half later, we'd walk in and his breathing would be so labored."

Luckily Tate hasn't gotten any other infections. His Down syndrome caused Liz to do some things differently than she has planned with him, omitting some things she considered very important. For example she planned to breast feed her children for at least one year.

Tate's oral muscle tone was so weak that he couldn't nurse and had to be fed with a syringe for a very long part of his infancy. At first she tried to nurse him without any supplement until a lactation specialist told her that Tate was working so hard to nurse that he was expending more calories than he took in. After that, she pumped breast milk and fed him with a syringe. She was glad to do it for his health, but missed the bonding, warmth and ease. She kept it up as long as she could, but knew when it was time to stop.

> Liz: I got to the point where we had gone camping and I was sitting in the pickup pumping, attached to the cigarette lighter. And it was hot in the middle of summer and I just got fed up. I couldn't do it any more.

Support. Clearly, these young women are coping with some difficult challenges and bumps in the road as they raise their children. Support services were different for each family in style, amount and success. One outcome of federal legislation guaranteeing access to special education services is provision of a source of support to the family for early intervention services for children from birth through age five. In Montana, children born with Down syndrome are eligible for support services through the Department of Health and Human Services. A variety of agencies throughout the state contract to provide what is often referred to as Part C services. In western Montana, the providing agency is the Western Montana Child Development Center (CDC). A family support specialist (FSS) typically works with the family to provide support, education about the disability and links to other needed services for the child's development. The three Montana participants had connections to this service as well as other unique supports. Liz received similar services in Minnesota, although they are provided through the public schools from birth.

Supports in a variety of guises were mediating factors for these women, helping them cope. Hines and Bennett (1996) evaluated over 50 studies published between 1960 and 1994 and determined that “the conclusion that children with Down syndrome and their families are likely to benefit from early intervention is generally a consistent finding” (p.100). In her extensive study of the experiences of mothers of children with disabilities, Landsman (2009) looked at early intervention from the perspective of the caregivers and found that many young mothers now bear the primary responsibility to care for and teach their little children with disabilities. Several participants discussed stress from all the teaching. All four women spoke of their families providing them with some degree of support. Support is a theme that touched all the mothers, although in different ways. As illustrated in the descriptions below, community, family, intellectual growth, social interaction and faith were important to participants in this study.

Anne. The support system that Anne’s FSS helped engineer for their family is still intact, even though Sonny has started preschool, with speech and language therapy provided in her home twice weekly. “We always used to say, his girlfriend is here. He would always get so excited. He loves her.” Consultations continue with Sonny’s physical therapist, who is making a new set of orthotic shoe inserts for him. The weekly visits from the FSS stopped when Sonny made his transition into preschool special education services through the public schools.

> Anne: It’s great, like I love them. Like I don’t know what I would have done without them. CDC... we immediately had her come over and she was there every

> week. It was great. Usually she would talk to me about what was going on and how she could help and what I am doing and stuff like that. Brainstorm things that I could be doing, or should be doing. Or like resources, you know that might help with whatever. Like just basically there to support me. It's really great. It turned into like a friendship.

During one interview I noticed that Anne had a Buddy Walk calendar on her dining room wall. The Buddy Walk is an annual walk sponsored by the NDSS to spotlight community attention on Down syndrome and to provide a fundraising opportunity. She spoke with enthusiasm of the camaraderie of the walks and of the financial help she received from the organization.

Family members also provide support for Anne. Throughout her life, her father has been someone upon whom she can rely, a source of support and stability for her. He continues in that supportive role. She works for her uncle, whose business allows her flexibility in hours. He understands…I mean he doesn't *understand* but he understands…sort of." (her emphasis)

Candace. The morning of our second conversation Candace had completed a transition meeting to begin to plan for Max's preschool education. Her FSS had organized the meeting and attended it with Candace. She values her support system and will miss the home visits of the FSS.

> Candace: So helpful! So unbelievably helpful! I love Karen. I just saw her a couple days ago... I just wanted to cry that I won't be able to meet with her anymore after he's three or four. Sometimes I counted the hours till she came because...I had so many questions.

Candace noted that her family has been a big source of support for Candace. Her parents are both special education teachers. Her sister is a social worker and an aunt is in the field of special education. Their comfort with and knowledge of disabilities has been a strong source of support. They provide respite care infrequently because Candace rarely leaves her children, but they are key people in Candace's day-to-day life and provide emotional support and companionship. Candace spoke of a childhood that involved much relocation. "We moved around a ton and I liked that. Oh, I like meeting new people." Her family became close when she was growing up and they remain so today. Her sister lives next door. Her parents are young and they are like friends.

> Candace: So they are young enough so that really some of our friends are not that much younger than them. And so they are vibrant and really involved. They are here all the time and like I say, with my sister next door, they visit their grandkids all the time. It's really fun.

Her husband is now a close friend of her sister's husband. When asked about her family Candace named and described her parents and siblings before her husband and children. Her social life and daily life revolves around family.

Candace's oldest daughter was born during her first marriage. She reported that her relationship with Ariel's father is smooth. "She is from my first marriage and her dad is in (nearby town) and we all get along just fine."

Candace has also found support in reading many books about disability and Down syndrome. She appreciated the library provided by the Montana organization Parents Lets Unite for Kids (PLUK). Like the other Montana participants, Candace became actively involved with the Buddy Walk, serves on the committee, and photographs the event. She couldn’t think of any support that she needed or wished she had been offered. “But I have never been one afraid to ask for support if needed even if it is off the wall. I’m like ‘Hey how about this? Can we do this?’”

Candace’s faith also provides a source of support and strength. She was open about it and brought it into the conversation often. She often said that knowing that God chose her for this important role empowers her and gives her joy.

Kelly. Support from Part C, the family based service program provided from birth through the Montana Department of Health and Human Services, was excellent for Kelly’s first child. Her daughter Nicki was premature and required extensive hospitalization making her eligible for Part C services. With Nicki, Kelly felt they were useful, especially the toys that they provided that were designed to help with development at her daughter’s level. With Kyle, who was born in a different town and has Down syndrome, Kelly did not feel that the agency provided as much help. Part of this perception may be due to the complicated care schedule she and Tom devised for Kyle. The Family Support Specialist (FSS) came to the home when Tom was with Kyle and Kelly was at work. It appeared that she had established a strong relationship with Tom but not with Kelly.

Shortly after having Kyle, Kelly spoke with a woman in town who had a daughter with Down syndrome and found in her a source of trusted information. “After he was born I talked to Mary quite a bit and she you know, told us things to ask and look for just to make sure and we did that.” Mary was the one who told Kelly about the Buddy Walk, an event that she values. Kyle is already five years old but only recently, through an advisory group experience did she learned that she could apply to the Buddy Walk group for financial help for activities such as Kyle's swimming.

Kyle's schedule provides a sort of support for Kelly, giving her respite and time to do necessary errands, such as grocery shopping. Speaking of their schedule she said "His dad's off Sundays and Mondays so then I have him Tuesday night through Saturday. My mom takes him Fridays...so I like having him but (referring to her free time) I think it helps me gather my patience for when I do have him."

Kelly likes to read and research to increase her knowledge about new situations. She feels that there should be more books describing expected developmental sequence for children with Down syndrome. She had recently participated in a state wide focus group for parents of children with disabilities. She found that group to be an important source of information and support.

> Kelly: I learned some stuff at that focus group that would have been helpful to know, but no one told us. There's a lot of information and things out there that people don't know about. I mean these people found out that they could get a prescription for diapers too because their child pretty much can't get up, but I am thinking, if we could have had a prescription it would have been great.

Kelly initially participated in Kyle's speech and language therapy session, but stopped when they decided that Kyle might be more cooperative if she wasn't there. Family is also part of Kelly's support network. Her mother moved to be closer so she could be of help to her. She is part of Kyle's scheduled care and has provided weekly respite care for Kelly and, when needed, for Tom, even after they separated.

Liz. As soon as she came home with Tate, Liz began an extensive study of Down syndrome. Perhaps because of her deep knowledge she shows gratitude for many facets of their life with Tate, starting with his diagnosis and its effect on her family. “I know we have different challenges than other families but I also know that we have different blessings than other families that they can’t experience.”

In spite of a string of pneumonia incidents and emergency room visits during Tate’s first year, she feels that she and Josh have been lucky with his overall good health. She puts some of her worries about coping with day-to-day events in perspective.

> Liz: I think that in lot of ways we feel fortunate either to have the luxury of worrying about the little things, like dealing with “How is our life going to change?” rather than dealing with like “How are we going to afford heart surgery?” and “ Is our child going to survive?” When you think of heart surgery and that, our concerns are so minor.

She is active in visiting other parents of children with Down syndrome when possible and is grateful for the proactive efforts of other parents. She spoke of some people at her church who have two sons with autism and started a teen-aged Sunday school group.

> Liz: They started a group called Triumphant Teens. It is a Sunday school for kids who have any sort of disability. And you can bring your support person or your parents or whoever you need so you can participate. And they teach kids in a way that is right for their abilities, not like just any junior high kid, but they minister to them in a developmentally appropriate way…So I am excited about it.

Liz is also appreciative of all her extended family members. She spoke of being happy she had moved back to her home town.

> Liz: It's been a blessing and I have met so many great people through having Tate. Countless friends we wouldn't have met if we were not in the support group and other groups that we are in around town because of having Tate.

When describing her supports, Liz spoke of being happy that she and Josh chose to live in a smaller town near many old friends and family members. This community has helped her to find several important links in their support system, including a family practice doctor who has a child with Down syndrome herself, and is also her early intervention teacher's family doctor. Liz grew up surrounded by her large family, including grandparents, parents, aunts and uncles, brothers and sisters and fourteen cousins. She values her family and has lots of long-term friends. She grew up in an atmosphere of respect for differences.

While she left the hospital without being told of any supports, she quickly found them through family, friends and research. Liz lives in Minnesota and describes it as providing "phenomenal" services. Her early intervention teacher turned out to be a teacher with thirty years experience who is the mother of a childhood friend. That situation has been ideal. "And that was another blessing too. We never knew that we would need her services. But to have her come was so comforting to us..."

Day care is an important linchpin in Liz's support system. Many of Tate's therapy sessions take place there. "Yeah it was tough to find a good day care, but we did find one and it's wonderful. She is comfortable having all the therapists come in and it is great."

While overall she is pleased with Tate's services, Liz does not feel the school system provides him enough therapy services. He doesn't qualify for physical therapy and gets occupational and speech and language therapy only once per month. In a manner that seems typical for her, she has found a solution.

> Liz: There are a few other things I don't agree with, but my husband being a school employee, I have to strike a balance between being a school employee's wife and advocating for my son. And the way we handled it was we have great insurance and we have speech, PT and OT therapies come in to complement what he was getting through early intervention.

She values her support groups, finding in them emotional support and a great source of information and insights.

> Liz: To have other parents in a really active support group in town has been really great too. They don't tend to do support group activities, but tend to once monthly have a family event, where maybe we'll go to a local baseball team and watch them play. It's not so… we don't feel like we have to stop our lives and focus on Down syndrome for the night.

Liz also thinks that these groups will become a good resource for Avery, their five year old daughter.

> Liz: It was nice, too to meet families who have kids who are older who don't have Down syndrome so that my daughter Avery, as she gets older can have friends who are…She's fine with it now…but when she's twelve and is frustrated because he takes so much of our time and she hates it she will have someone who understands. I am not saying that is how it will be but she will have someone who understands her situation.

She and Josh also are part of a group called the Experienced Parents Project. Like many aspects of a life journey with a child with Down syndrome, the group did cause some emotional stresses.

> Liz: And there is a lady who leads it and her kids' ages are birth through five and she is in a neighboring county but we always go and are part of it. There is a specific group for kids with Down syndrome. We just go and talk to other families. The first time we went was when Tate was about five months and it was really hard for me to see a boy who was age seven and not potty trained. And some kids who were non-verbal and who signed what they could sign to communicate. I just wasn't there yet, but now it's just a great support system for me and you know we go all the time.

Career. Kelly and Liz both spoke often of their careers, using them to help define who they are. Both these women were established in these careers before having their child with Down syndrome. Neither woman ever spoke of considering not continuing her work after she had her little boy. Anne has not yet decided on a career, but does have a job and supports her family. Candace works at home, caring for and teaching her small children. In the following pages I present each woman's perspective of her work or career.

Anne. At twenty five, Anne has plans to go back to school, but not until Sonny is in school full time. She started at the University of Montana, but had to quit because she was too sick during her pregnancy with Sonny.

> Anne: What doesn't need to happen is me going back to school when he is not in school yet, because I need to be able to focus on it and Sonny's not able to…And

> his schedule is just…there's not enough time to focus. So I know that…I am excited that I will be able to focus more on it.

At this time Anne cleans and paints apartments between rentals, working for the uncle who "understands…sort of" her need for flexible hours. "It's really hard, because I feel that I'm not as dependable as I could be and I just I wish I could be there more, but I can't."

Specific career plans are in the future tense. Anne has always wanted to work with children, at one time considering a career in child psychology. She still is likely to go in that direction. I spoke to her about speech-language pathology as a career, since she has watched and participated in it so much with her little boy. She liked the idea.

> Anne: I am sure it would be challenging…I want a job that's rewarding. And you know I think working with kids with disabilities is absolutely rewarding. So I think that would be great! I think I just found out what I want to do! (long pause) At least for now. (pause and laughter) I don't know if it will stick.

Candace. She takes her responsibilities as a stay at home mother very seriously. She has training as a photographer and does some weddings, mostly for friends. Candace maintains a website, but does not do any other advertising, except for word of mouth. She may go back to it when her children are more independent. Her work is featured on the local Buddy Walk website, chronicling many of the participants. As she says "I am in practice mode. I'm buffering my skills for later on. Someday we'll emerge…maybe." Speaking of her future she said,

> Candace: I will do my photography, God willing, because that is what I like to do, but I like to leave things open just because I am here for...what ever I need to

> be here for. So, if it's for my kids, that's more joy than I even deserve. I know I have things that I want and I have plans that are tentative but I didn't feel that I was missing out on anything. I mean a career can wait for me. For now I have kids and that's good.

Kelly. She is proud of her career. Kelly has built on her early training as a legal secretary to become a skilled paralegal in a large law firm. She carries significant responsibilities. She does not feel that she would be doing anything different if Kyle did not have Down syndrome. It seems that her first child, born when she was 20 and still a student, may have changed the direction of her work. Originally she had planned to attend law school. She studied for two years toward an undergraduate degree before moving to a part of the state where she had more family support. Then another relationship and another pregnancy came along.

> Kelly: This town is way different than I thought...I actually got a job in a bigger law firm that I liked and didn't finish school... just continued on and...worked into bigger positions as a para legal rather than just a secretary. So I was pretty set in what I was going to do and so it has continued.

She obviously enjoys her job and values it. She stated that her career was not affected by having Kyle in her life. However, she did mention that she would have been too busy to go to school anyway. “That's one of the reasons why I did not keep in school. I don't have time... to study. I am barely keeping things going as it is.…” Kelly values the good insurance and the willingness of her firm to be flexible with Kyle's illnesses and appointments. She and Tom don't want Kyle to have to go to day care, and have put considerable effort into arranging a schedule so he does not have to.

Liz. As a chiropractor she believes in doing what is naturally healthy. Her profession is very central to who she is. She is proud to be doing work she believes in. She used the phrase "As a chiropractor" several times during our conversations to explain some of her beliefs. "As a chiropractor I am very, very natural. I only do unprocessed foods with my family." When telling me about Tate's diagnosis she said,

> Liz: As a chiropractor, I am as natural as you can be. I eat all organic food. I take the supplements. I didn't drink for three months before getting pregnant with him just to be sure that everything in my body was working well.

Liz lives her profession, describing why she adjusts her children regularly, knowing that she is providing them with a valuable service.

> Liz: If we keep the nervous system functioning well, boosting the immune system, you are going to get fewer infections. And so part of this I chalk up to that ...both my kids are adjusted once a week. And they are so healthy because of that.

She owns her own practice and has arranged the schedule so that she can have a day and a half home with her children until they are in school full time, working until six three nights a week to make it happen. The fact of owning her practice made it necessary for her to go back to work with Tate when he was only a month old, even though she had ten months with her older daughter, Avery before working.

> Liz: I would have liked to have taken more time off. I had a hard time with it emotionally. It took the whole month to get back to where I was before he was born. It was different than what we had planned and it was difficult for me to

> process that. When I went back to work it was like you know the patients were glad to see me and I was glad to see them. But it was hard for me.

Good child care is a necessity for this all to work. Finding the right care for Tate was harder than for her daughter Avery. “People were very hesitant to say they would take him.” Before his birth she had found what she described as a learning-based day care that she had thought would work for both children.

> Liz: But it would never work for him. And so we were kind of worried about finding a place that would work for him. Would one of us have to quit our job? Because you don’t know when a kid with a disability is one month old what his future is going to be like.

Liz did find day care, with a person who loves Tate. She is pleased with his success and welcomes the parade of therapists into her home.

I asked Liz if she would have done anything different if she knew that she was going to have a child with Down syndrome. She would have taken more pediatrics and courses about handling children with Down syndrome, cerebral palsy or sensory issues. “I would have done more of that had I known, and now life is too busy.”

Liz said that having Tate has had a positive impact on her profession. She spoke first of the business aspect.

> Liz: At first I did have some concerns that it would affect my practice negatively but, and not that I would have changed the situation, but when you own a business you do have to make it financially feasible, and I was afraid at first that I wouldn’t be able to work and that. And so it’s just between having a husband who can help out in the afternoon so I can work my hours and having a day care that we love

> and having therapists that we love and trust, all that has allowed me to do the career that I love too.

With enthusiasm found typical for her, she explained how personal growth has enhanced her professional skills and broadened her practice, especially after a local magazine featured her family. "And so lots of moms of kids with special needs called and 'Do you think chiropractic would help this?'"

> Liz: I actually treat a lot more kids with varying special needs than I used to just because...just various therapists always asking me this and that and how would chiropractic... can I bring this child with cerebral palsy to you and see if you can help or this child with sensory issues comes to you...Yes I have more patients, but I also get to meet these kids and help them live a healthier life.

Given her career choice, education, practice ownership and professional schedule, she described Tate's place in the picture. "So, he just fit into the plan we had. Perfectly!"

Personal growth. All four women described personal and emotional growth gained through their experiences. They grew in knowledge and practical skills. They appeared to grow emotionally, becoming more patient, tolerant and appreciative.

Anne. She has accepted the responsibility for supporting her family financially without putting Sonny in child care, which she feels would be a difficult situation for him. Anne is proud of that. "I just choose to struggle but that's so he doesn't have to struggle so..."

School was not important to Anne when she had her first child at fifteen. Several years later, when she was again pregnant, her first semester of college was difficult.

Now, she has matured into a realization that post-secondary education is important for her and she is planning for it.

> Anne: Yeah I am excited that I will be able to focus more on it. It was like, before, I was pregnant when I went and I was like (sigh) yeah its ridiculous. The kids will be in school full time and I think it will be fun (with emphasis) and it was not fun when I went. I am looking forward to that.

Anne's description of the birth of her first child gives depicts a young teen not fully aware of the details of her own childbirth and postnatal care. Her later confidence in recognizing symptoms and advocating to medical professionals for her needs shows growth and strength. In the following statement she describes her experiences when Sonny was chronically ill at about sixteen months. She told of her search for answers about her sick little boy.

> Anne: I knew pretty much right away that something was not right. That pretty much this was not normal. And I talked about it and was frustrated about it forever. And then when he was 16 months old it had gotten so bad that he was like white, lethargic and dying! And in a lot of pain. He was in a lot of pain all the time. And we took him to the hospital and were like "We are not leaving until you figure this out. This is like a chronic condition and we are not leaving."

Perhaps the key element of personal growth for Anne has been her profound realization of the value of life. I asked Anne about the benefits of having a child with Down syndrome.

> Anne: I think it makes you...really it does help...it made me grateful for health you know because dealing with complications and you know almost like a near death

> complication with Sonny and losing a child. It's like...it really makes you appreciate the health that you have, really with your other kids or with yourself. And it almost makes me appreciate him more. You know because he has had to struggle and struggle and struggle in many different ways. You know really I think it helped me love him…even more.

Candace. A profound moment of growth for Candace occurred while she was still in the hospital with Max. She had no idea how to create a mental image of a child with Down syndrome. Except for his health needs, her infant really didn't seem very different from other babies. A family with a little girl, Alanna, who had Down syndrome, came to visit. "I sat there and cried and I was staring at Alanna and couldn't believe it. Oh, she was talking and walking and I totally didn't know what to expect."

Candace also described learning about flexibility and making the most of the situation she is in. "You think that we try to put everything in containers...everything should be the same so that we know what to expect. Things become beautiful when you accept them how they are and try to bloom where you are." She also discovered that she enjoys helping teach Max and creating situations that help him be challenged much of his day.

> Candace: Whatever we do we just encourage him. Like when we go for a walk I will just sing almost the all the time. I'm sure the neighbors think I'm crazy. Like I will sing *Hickeldy Pickledy Bumble Bee* and just try to make him realize that's a tree, that's a leaf, that's a car…I want to make sure he's exposed to all those words.

*Kelly***.** Kelly also spoke of ways that she has grown through her experience. She has participated in a focus group concerning the needs of persons with disabilities. This event seemed to increase her confidence. She has learned much in terms of information and self-advocacy. As most parents do, she has learned of some parenting styles that she can change to help Kyle develop more mature social skills. Her skills and confidence in this area seem to be slowly growing. “I’m like...maybe I should try and quit treating him like he doesn’t understand because I know he does.” This type of emerging self awareness is a key in terms of making some behavior changes for both herself and Kyle.

> Kelly: I think it’s more like that with Kyle probably that we tend to kind of baby him and do more stuff for him and probably underestimate his abilities a lot, thinking that I just tend to be more protective of him.

Kelly described herself before she had Kyle as a person who was ill at ease with people with disabilities. Her realization that she no longer feels that way is a profound illustration of her move from sympathy and avoidance to empathy and acceptance.

> Kelly: I was at Kmart a while ago and I was buying a bottle of wine and some gardening stuff and the guy behind me had a little machine and it would talk for him. And you know way back when I would have been really nervous and like woo...(with a frightened intonation), but now I’m just kind of nervous and I'm waiting for him to type out his thing for me. It’s about a party or something and you are going to garden and have some drinks and it was kind of funny and then I just really realized that you know back then I would have been like most people. You know unaware and nervous and probably wouldn’t take the time to listen to someone like that and it was just kind of just like second nature for me to just let

> him do his little thing and...when he would talk sound would come out. I'm sure you have been around people who couldn't talk. You know it was really necessary for him...Then he laughed and it was really...funny. And so you have people who maybe they can't talk but they have a personality and joke with you and I don't know even though there is a lot of awareness in my town, especially and just in general now, I still don't think its all that it should be because there are so many more today. So many more people born which means so many more people with disabilities kind of thrown on the back burner and ...(long pause)

Firsthand experience is the best teacher. Kelly described this moment of awareness. She may have had this awareness many earlier if students with disabilities were part of her school experience.

Liz. Throughout our talks, Liz, a well educated and a practicing professional, presented an air of confidence in her knowledge and in her decisions. She has planned her life and most of her choices have been researched and thought out. Having Tate was certainly planned; having him born with Down syndrome was not. Liz is very different from Anne, but both of them spoke several times about learning not to take things for granted. "It taught us to appreciate the small things. It doesn't have to be the biggest or the best as long as he's doing his best. We'll celebrate that." She spoke of expecting her daughter to meet milestones, not realizing how wonderful achievements are for any child.

> Liz: And the things it makes you see. I think as a typical parent you are proud of all the things they can do, like" Oh look, she's reading, oh look, he's walking" or "oh look, she's talking", and all these things. And if the chart says that she is going to crawl between six and ten months you take for granted that she is going

> to do it. And we didn't know that with him. With my daughter, with every development she made it was like "Oh good job, but we knew you'd do it." Not that it wasn't a celebration, but we knew she would do it. And with him, he didn't sit until the day before he turned one year old. And we had worked so hard on it. I tell you it was like a celebration. And now it has transferred over to my daughter too. That everything she does is worth a celebration. That you should never take for granted anything that she does because you have to work hard for every achievement. And that's the biggest thing that he has taught us as a family.

When Tate was born, Liz lost herself for three weeks as she used the internet to research everything she could find about Down syndrome. "I wanted to know everything that could potentially happen. I don't know if that is from my own training as a scientist, but that is how I deal best with situations." She continues to value well researched information, but she has grown into a person who can accept a situation as it happens, rather than feeling she has to know everything up front.

> Liz: I always tell parents that...if you had a window for three years down the road or like five years down the road, if you could see what your life is going to be like, you would realize that its not such a big deal as you make it out to be right now, that things will get figured out and things will settle back into a comfortable routine, whether that's therapies or whatever it includes, what you don't realize is that you are gonna be okay and I don't think you see that right away.

She went on to describe a new mom who was overwhelmingly concerned about researching possible future events.

> Liz: I met a new mom, Renee, who was so concerned about researching group homes and all these things for when this girl is in her twenties. And I said , “You know I understand that this is part of the way you’re coping because…I did it myself, I looked on the internet for countless hours for health concerns and all those things”...Everyone has to grieve and process the information in their own way, but you just have to tell people that they will be ok. “You’ll live through it and you will be ok. You will be better because of it and most days you will not even remember that your child has this disability.” Honestly you don’t… it’s just such a part of our lives that I don’t even think about it any more. I think that you can’t wrap your brain around that when you get the diagnosis initially.

Liz’s chiropractic practice continues to be successful. She now has many more patients with disabilities and learned and grew through that experience. “I now see things more the way some people with disabilities would.” Overall she felt that one of the benefits of having Tate join their family was, “watching him grow and develop and watching him teach me about things about myself that I didn’t know.”

Living in a child focused era. In Chapter Two I spoke of this era being a time of financial uncertainty as well as a time when, as Donahoo (2007) wrote, we spend tremendous amounts of time and energy trying to create the perfect child or perfect childhood. The participants spoke of how the times we live in shape the paradigm of motherhood for them. Reichman, Corman and Noonan (2007) found that the many elements of raising a child with a disability are likely to affect parents’ allocation of time and resources to other children, their parenting practices, expectations of healthy siblings in terms of achievement, responsibility and short or long-term contributions to the household.

Candace's life is closely woven around her own children and close relatives and friends and has a somewhat limited exposure to the general community. Kelly, Liz and Anne are out of the family circle more often and have faced spoken or unspoken comparisons of their children with others.

Anne. She has noticed competition among moms wanting to give their kids the best clothes. She can't keep up and says she doesn't worry about it. She described socializing with some other young mothers and their children. "It's great and there are no differences." I asked her if she ever felt that her friends could not accept or understand children with disabilities. Referring to anyone who did not think her kids were perfect, she said bluntly, "I wouldn't subject me or my children to that."

Candace. Candace's focus is almost completely on her own family. She is very close to her parents and sister. With Ariel at nine years of age, Josh almost three and one year old Cecile, she does focus her time ant her thoughts on her children, influenced more by faith and family approval than by current trends and popular values.

Kelly. In contrast, Kelly has felt awkward in some conversations with other moms, not knowing how to include her little boy in their discussions and feeling left out.

> Kelly: They are playing soccer, they are going to dance or in a play or whatever so that's kind of hard…I have a few friends like that or their kids are doing this or doing that. It is really hard to really be into that to know about that. I don't know, maybe I feel a little resentment or hurt because, you know my life is so

> different and its hard...I am constantly busy doing stuff and going and doing this or that.

Liz. With her first child Liz had calmly accepted her daughter's skills, such as reading at age three, as really no more than she had expected. She credited Tate, her little boy with Down syndrome, with helping her realize that all achievements, great or small are wonderful, and that success can have varied dimensions. She still found it hard to face comparisons. Part of the draw that led Liz and Josh to move back to her hometown was the presence of old friends and family. She had troubles at first both with facing her old friends and making new friends who shared the Down syndrome experience.

> Liz: At first I avoided my friends with typical children. We are similar ages and our kids are the same ages. I blocked them out. There were three of us with babies due at the same time and one of my friends called when I was still in the hospital and was very emotional and said 'I just don't know why I got two healthy children and you and Staci didn't and Staci is another friend of mine who also has a child with a disability. I said "Why can't you accept Tate as perfect?" She didn't mean anything by it but it was hard for me.

Living in an era of prenatal testing and choice. As Landsman (2009) observed, we live in "an age in which infants are commodified and technology seems to hold out the promise of 'perfect babies'" (p.3). The social mores of 2010 and the availability of prenatal testing and abortion form part of the societal background for the lives of the participants. Termination of pregnancy is not uncommon. Amniocentesis, a prenatal test that can determine the presence of Down syndrome, has been available for many years. Mansfield, Hopfer and

Marteau (1999) noted that termination rates after a prenatal diagnosis of Down syndrome are estimated at between 90 % and 93%. Discussing the availability of this test and its implications was very personal for most of the participants of this study.

Anne. In a very limited percentage of persons, Down syndrome can be inherited. Anne knows that she is a carrier of Down syndrome, but has not had the genetic testing that is now available.

> Anne: Yeah…but I didn't actually have to have the genetic testing done. It would have cost a lot of money and like blah blah blah. And I mean it wouldn't have made a whole lot of difference. I mean the difference…The biggest difference they said it would make is that like I would know about my children. Like Leon having the same thing I do...Like maybe some day...but like right now I can't afford it and its…I know what I have...like it's very clear.

Candace. This participant's story intersects cultural mores of testing and choice. Referring to the fact of Max's Down syndrome, she spoke of the response she had received from some friends.

> Candace: Like I had a couple friends who were like "Oh don't you wish you had known so you could have just tried again?" And I'm like "You obviously don't know Max because there's no way even if you could wish it away or pray it away there is no way."

Kelly. She spoke of counseling a friend who was pregnant and who had undergone amniocentesis, referring again to the book *Roadmap to Holland* by Jennifer Groenberg.

> Kelly: I had a friend who thought she was going to have a child with Down syndrome. But she wasn't sure if she wanted to get rid of it or not. I actually pointed her to that book by Jennifer and maybe I wanted her to read that one so that she could get personal experiences about what to expect and that would have been a good book for someone to read before going through everything. I think the personal experiences would be good to read before so that you kind of have an idea what can take place.

Liz. I had mentioned to Liz that some of my reading had raised the issue of providing extensive prenatal testing to all women, not just to women in older age groups. Liz was more emotional and passionate about this subject than any other in our conversations. "Oh boy! It is a hot button issue in the disability community... Parents of kids with Down syndrome I know and parents of other disabilities take it as a slap in the face." She continued:

> Liz: Yeah Like our kids aren't *good enough* (with a put down tone of voice) or 'Why would you want a kid like this?' I think that part of the problem is that the medical community paints it as a scary thing. And there are unknowns certainly. You know that I did not have the prenatal diagnosis so I didn't have to think about it, because there was no risk. I would have never had the amnio because I wouldn't do anything different even if I did. But, already the Down syndrome termination rate with the prenatal diagnosis is over 90% which is sad, terribly sad and I think if every woman was tested there would be even more. I honestly believe that Tate's generation will be the last generation born with disabilities as prevalent as they are now. And not that it's a bad thing but I do think that there

> will not be kids like Tate anymore. I do think that most women will test, and that the termination rate will go up and I think it's sad and I think that a lot of it is fear of the unknown. I know we have different challenges than other families but I also know that we have different blessings than other families that they can't experience...I don't think that is something that most people consider when they get the diagnosis of Down syndrome prenatally and you haven't had a chance to bond with that child yet and you don't think you can do it or you don't think your other children should have to do it.

Considering the world in which they live gave perspective to the participants' stories. Looking at their choices, actions and reactions highlights their important beliefs. A different perspective is gained from looking at what they do every day.

Sub-themes. Several themes pertained to coping. I noted earlier that stress and negative interactions in families appear to happen more because of behavior problems than because of the developmental delay (Eisenhower, Baker, & Blacher, 2005). For one mother the behavior of her child was an important theme. Several themes were unexpected outcomes of adjusting and thriving. The role of acting as their child's teacher was discussed by some of the participants. Humor determination, leadership and gratitude were woven through the narratives of some mothers

Mom as teacher. Joyful love and optimism glow throughout Candace's conversation about her life. She presents an aura of contentment and positive purpose. She knows that her son with Down syndrome is a wonderful addition to their happy family. Candace returned often in our discussion to the role of a stay-at-home mom. She considers her duties to be important and to include helping teach her son to progress on his goals. She feels that the job has turned out somewhat differently than she expected.

> Candace: We have like ten hours of therapy per week...Like I was telling my husband last week. I don't usually feel...I don't ever feel like a stay-at-home mom. Like I am, but I don't ever stay at home. There are hardly ever times when we are not really busy doing things or preparing for things.

Returning to the topic later, she said she was finding that having many things to do and many appointments were stressors for her.

> Candace: I guess sometimes, not very often, but occasionally now I have had a feeling of stress with all the therapy we do. Thinking I should have gotten a degree in physical therapy of some sort... So sometimes that stresses me out but it is usually a misplaced stress like I said, kids are sick or something else is wrong. I don't think it's the therapy that stresses me out it's the… like there's too much on my plate and I get sort of in my mind a sense of entitlement like you are supposed to be a stay-at-home mom or whatever, but I never feel like I am home.

Comments from Candace that reflect stress or dissatisfaction were few. She obviously loves her role as teacher and was happily descriptive of some of her teaching techniques.

> Candace: I do not think I should be at home with him all the time and not be working. You know what I mean...Like there's lots of times Max likes to play by himself and I have to chase him and sit in front of him and so we have kind of figured a way for him to work in secret ways. Like if I turn on the TV which I never used to do and now I do, I know he will stand up to watch it. I'm like let's

> get Max to stand up for 20 minutes and he will think he's playing alone. It's a good deal! ...I will jump on his bed with him which is not very good example but it helps him with the moving and the jumping and little things like that that kind of make it fun.

. Liz and Josh have lost some of their privacy and have found themselves sharing his upbringing with other people:

> Liz: You don't always want all these other people involved in raising your child to the extent that we have them involved. You know there are some Tuesdays that I just want to have time with my kids. I don't want to have a teacher or therapist over. I just want to have time with my kids and just be Mom...It can kind of get old. We are always grateful for the help and the services but it also can get to be a burden some of the time.

Humor. Kelly and Anne used humor to help tell their story. They both often told funny stories or made humorous remarks. They seemed to use humor in different ways, possibly for different purposes.

Anne. Conversations with Anne were filled with laughter. She laughs at and with her kids. She laughs at herself. She laughs at the world around her and at her own difficult situations.

Anne doesn't get worried about small mistakes and details. During one interview at a coffee shop I felt that I had let the interview go too long and asked her how she was doing for time. She laughed and said "I have no idea. My phone's dead, I don't have a watch." I replied that I didn't have a watch either but I knew she had to meet Sonny's school bus at her house. She laughed again and told me about getting him ready in the morning and not watching the time. “I will look out the window and Oh the bus is here. I don’t know how long it has been here.”

Before Sonny’s birth Anne had decided not to have an epidural, a technique which is commonly used for pain relief during birth. From her earlier experiences she hated the entire process. “I don’t like...you know bending over and being completely still while someone sticks this giant needle in my spine. It’s like…yeah that sounds really nice. I think I’ll do that, sign me up.” She then talked about her experience with natural childbirth. “I was like...Oh my God I didn’t know it was this bad…” She laughed as she finished with “I am really glad that I did it...but I’m like...don’t know if I will do it again. I think I might go with an epidural.” She did then mention that she doesn’t really want any more kids.

Anne enjoyed the interviews and the idea of being part of my dissertation. She liked that I was working on a doctorate at an older age than is typically seen. I told her that she has big things ahead and that she doesn’t know what she will be doing when she is sixty. Her reply? “I don’t even know what I am doing now.”

Kelly. She is a witty woman, spicing her conversation with dry humor, often at her own expense. It appears that it is difficult for her to address some concerns, especially with emotions, behavior or health issues. She seems to use humor as a tool for addressing some topics or avoiding others.

Kelly was concerned with a serious health condition that Kyle was facing. She described her concern about his pain and his lack of mobility, with her home having only upstairs bedrooms and Kyle weighing over 60 pounds. She said with rueful, frustrated laughter. “But he works it. He gets me to carry him up and down the stairs.”

Later on, when we were discussing some behavior issues, she laughed again as she spoke of having to carry him.

> Kelly: Yeah, if we are like going out, like to the river, I will put him on my back and then that doesn't hurt me at all, carrying like that, its carrying with my arm. (indicating that it hurts). I just try to think of it as my upper body workout system. I don't have to do weights because I have to carry Kyle.

While Kelly does feel that his behavior is improving, she still worries about this area. She told a story of Kyle controlling the music they listen to in the car, *Boom Boom Pow* or songs from a hamster movie called *G Force*. She made it very funny, but it illustrated a part of her day to day life. I said that it was a good thing that he was still in the back seat. She responded, laughing, "Yeah, sometimes he takes off his shoes and hits me with his shoes and socks...Sometimes he takes off his coat and sometimes his shirt." Her manner of telling it had us both laughing. Then her sigh, rueful laugh and comment, "Yeah he's got it made." gave the story a bittersweet tinge.

Determination. Anne and Liz are very different women living totally different lifestyles, but they do share the trait of determination. This feature appeared to help them accept and move forward.

Anne. Whether shaped by early events or a natural trait, Anne has gumption and nerve. She may not have understood what was happening during her first pregnancy, but she did try to make her own decisions at that time. Near the end of her pregnancy with Sonny she described feeling "different" and going in to the emergency room.

> Anne: Yeah, I actually requested a…what it is called...oh an
> ultra sound just because…I wanted one. That is how they found about the

> calcified placenta and determined that he needed to be born right away. I am like what the heck? So I am terrified and I am like "Come on people get it together. What am I going to do? What are you going to do with my body?"

Anne's determination seemed to strengthen as she matured. I described earlier how she showed determination in dealing with Sonny's gastrointestinal blockage. She knows that she saved his life through her persistence with the medical community in insisting that he was a very sick sixteen month old. Her strength was evident in her interaction with the hospital staff at that time.

> Anne: It took like a whole day. She was still trying to say that it was not a big deal…She said, "You can go home after this" and we were so angry. It was like this test…that found an actual obstruction in his intestines…I am not patient. I am not patient at all. When I want something I want it now. And so I just was like, God I just want to know and I want to know now. I was just getting anxious and impatient and antsy. But I am really glad that I was being annoying, which I always am, because it saved his life.

Referring to a more recent difficulty, Anne is proud of how she has handled her recent divorce, when she tried very hard to make it as good as it could be for her boys.

> Anne: I just I didn't want them to have. I don't know. My childhood was not like my kids child hood. I mean, not…so you know I am a whole lot more open with my children and um that makes a lot of difference.

Anne has the boys with her all the time except for a three hour family visit with Pat on Thursday, and seems comfortable with the situation. She laughs as she told about their tight budget.

> Anne: I have the financial role too. So it's difficult, but I also I take pride in it but its still really hard. But I can do it... I can be good for my kids and do a good job and provide. I don't know how but I do. Barely (pause) barely so… but I do.

The work she does for her uncle can be very tedious. She is determined to do a good job. She told me of her most recent job assignment.

> Anne: It was really hard. I had to clean the walls and the ceilings before they could be painted. Oh God it was gross!... It looks great now! The whole place is clean. It is all white now. The whole place is clean. I had to work really hard to get it as clean as I did. So it was cool to leave yesterday and go "Wow"…I worked really hard and it looks so much better which is something. I don't usually feel real good but I did.

Like many moms of preschoolers, especially little ones who are endearing and have been ill, Anne is challenged to teach Sonny compliance and good manners. She was comfortable interrupting our conversation and taking Sonny aside and explaining that he couldn't throw a large plastic toy and requiring that he set it down gently, a process that took several repetitions of her request. She said,

> Anne: Yeah. He's doing pretty good. I mean I have to chase him in stores. There's all this great stuff. He wants to run everywhere. Do whatever he wants so but that doesn't stop me I'm not gonna like… put my life on hold and not do the things I would normally do.

I mentioned earlier that Anne's determination may have had an effect on the direction of her life. At fifteen she was living with her mom when she became pregnant, returning to her dad's to complete the pregnancy. She spoke of going to stay with her mom when she wanted more freedom and with her dad when she needed stability. She laughed, apparently at her younger self, when she described her son Leon's future. "But whatever he wants to do is great… for the most part anyway, I think. (with wry laughter) Not everything, but…"

Liz. Liz gets things done. She evaluates a situation, decides what is needed and then make it happen. Her life with Tate offers many examples of this trait, starting with the night of his birth.

> My husband called and said that we were coming in and it was still three weeks until our due date and they were like "just get in a warm bathtub" and...I told him we are not getting in the bathtub! And we went to the hospital.

If she believed that something was the right thing to do she made that her focus, sometimes using that focus as a way of coping with complicated situations. Her description of working on breast feeding while his diagnosis of Down syndrome was still in process showed this,

> Liz: It was really important to me that he breast feed...It was a little bit of a blessing that he couldn't right away, because it took my focus off...I had been so preoccupied with Down syndrome and then I focused on "How we are going to get this kid to breast feed?" I didn't want to feed him formula, and I had to find a way and that was what I focused on for the first few days. I was like you guys do what you have to do with the diagnosis, but I will make sure that he gets the food that I want him to have.

Liz and her husband were left to find most of their own information and support. "And so we left with literally no information...anyone to help us. And so I told my husband, we have to figure out what to do." She took this search to heart, perhaps using the search process as a way of coping with the information she was searching for.

> Liz: The first few weeks my main concerns were the *what ifs.* I wanted to know everything that could potentially happen. I don't know if that is from my own training as a scientist, but that is how I deal best with situations like that...I did search out the Down Syndrome Society of Minnesota, and they sent a packet with the book *Gifts*.

The packet from the Down syndrome society provided her with many of her most useful links and helped her connect with others in similar situations. Her determination stood her in good stead when she followed up on a suggestion from her early intervention teacher.

> Liz: She said, "You should go to the doctor that I see"... And I was told that she wasn't taking any new patients. And I said let me tell you the situation. I have a little boy who has Down syndrome who is three weeks old and who needs the care of a medical doctor and would she see him?

Her perseverance with that phone call yielded her not only a physician, but a friend. The friendship that she developed for her early intervention teacher, notwithstanding, Liz felt at times that she didn't have enough time just to be a mom with her kids, alone with them at home. Despite this, she said, "We felt that to give him the best chance…we provide all these therapies for him."

As a strong person, it seems logical that Liz would feel protective of her children. She described her feelings,

> Liz: You tend to be protective of things, I thought I was protective of [Avery] but you know we always jokingly call it the *Mama Bear* instinct was in full force because there was no way anyone was going to say anything to him or hurt him. There was no way.

Her protective instinct continued when she told people about his disability. She wanted to control the message they took away.

> Liz: It was hard for me. It was like 'Who should I tell?' and 'How should I tell them?' and I didn't want them to hear that I had a son with a disability. First I wanted them to know that I had a son and that he was awesome and then that he had a disability and it was fine. I didn't want that to be how they identified him

I have no doubt that Liz will continue to see what is needed and continue to find a way to make it work for her family.

Leadership. Liz and Josh were not given any information about services for a child with Down syndrome at the hospital when Tate was born. She has worked since then to help share information with new mothers, to talk to them when they are ready and to be a strong part of the Down syndrome community. She does this routinely, but not to the extent that she had hoped.

> Liz: We have actually tried through our support group to go into the hospitals and to give them a packet and a list of names of parents of young kids if someone is in the same situations that we have all been in or if they want to talk to someone who had been through this we would go there. They will give the packet, but they won't allow any names or other information.

Because her initial search for people to talk with wasn't fruitful, Liz has started to offer other parents this opportunity. “When I contacted the Down syndrome support group, they didn’t know anyone with kids younger than two that I could talk to. I would’ve given my right arm to have someone sit down and be like ’it’s gonna be fine.’”

She has given careful thought and preparation for when she is asked to talk with a family who is just beginning to cope with their newborn’s Down syndrome.

Her basic message to the new mothers is simple and positive. “You just have to tell people that they will be ok. You’ll live through it and you will be ok. You will be better because of it.” She continues with more information from the perspective of a few years. “Most days you will not even remember that your child has this disability. Honestly you don’t. You don’t. It’s just such a part of our lives that I don’t even think about it any more.”

Gratitude. Liz has studied Down syndrome extensively. Perhaps because of her deep knowledge she shows deep gratitude for many facets of their life with Tate, starting with his diagnosis and its effect on her family. “I know we have different challenges that other families but I also know that we have different blessings than other families that they can’t experience.”

In spite of a string of emergency room visits, she understands that she and Josh have been lucky with Tate’s overall good health. She puts some of her worries about coping with day to day events in perspective, saying,

> Liz: I think that in lot of ways we feel fortunate either to have the luxury of worrying about the little things, like dealing with how is our life going to change rather than dealing with like how are we going to afford heart surgery and is our

> child going to survive? When you think of heart surgery and that, our concerns are so minor.

She is active in visiting other parents of children with Down syndrome when possible and is grateful for the proactive efforts of other parents. Liz is also appreciative of all those extended family members that she has. She spoke of being happy she had moved back to her home town.

Concern and caution. Preventing problem situations is important to Kelly. She appears to have organized her life so that people are not mean to Kyle, so that he does not misbehave at people's homes or with their children, so that he is not exposed to illnesses, so that he doesn't have to ride a school bus, so that he doesn't have to go to day care and so that she does not have to face some unsettling emotions.

Concern and caution seem to have influenced Kelly's pregnancy and birth decisions. Most women would not have done prenatal testing at age twenty nine, because of the small risk of having a child with Down syndrome. Kelly's reason was different. She chose not to have it because she was afraid of it, saying "Do you test with an amniocentesis or something? I really didn't want to do that. I was afraid of that." She had been very interested in having a *v-back* birth which is having a vaginal delivery after previously having a caesarian section for an earlier birth. She researched it extensively, but decided against it because a friend's niece had a bad experience. "I think I will just have a caesarian and be safe …"

Kelly talked about preferring more technical information about Down syndrome, rather than learning about other mothers' experiences. She does want to feel prepared for eventualities and to know what the possibilities are.

> Kelly: I think I was just so freaked out that I wanted the technical books and reading what could go wrong. I think that was my main focus: worry about problems that could happen...I mean I thought that I could deal with the day-to-day stuff …

She is guarded and selective in seeking information. Earlier I referenced Jennifer Groenberg's book *Roadmap to Holland.* Kelly had an email conversation with the author and recommended the book to her friend, but did not read it herself. She seems to be cautious with all aspects of Kyle's development as well as cautious with her own emotional reactions. In trying to explain why she does not look for information about personal experiences, she said "I ask for advice from my friends and stuff, but, I don't know what the deal is." I mentioned some flaky information being out there. She said "I don't think it's that either. Maybe it's gonna bring up a bunch of emotions that…I try not to…I don't know…"

Kelly is proud of Kyle's successes and seems to be beginning to raise her expectations for him. This is a change. "We tend to kind of baby him and do more stuff for him and probably underestimate his abilities a lot ...I just tend to be more protective of him..."

Faith. While several women spoke of blessings and God, Candace's faith is a key force in her life, although she did not mention an organized religion. Her beliefs echo those expressed by Venestra, who, as cited in Thomas, Dowling and Nicoll (2004), said "These special children transform them into different people, stronger people, dare I say it? ...deeper people!" (p. 173). Candace understands that her son, Max, is a special gift from God. “I was surprised that God trusted me with Max and so…Sometimes I think he’s a little angel that’s helping us too.”

Candace did have some brief sadness about Max’s Down syndrome. Her faith was strength at that time.

> Candace: It’s good for all of us. Its invigorating to know that things are not always what you expect and put your trust in God and to know that he has things for us that we cannot even imagine. I mean like my happiest imagination is going to be superseded just because I have him and the girls.

She touched on her acceptance again later in our conversation, when we were talking about suggestions for families new to the diagnosis of Down syndrome.

> Candace: I learned that that was where my disappointment was coming from. Thinking I was going to choose my path and… I’m not the smartest judge of what I would like to do ... (compared with) a higher power…I have ideas but as far as I go with them?...We are ready for tomorrow and enjoying today.

At first Candace was surprised that God had trusted her with Max. Three years with him have changed that.

> Candace: It’s unbelievable to know that you are trusted with something so precious. I mean they are all precious but something that you...like I said didn’t expect…and something that you don’t know how to take care of it’s a great...it’s a great flattery. Like I can’t imagine being a virgin and being told I am going to have the Messiah, but I can imagine God trusting me with Max which is something I couldn’t imagine a while ago…

Behavior. Kelly's situation reflects the Saloviita, Itaalinna, and Leinonen (2003) finding that the main explanation of maternal stress was behavior difficulties in the child. Kyle has some behavior challenges. Kelly spoke of a time when she had brought a pizza over to a friend's house and he asked her and Kyle to stay to eat it. "I didn't think I would because Kyle's going to be real obnoxious and I just get really tired and I worry and I don't want him to bother other people." Another friend of hers has what she refers to as a "high maintenance child." They have started getting together sometimes.

> Kelly: My friend...has a little boy now that's pretty high maintenance. But now she understands …why I would be like I can't come over because Kyle's really cranky, something's wrong. But now she knows what that's all about. It just stresses me out…so I just take the path of least resistance most of the time.

It seems that in some respects she has painted herself into a corner, creating a limited life for herself, not because of his disability so much as because of the choices she made to protect him and herself.

Kelly worries about Kyle's behavior. She does hide these worries with laughter, but they are very real and valid. Her concern about his behavior or what she fears his behavior could be seems to be a dominant feature in her life. Kelly is very careful about where she takes him. When asked if Kyle keeps her from doing things she would like to do she answered.

> Kelly: Well, I don't have him all the time you know, so I try to plan my trips to the store most of the time without him…He's not that bad most of the time. Its most of the time it's just exhausting… or I know how it could be exhausting. It could be…I don't really like to… like my mom …used to take him

> to the train (a play structure at a local mall) quite a bit and she used to take him to McDonalds to play. And Tom will take him there. I don't really like to take him there and I don't know why I'm just... I really don't know why, I guess I'm kind of like...if...even though he won't do it now because he's been in school for so long he'll like push someone down or…but he wouldn't anyway.

Later on she was describing their day to day routines. It appears that the combination of his behavior and her worry about it is placing tight restraints on her life even at home.

> Kelly: I mean he always likes me to sit next to him and if I'm busy cleaning or doing dishes or whatever, he doesn't really like that so much so…I just kind of I have him Tuesday, Wednesday, Thursday and Saturday and so I pretty much just hang out with him.

Kyle's recent illness has added another dimension to concerns about his behavior. It is possible that some of his refusals to cooperate, sitting down in the middle of a store aisle, quitting walking and demanding to be carried may have roots in a painful hip condition. Kelly has very understandable concerns about the situation.

Participants' Long -Term Plans for Their Children

The participants are busy coping with the significant needs of their young children. They have many years of parenting ahead of them. I did ask them if they had considered the possibilities for their children's future. .

Anne. I asked Anne if she had ever thought of Sonny's long term future. She said that she has thought of it but that she tries not to.

> Anne: So there is so much that could happen that I don't know. Like a lot of

> people go to independent living. A lot of people live with their parents. A lot of people live with a group...I don't want Sonny to not be living with me. I can't picture him with me as an adult. But I can't picture him not living with me… so I really don't know. That is true. I don't want him to go live in a home, like with adults. Like they say it's like independent living. Like you know they say it's like (with negative intonation) *independent* living. You know it's such a long time and I just don't know what is going to happen.

Candace. Max may eventually have a supported living arrangement, but Candace hopes that he lives with her. If she is still in photography she thinks that he might have employment making frames for her. She knows that if he needed a home that her family members would fight over who got to have him. She wants him to feel like the blessing that he is and be wanted and needed. Candace and Dallas visited a farm that provided both a home and employment to some persons with disabilities. She was delighted with the idea and can see a possibility of doing something similar. She is confident of Max's lasting position in her family. "My dad is already trying to steal him. I know we will all fight over who Max gets to stay with."

Kelly. She loves to be with Kyle. She is proud of him, downplays the difficulties and speaks of them with wry humor. She hopes one day to get married and to have a nice home. For Kyle?

> I hope, you know one day, that he could possibly have a job and live on his own. With still guidance from us you know. I saw somewhere where kids that have Down syndrome are now going to college. If that's something that he would want to do then that would be kind of neat. I just want him to be happy and doing stuff

> that he likes to do and feel good about himself whatever that is.

Liz. She says that hopes and dreams for any of her children are similar. She now has an appreciation for any outcome that makes them fulfilled and happy.

> Liz: I hope they fulfill their potential and they don't get content to just be comfortable and just do something easy. That they choose to do what makes them happy in life and they have a career that is fulfilling...and that they meet someone along the way, whether it's a friend or a husband or wife or whatever the case may be just someone they enjoy spending time with someone who makes them happy.

Liz and Josh had planned to have another child by this time, but they know that Tate needs some more of their time and they are waiting a few years. She knows that Tate's Down syndrome will also be a blessing to their third child. One of the most difficult things for them has been their realization and acceptance of a different pathway. Their dreams and expectations had to change.

> Liz: The number one hard thing for me was…his dreams are going to be different. He might still play hockey but it will be adaptive sport hockey. He might still go to college, but he's not going to be an MD. He might go to technical school and get a skill that will serve him well in his life. That was probably the hardest thing ... coming to grips with the realities much earlier than we had expected.

Participants' Advice to Other Mothers

I asked the participants if they would like to offer any suggestions to other mothers of children with Down syndrome. With the exception of Liz, most of the mothers were somewhat reticent in giving advice to other mothers in similar situations. With my encouragement, they did have some to share as well as some suggestions for professionals.

Anne. Her basic advice is, "Trust yourself. You know your child better." She also suggested patience and acceptance, but noted that it is really hard. As she said, with rueful laughter, "And acceptance. Acceptance is really hard, but … Acceptance is hard. … I don't ever get that."

Anne's story gives credibility to her other suggestion.

> Anne: Appreciate too. It's not advice, but just like, embrace...Embrace and appreciate. Because you just never know. You never know what is going to happen. You really don't know. Yeah I mean Sonny is lucky to be here. I am lucky to have Sonny, too. There's been numerous times where he's almost died. And so I appreciate. Love and embrace what you have.

I asked Anne to talk about characteristics or qualities she wants in professionals that offer supports to families of kids with disabilities.

> Anne: Parents are the professionals for their children. [I want them] to listen. It sounds so silly and so simple. But that was like the simplest thing that didn't happen. So just to listen. And um... (long pause) and be respectful…and I don't know...Honest… (Long pause)... funny is good too…But not required.

Candace. She enthusiastically shared her ideas for teaching children new skills. After saying that she would tell a new mother, "Just relax and enjoy the baby." She suggested, "To worry about the future is unnecessary because you are never right. You can't control it anyway. Don't waste the time you should be spending loving your children. It's just a waste."

Kelly. She offered advice that was limited, but carefully thought out and important. She suggested that a mother should

> Kelly: Follow her instincts on working with your child and anything that might be wrong with him and push for getting stuff checked out...um definitely just to not worry about the progress they are making and what time it is cuz they will make their progress…Just never underestimate them. I still tend to do that quite a bit. …And definitely enjoy them and try to not think about what could have or should have or whatever… Just think about this is how its gonna go and it's not bad. It's good in a different way.

Kelly has an idea for a binder that doctors could give to parents when a child with Down syndrome is born to them. She said, "I think Doctors should be informed and helpful rather than looking at the kids and saying 'He's healthy, Bye', give him shots and be done."

Her binder would contain information about developmental milestones specifically for children with Down syndrome and local sources of help and support, including a list of doctors in the area that work well with their little ones. She would also include a list of possible problems that might be encountered. Activities for working on gross and fine motor skills would be a part of the binder. Kelly dreams of making this binder to share with families.

> Kelly: Maybe people could donate (to cover) production of it. Just give it to people as they need it. Give it to the hospital you know, maybe with a blanket and a hat. They could just give those to the people who have kids with Down syndrome.

Kelly would agree with Anne’s advice to professionals to listen to parents. She also suggested that a speech language pathologist guide a group for young parents to learn sign language, as the parents are the ones who will teach that to their child. While not a suggestion, Kelly did note the importance of a job with flexibility and good insurance.

Liz. She has given careful thought and preparation for when she is asked to talk with a family who is just beginning to cope with their newborn’s Down syndrome. Her basic message to the new mothers is simple and positive. “You just have to tell people that they will be ok. You’ll live through it and you will be ok. You will be better because of it.” She continues with more information from the perspective of a few years. “Most days you will not even remember that your child has this disability. Honestly you don’t. You don’t. It’s just such a part of our lives that I don’t even think about it any more. “

If parents don’t feel that they can face other people, Liz suggests using on line support groups. She says that they can be very personal and meaningful. She is a leader in a local support group now. I mentioned earlier of her groups wish to make family to family contacts with new parents of children with Down syndrome. Liz recommends that the medical community find a way to allow this to happen and offered another more general suggestion to persons in the medical community.

> Liz: Just treat our kids just like you treat all kids. You know they are really more alike than they are different from other kids and they have the same wants to be…smiled at and hugged and given a high five or something and even if you... don’t know fully how to handle a situation, treat everyone involved with respect because that’s part of what we felt like we…weren’t given…If you respect us

> then you will talk to us in a professional, positive way and not…just dump the information on the plate and then tiptoe around it like its something you shouldn't talk about.

Summary

The love and enjoyment that all the participants told of experiencing with their children illustrates the term *Down syndrome advantage*, coined by Hodapp, Ly, Fidler and Ricci (2001). They found that families of children with Down syndrome report less stress and more rewards than other families with children with disabilities. Several themes that emerged from the young mothers' narratives reflect that advantage, including personal growth, gratitude, leadership and faith.

Interactions with the medical community were a common thread for all the participants, with resultant impacts on many other facets of their lives. Participants coped with cardiac, hearing and vision conditions, gastrointestinal symptoms and respiratory illnesses, four of the five potential conditions described by So, Urbano and Hodapp, (2007). Three of the families experienced at least two hospitalizations.

I found the descriptions of the mothers' discovery of Down syndrome very powerful. As Kelly said "I felt scared…I didn't want to feel bad about it, but I did. It didn't make me not love him…"

All of the participants remember few other students with disabilities in the school or communities when they were children. Now as adults they find that they have a part in the dialogue of prenatal diagnosis and termination of pregnancy. Support and coping combined as a theme that permeated all discussions. Different participants discussed humor, determination, gratitude, leadership, concern and caution, faith, and child's behavior

Participants shared some advice for other mothers of children with Down syndrome. Several of Anne's comments resonate: "Appreciate too. It's not advice, but just like, embrace...Embrace and appreciate. Because you just never know," as well as "Parents are the professionals for their children. [I want them] to listen."

In the final chapter, discuss the research questions and present conclusions and implications and recommendations for future research.

Chapter 5: Discussion

The purpose of this study was an in-depth inquiry into the life experiences of young women who have children with Down syndrome. Data were obtained from detailed and lengthy interviews with four purposefully chosen young women. Because I wanted to tell the stories of young women and their children, I chose to do a qualitative study in the narrative tradition. As Glesne (1992) wrote, “The openness of qualitative inquiry allows the researcher to approach the inherent complexity of social interaction and do justice to that complexity, to respect it in its own right” (p.7).

The myriad factors that constitute life as a young mother of a child with Down syndrome cannot easily be measured as much as described. Adjusting to the birth of a child and raising that child is a complex process for all young mothers. Certainly, adding the reaction to the news of a diagnosis of Down syndrome, the reality of the child’s disability and related conditions, and moving to acceptance and coping is messy, uneven, illogical, emotional and values-based—and occurs as a process throughout the life stages of the child. As Connelly and Clandinin (1990) noted, “The study of narrative...is the study of the ways humans experience the world” (p.2).

Qualitative inquiry, in the narrative tradition, is the study of individuals’ stories. It provided an orderly method for me to study the disorderly world of young mothers who have young children with Down syndrome.

The interview is the primary tool of narrative research. In my interviews I utilized the principles described by Hollingsworth and Dybdahl (2007). I tried to develop trust, listen non-judgmentally and help scaffold conversations. I met with my participants multiple times in locations that they selected. I shared my own story, making myself vulnerable. In doing this I tried to encourage talk about controversial or difficult issues and allowed space for unexpected topics and turns in my conversations with participants. Adhering to these principles allowed for rich conversations with these women. The value in their shared stories lies in that richness. Hollingsworth and Dybdahl (2007) noted, "…that conversational narrative inquiry has impacted policy and practice across the professional fields of education, medicine, social work, business and law" (p. 79).

Research Questions

I began my study with initial guiding questions. These helped to focus early interviews, but as I spent time with each participant, of course additional questions emerged. In this section, I examine the themes I developed in my results chapter and interpret these findings in light of the literature, ultimately finding some answers to my questions.

Personal background. Accepting and coping with Down syndrome is a private and individual process. The shape of acceptance depends partly on an individual's background. The participants came from different families, with a variety of income and educational levels. I found one background element of key importance. All four women went to public school in a time when students with disabilities could and should have been an integral part of the school community. This was not the case with these women. They recalled thinking of students with disabilities as frightening, separated or invisible. Landsman (1998) wrote, "Women who grew up in an environment in which disability was highly segregated from everyday life and in which they themselves had little contact with individuals with disabilities, are now the primary caretakers of such individuals. With little experience and few role models these mothers take on the tasks of negotiating individualized service plans and integrating their children with disabilities into the mainstream society" (p. 89). I now see more clearly another reason why inclusion of students with disabilities is for the good of all the students. If, as children, they had shared some time with other children with disabilities, these mothers would most likely have been better prepared for their roles.

Diagnosis. Parents must learn of Down syndrome before they can cope with and accept it. Conversations about this topic were among the most emotional parts of all the interviews. Each of the woman told of hearing the news presented in a seemingly insensitive manner. To provide perspective, however, a comment from Anne is worth repeating here. I had told her I might write about sharing the diagnosis of Down syndrome. "Yeah that's a good idea. But I don't think anything would ever be right though."

The mothers described many painful memories of learning of the diagnosis. One mother was told over the phone, when she was alone. Another was left alone after she was told. In Kelly's instance, medical professionals came in and talked about the diagnosis while her mother, who hadn't yet been told, was in Kelly's room. And you will recall that Liz was questioned about her alcohol use during her pregnancy.

These births occurred in 2007 and 2008; the lack of sensitive handling of the diagnosis speaks to the lack of consistency, comfort, and familiarity with children with disabilities in our society, and underlying attitudes toward persons with disabilities.

On its website, NDSS (2010) provides suggestions for healthcare providers, *Presenting the Diagnosis.* Some of their ideas include:

> -If at all possible, give a prenatal diagnosis in person rather than over the telephone.
>
> -...tell both parents together. Otherwise, the mother will have to tell the rest of the family by herself.
>
> -A health care professional with a relationship to the mother should give the diagnosis.
>
> -... there may be clear indications of Down syndrome in the last stages of delivery. It is best to wait until the mother is in the recovery room to inform.
>
> -...do not express an opinion about the parents' situation. Ask what information they would find most helpful. Give resources: support groups, early intervention centers and literature.
>
> -Make sure to discuss the diagnosis and field questions from the parents on more than one occasion. Parents may not be able to retain all the information in one sitting...(*Information for Health Care Professionals, p 3).*

There is a decided gap in the literature and expert knowledge base, as that knowledge base translates into practices through and across various segments of our society. These women were not given helpful information. Medical care providers were clearly uncomfortable with the news, and many presented the news as a tragedy.

Medical complications. Three of the children have had major medical conditions, requiring hospitalizations. Tate, Liz's little boy, did not have any hospitalizations. He did have pneumonia six times in his first year, with many trips to the emergency room, sometimes more than one in a night. Liz demonstrated understanding of what her little boy could have gone through. "He's really healthy. One ear infection and pneumonia is all he has had." The medical complications of the other children affected family life, maternal career and education in addition to the child's comfort, education and behavior.

For three participants, medical complications started early on, as their children needed neonatal intensive care and/or hospitalization after birth. Those children were all hospitalized two or more times in their first year. One child's major medical need is apparently not related to Down syndrome, but his communication and behavior difficulties have made the condition more difficult to diagnose and treat than it might have been otherwise. Difficulty in diagnosing specific illnesses in a child with Down syndrome is likely when considering that Kumin (1994) found that of parents of children with Down syndrome below age four, almost 60% of them reported that their children frequently had difficulty being understood.

The worry, stress and uncertainty were not unexpected consequences of these complications. I also found that health insurance needs were a factor in career choices of at least one participant and another participant's husband.

The children's illnesses had a greater impact on the day-to-day lives than the Down syndrome. It appears that systems of support and education need to always be cognizant that Down syndrome involves more than developmental delays, and consider the recurrent illness, chronic conditions and hospitalizations found with these co-occurring health-related issues.

Information for health care providers is readily available on the NDSS website, which offers *Information for Health Care Providers (2010)* and *Down Syndrome Health Care Guideline*s (2011.) *Information for Health Care Providers* includes the information presented earlier in this chapter regarding diagnosis as well as more general information and a video presentation for health care providers giving suggestions for presenting the diagnosis. In another part of the NDSS website, a section entitled *Healthcare Guidelines - Health Care Guidelines Downloadable PDF* (p.3) presents suggestions for physicians for neonatal care that include screening for the type of gastrointestinal blockage that Anne’s son had. Based on the stories of the participants, it appears that the NDSS information had not filtered down to the person providing neonatal care for Sonny.

Support. The unmistakable physical and genetic evidence of the condition appeared to facilitate the process of accepting their child’s disability. For these women, denial was short lived. These women all understand that Down syndrome does not have a cure and that it is a life-long disability. The realities of the care needed by their three, four and five-year-olds are paramount, and they have all embraced these responsibilities. The charm and personality of their children, combined with such things as faith, humor, determination, extended family, knowledge and support, emerged as strong features in their process of accepting and coping.

Membership in a community of other parents of children with Down syndrome appeared to be important and meaningful to some degree with all participants. The three Montana women all spoke of the Buddy Walk as an important event for them, finding community and a funding resource for some of their children’s individual needs.

Relationships with significant others, family members and friends are challenged by the schedule, responsibility, worry and care needed by children in general. Having a child with a lifelong developmental disability exacerbates these challenges. My participants shared numerous examples of these challenges. Each woman also spoke of the stress that came with the amount of support and therapy needed by their child. They all have, in various ways, engineered their social life to fit with their responsibilities

Two of the women significantly restrict their social lives, one by only seeing friends in her own home late in the evening; the other by focusing only on her child in her home on the days she cares for him. One mother simply chooses not to see people who aren't accepting and welcoming. Another mother has rebuilt much of her social life around other families who have children with Down syndrome or other disabilities. This reflects the findings of Seltzer and Greenberg (2001). They found that parents of a child with a developmental disability have several characteristics that distinguish them from parents of typically developing children, including lower rates of social participation.

Immediate family structures also appeared to make a difference in support. Two women were married, with extended family members nearby and seemed to have fewer difficulties related to their child's care than the two women who were single parents. This additional individual, personal support for these mothers and their children appeared to be a major aid in coping.

Three of the participants spoke of finding useful information, camaraderie and support through the internet. For three of the women, the support offered by a family support specialist or early intervention teacher was embraced, with strong, almost familial bonds growing between the mothers and their support personnel. This type of positive relationship was more difficult for the other mother, who did not see much of that potential support source- nor was she able to meet and collaborate with support personnel much (perhaps due to the time constraints of her job).

Career. Three of the participants had at least one child by age twenty. For these three women simply being a mother at a young age may have had had a greater impact on their future plans than did being a mother of a child with Down syndrome.

Two women resumed their careers after having their child with Down syndrome. Kelly (age 34) was established in a professional career as a para-legal, Liz (age 32) owns her own chiropractic practice. Continuing on their career paths has not been easy, blending demanding professions with childcare, educational and therapeutic needs for their children with Down syndrome. For the other two women, career or higher education, and in one case, high school were reshaped or delayed because of their responsibilities. Anne and Candace were both younger, having their first children at ages 15 and 20, and had not yet developed clear career paths. While all these women met my inclusionary criteria for "young" for the study (aged 35 or younger)—the time each had her first children and the birth of their child with Down syndrome made a difference in delaying career development.

The levels of thought given to their own future varied among the women. Their children were still very young. Anne plans to go to college. Candace is content to focus on home and family at this time. Kelly had planned to complete college and go to law school. That plan changed in part because of the time demands of motherhood with her first child, who does not have Down syndrome. These women are busy and their children are in a stage of life requiring significant care. It is difficult for the mothers without established professions to find time to do any significant preparation for the future, such as higher education or starting a business.

In addition to difficulty in finding appropriate childcare, there is another important factor affecting the career status of parents of children with Down syndrome or other disabilities. Early education and supports are typically home-based, requiring parent or care-giver participation. This may put additional pressure on the mothers to work at less demanding jobs, or put off further higher education. As Anne said, “What doesn’t need to happen is me going back to school when he is not in school yet, because I need to be able to focus on it...there’s not enough time to focus.”

A surprising finding from my study is that three of the mothers felt that childcare outside of family did not work for them-- or would not work for their children with Down syndrome. The fourth mother had found good childcare while she worked, although she said that this was difficult. She noted that, because of some of her child’s behaviors, she did not trust anyone but family for any other babysitting.

This created more of a challenge in that respect than faced by many families. Difficulty finding appropriate day care is an instance where the factor of Down syndrome is more impactful than simply having a child at a young age. As Skinner and Weisner (2002) found, the high level of care needed by some children with disabilities can lead to stress in getting adequate childcare and workplace flexibility. “Even if the child is in a school setting, caregivers are still ‘on call’ for medical and behavioral emergencies” (p.310). This also speaks to the knowledge-practice gap in provision of consistent, accessible quality services for children with disabilities and their families, despite the fact that IDEA mandates quality services for children with identified disabilities beginning at birth. Training and support for child care for children with disabilities does exist in Western Montana. For example, Child Care Plus+: The Center on Inclusion in Early

Childhood provides a variety of support and information for quality childcare for children with disabilities. Three of the participants live in Western Montana. They did not access this service and childcare remained a significant barrier.

Personal growth. All four women described deep personal growth and maturation, in response to having and raising their children, particularly their children with Down syndrome. They gained in confidence, maturity and the ability to see value in persons with disabilities. They gained in specialized skills and knowledge and, to varying degrees, confidence. Candace’s words show the philosophy she has developed. “We try to put everything in containers and think everything should be the same so that we know what to expect. Things become beautiful when you accept them how they are.”

Living in a child focused era. The participants faced an unexpected challenge in the reaction their friends had to Down syndrome and their children. Some friends saw the disability and label before they saw the child and reflected a bias against both. All the mothers mentioned reacting to and navigating that perceived lack of societal value for persons with disabilities, especially Down syndrome. Each of my participants mentioned that their lives were very different from the lives of many other young mothers as they have had to redefine their expectations about their children.

The availability of prenatal genetic testing for Down syndrome and resulting decisions regarding choice were emotional topics during the interviews with all participants. In the words of Liz:

> Yeah Like our kids aren’t “good enough” (with a put down tone of voice) or ‘Why would you want a kid like this?’ I think that part of the problem is that the

> medical community paints it as a scary thing… already the Down syndrome termination rate with the prenatal diagnosis is over 90% which is sad, terribly sad.

Liz's comment is reinforced by results of a study by Mansfield, Hopfer and Marteau (1999), who found a 92% termination rate for Down syndrome.

Sub-themes

Trute, Nenzies, Worthington, Reddon and Moore (2010) found that, even in two parent families, the mothers tend to meet the special caring demands of their children with disabilities. They found that the "higher the level of positive appraisal that mothers can identify that childhood disability has brought to the life of the family (e.g., improved family values, sensitivity to others in the community, heightened spirituality, etc.), the higher the overall adjustment of the family"(p.41). Each participant was unique in personality and approach to life. I found that the positive sub-themes of humor, determination, gratitude, faith and leadership reflected these individualities yet were also recurrent subthemes across the participants-- among very different people.

Concern, caution and child's behavior. Behavioral difficulties and medical complications were roadblocks to coping and they became major factors in one mother's life. These findings reflect the work of Eisenhower, Baker, and Blacher (2005), who stated, "Interestingly, greater stress and negative interactions appear to be more attributable to the increased levels of behavior problems among children with developmental delay than to the presence of developmental delay itself" (p.659). It appeared to me that the caution and avoidance that Kelly used in response to her little boy's behavior may have increased the problem.

Participants’ Long -Term Plans for Their Children

The future is far away for these mothers and for the most part, not something they often consider. As Anne said “I try not to think about it.” They understand that their children will always need some level of care. They expressed hopes for some sort of postsecondary education for their children

While all the participants see the possibility of semi-independent living, two of the mothers hope their children will always live with them. One of these mothers dreams of creating a family-style group living situation for several adults with disabilities in a farm setting.

All the mothers plan for employment for their children, although only Candace had any specific ideas. She thinks Max could one day make frames for her photography business. As I mentioned in Chapter Two, The National Council on Disabilities (2007) published suggestions and recommendations for incorporating persons with disabilities into a wide spectrum of modern life. While important possibilities do exist, the reality is far less than optimum. The Bureau of Labor Statistics (2010) reported that only 19.2 % of persons with disabilities were employed. Eight of ten persons with a disability are not in the workforce at all.

Study Limitations and Recommendations for Future Research

My study was limited in that I conducted in-depth interviews with just four participants, each of whom was a young mother of a young child with Down syndrome. While this afforded a window into their lived experiences to some extent, it also raised other questions. For example, additional studies might explore socio-economic status

(SES) in relationship to coping abilities in young mothers with children with disabilities, or the explicit impact of birth order, and the age of first and subsequent pregnancies on adjustment/coping skills. Another researcher might also replicate this study with women from other parts of the country, particularly in different demographic situations (less rural).

Another question raised is the impact on young fathers. They also have careers, backgrounds and lives that may be shaped by their children with Down syndrome. Hatton, Emerson, Graham, Blacher and Llewellyn (2010) studied families of children with cognitive delay at nine months, three years and five years. They found that the children "were significantly less likely than other children to be living in households with both biological parents or in households where the mother was married at all time points." (p.23.) They also found the differences in family composition accounted for by differences in socioeconomic circumstances. Porette, Jr., Meadon and Doubet (2010) reported that need, stating that "great challenges remain in trying to understand, include and provide family-centered services to fathers of young children with disabilities. The lack of research and research-based strategies for these fathers may result in an ongoing reliance on status quo perceptions and previously employed family strategies, which may have the unintended effect of minimizing fathers' involvement in service delivery." (p.387)

My study also shows that support and service coordination for families of children with Down syndrome are of vital importance. Based on the experiences of these participants, it appears that creative models of support that are tailored to the needs of divorced or separated parents, young, single mothers, as well as mothers and fathers with full-time employment are needed. Moreover, because of the high possibility of recurrent illnesses and hospitalizations for young children with Down syndrome, schools and service providers could consider designing programs that allow the child to access as much education as possible when he or she is healthy.

Lessons Learned by the Researcher: Interaction, Reaction

I thoroughly enjoyed every minute of my interactions with these young women, even when we were both wiping away tears. Although I allowed the conversations to go where they took us, I did introduce topics. I found myself telling parts of my story to them, sharing some of my values. My half of the conversation may have influenced their answers. They knew that I am a speech language pathologist, a preschool educator and I told them all about my brother Steve who has Down syndrome. These features may have also been influences. I was somewhat successful in controlling my recurring impulse to give them advice.

Immediately after each interview I wrote extensive field notes, chronicling nuances of conversation, gestures, emotions and other nonverbal communication, as well as my reactions and judgments to what we had shared. This helped me to keep my therapist and maternal voices in check, for the most part. I felt I had achieved some sort of balance as an interviewer when Candace, while happily describing some of her home teaching techniques said, “Therapy at home stuff is not home work. It’s not difficult...I don’t torture him like the therapists have to do.” She glanced at me and, perhaps remembering who I was, quickly said “You know for his benefit of course.”

As noted, I am a mother of five adult children. These four women are all in the age range of my kids. I expected that would give me a connection to them and hopefully some credibility with them. I didn’t expect to feel so maternal toward them, but that was part of my reaction. I admire them. I really like them. Their resilience, love, humor and skill affirmed that I can have high expectations from the mothers with whom I work, and gave me hope for the new generation of parent advocates for children and youth with disabilities.

From these women I was reminded that mothers want clear information, but they are ready for different messages at different times, with honesty at all times. In my work, it is my responsibility to determine the best way to give each that information… but perhaps more importantly, to be open to what I can learn from each of the parents with whom I work. Teaching and learning are reciprocal.

I learned that mothers may need my approval as an education professional to just have fun with their child, not to feel like they have to always “work” with them.

I was reminded that a mother may have been up all night with an illness, or awake listening to her child’s breathing while sleeping so she can she can safeguard his life and understand his sleep disorder. A missed appointment is not all about my busy schedule.

I learned that sometimes I have to listen hard, that emotionally-loaded or important topics might cause a mother to give mixed or convoluted messages.

I learned that, while helping their child grow and develop is an important thing to mothers, it isn’t the only important thing. Their personal hopes and dreams are vital.

I also learned, to my sorrow, that going to school in a time when all children with disabilities are entitled to free and appropriate public education doesn’t necessarily mean that so-called typical students have any familiarity or comfort with them—inclusive education is as inconsistent and elusive in practice as accessible childcare and sensitive treatment of the diagnosis of disability. As special education professionals and family members of persons with disabilities, we still represent the exception in terms of our worldview, knowledge-base and firsthand experience with persons with disabilities, and our vision of what is possible for them.

Conclusion

The stories of these four young mothers told to me over a few short months while their children with Down syndrome were still preschoolers have afforded a glimpse into the processes that have affected and shaped their learning of the diagnosis of disability, learning to cope, and the impact of that disability on their day-to-day lives. I have examined the intersection of some of the most salient issues in their lives at this time: being young themselves, and still navigating their own relationships, lifestyles, and career choices; meeting the needs of their other children and family members while learning about and caring for their children with Down syndrome; and confronting bias in their immediate social circles and local communities, gathering support, and beginning to grow into advocates for their children. I have also presented evidence that there still exists a profound gap between expert knowledge, legal supports, and actual practices and widespread beliefs about the value of persons with disabilities in our society.

The value of narrative is in lending depth and context to the statistics. The emotions expressed through these narratives serve to personalize the impact studies. The shared experiences provide insights into what it really is like to be a young mother of a child with Down syndrome, a qualitative study done well offers a glimpse and commentary, and raises as many questions as those answered.

In closing, I am reminded that while many of the issues these women have faced have been difficult, there have also been benefits. As Liz: told me, “I know we have different challenges than other families but I also know that we have different blessings than other families that they can’t experience.”

I will give Anne the last word:

> It’s fabulous. It’s amazing. I don’t think that I even had to rise to the occasion or anything like that...For some people in some ways it could be like that. But I don’t feel like that all. I just think of it as just part of my life I am really glad.. It’s a good part of my life.

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Appendices

Appendix 1 Institutional Review Board (IRB) Checklist..a

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Appendix 1 a

IRB Protocol No.:

Form RA-108
(Rev. 7/08)

THE UNIVERSITY OF MONTANA-MISSOULA
Institutional Review Board (IRB)
for the Use of Human Subjects in Research
CHECKLIST / APPLICATION

At The University of Montana (UM), the Institutional Review Board (IRB) is the institutional review body responsible for oversight of all research activities involving human subjects outlined in the U.S. Department of Health and Human Services Office of Human Research Protection (www.hhs.gov/ohrp) and the National Institutes of Health, Inclusion of Children Policy Implementation (http://grants.nih.gov/grants/funding/children/children.htm).

Instructions: A separate registration form must be submitted for each project. IRB proposals are approved for three years and must be continued annually. **Faculty members** may email the completed form as a Word document to *IRB@umontana.edu*. **Students** must submit a hardcopy of the completed form to the Office of the Vice President for Research & Development, University Hall 116.

1. Administrative Information

Project Title: Life Experiences of Young Women Who Have Children ,With Down syndrome.	
Principal Investigator: Janice Driscoll Nugent	
Email address :Janice.nugent@mso.mt.edu	
Work Phone: 720-2400-5031	Cell Phone: x
Department: C&I	Office location: 1700 South Avenue West, room 209

2. Human Subjects Protection Training

(All researchers, including faculty supervisors, must have completed a self-study course on protection of human research subjects ***within the last three years*** *(www.umt.edu/research/irb.htm) and be able to supply the "Certificate(s) of Completion" upon request.*

NAME and DEPT.	PI	CO-PI	Faculty Supervisor	Research Assistant	DATE COMPLETED Human Subjects Protection Course
Janice Nugent	☐	x	☐	☐	11-12-08
	☐	x	☐	☐	
	☐	x	☐	☐	
	☐	x	☐	☐	
	☐	x	☐	☐	
	☐		x	☐	

3. Project Funding

Is grant application currently under review at grant funding agency? ☐Yes *(If yes, cite sponsor on ICF if applicable)* xNo		Has grant proposal received approval and funding? ☐Yes *(If yes, cite sponsor on ICF if applicable)* xNo		
Agency	Grant No.	Start Date	End Date	PI
Is this part of your thesis or dissertation? ☐xYes		If **yes**, date you successfully presented your proposal to your committee: 10-27-09		

For UM-IRB Use Only

IRB Determination:

_____ Approved Exempt from Review, Exemption # ____ *(see memo)*
_____ Approved by Expedited/Administrative Review *(see* ***Note to PI***)*
_____ Full IRB Determination
_____ Approved *(see* ***Note to PI***)*
_____ Conditional Approval *(see memo)* - IRB Chair Signature/Date: ___________________________________
_____ Conditions Met *(see* ***Note to PI***)*
_____ Resubmit Proposal *(see memo)*
_____ Disapproved *(see memo)*

*** Note to PI: S**tudy is approved for one year. Use any attached IRB-approved forms (signed/dated) as "masters" when preparing copies. If continuing beyond the expiration date, a continuation report must be submitted. Notify the IRB if any significant changes or unanticipated events occur. Notify the IRB in writing when the study is terminated

Final Approval by IRB Chair: _________________________________ Date: _______________ Expires: ______________

4. Purpose of the Research Project (not to exceed 500 words): Briefly summarize the overall intent of the study. Your target audience is a non-researcher. Include in your description a statement of the objectives and the potential benefit to the study subjects and/or the advancement of your field. **Generally included are literature related to the problem, hypotheses, and discussion of the problem's importance.**

The National Down Syndrome Society reports that, although older mothers are at greater risk for conceiving a child with Down syndrome, 80% of babies born with Down syndrome today are to mother's age 35 or less. The presence of the child with Down syndrome presents some unique challenges, stresses, satisfactions and joys not faced by other mothers of children ages two through five. Young women below age thirty five are in a life phase that may include completing education, developing career goals and a career, developing and enhancing relationships, making financial decisions. The mother of the child with Down syndrome works to prioritize and balance time between her own needs, the needs of her family and the needs of her child with Down syndrome. Crnic, Friedrich, and Greenberg (1983) conceptualized the child with an intellectual disability as a "stressor in the family system" which could bring about positive or negative effects.

Lott. I. T., et al., (2007)state that "Demographically represented populations will also extend our abilities to understand not only the impact on the family of having a child with DS but also how families can be positioned to improve the environment for individuals with the disorder." Studies have reflected on the situations of economic status, family size, age of child, marital status, type of disabilities and other factors. There appears to be a lack of research focusing on young mothers and more specifically, young mothers of children with Down syndrome.

Using data gained through open ended interviews, this qualitative study will explore and analyze the life stories of up to four women ages thirty five and under who have children ages two through five with Down syndrome. Their narratives will help to gain information and insight into these life experiences of these young mothers.

Reference List

National Down Syndrome Society –Down syndrome Fact Sheet. Retrieved May 6, 2009 from http://www.ndss.org/

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5. Subject Information:

a. Human Subjects *(identify, include age/gender)*:

All human participants will be women age 35 or below, but over eighteen who have young children with Down Syndrome. .All are female. All are over eighteen.

b. How many subjects will be included in the study? Up to 4

c. Are minors included *(under age 18, per Montana law)*? ☐ Yes x No
If yes, specify age range: to

d. Are members of a physically, psychologically, or socially vulnerable population specifically targeted?
☐Yes xNo
If yes, please explain why the subjects would be considered physically, psychologically or socially vulnerable:

e. How are subjects selected or recruited? What is inclusion/exclusion criteria? *(Attach copies of all flyers, advertisements, etc,. that will be used in the recruitment process as these require UM-IRB approval)*

Participants will refer themselves to the study. The researcher will request permission from the administration of Missoula County Public Schools to inform special education teachers of the research study, asking them to inform eligible participants of the study by flyer. Leaders of three organizations: Western Montana Child Development Center, Parents Lets Unite for Kids and Missoula Buddy walk will be asked to share the flyers with eligible parents.
The inclusion criteria is:
Female
Age 35 or under
Has a child age two through five who has Down syndrome.
Letters to agencies are attached.

f. How will subjects be identified in your work papers and in your publications: *(may check more than one)*

☐ Identified by name and/or address or other
(Secure written [e.g., ICF] or verbal permission to identify; if risk exists, create a confidentiality plan.)

x Confidentiality Plan
(Identity of subjects linked to research, but not specific data [e.g., individuals identified in ICF but not included in publications]; identification key kept separate from data; or, data collected by third party [e.g., SurveyMonkey] and identifiers not received with data.)

☐ Never know participant's identity
(An ICF may be unnecessary [e.g, anonymous survey; identity never tied to data] ***unless*** *project is sensitive or involves a vulnerable population.)*

g. Describe the means by which the human subject's personal privacy is to be protected, and the confidentiality of information maintained. If you are using a Confidentiality Plan (as checked above) include in your description a plan for the destruction of the confidential materials.

The human subject's personal privacy will be protected and the confidentiality of information maintained by assigning a pseudonym to each participant and labeling interview data with the pseudonym. After transcription all interview data will be identified by pseudonym The original recordings and all information containing the participants' names will be deleted electronically and shredded if on paper.

h. Will subject(s) receive an explanation of the research – separate from the informed consent form (if applicable) – before and/or after the project? xYes *(attach copy)* ☐ No
Note: subjects will receive a copy of the completed research.

6. Information to be Compiled

a. Explain where the study will take place *(physical location not geographic. If permission will be required to use any facilities, indicate those arrangements and attach copies of written permission):*

Interviews will be conducted in homes of the participants or another location of their choice.

b. Subject matter or kind(s) of information to be compiled from/about subjects:

The subject matter will include experience and emotions regarding having a child with Down syndrome, family and career development, benefits and challenges of having a child with a disability. The interviews will be open ended. The information will be verbal responses to interview questions.

c. Activities the subjects will perform and how the subjects will be used. Describe the instrumentation and procedures to be used and kinds of data or information to be gathered. **Provide enough detail** so the IRB will be able to evaluate the intrusion from the subject's perspective:

Participants will be interviewed and will give narrative, subjective and personal information regarding their experiences as young mothers of children with Down syndrome.

d. Is information on any of the following included? *(check all that apply)*:

☐ Sexual behavior
☐ Drug use/abuse

☐ Alcohol use/abuse
☐ Illegal conduct

☐ Information about the subject that, if it became know outside the research, could reasonably place the subject at risk of criminal or civil liability or be damaging to the subject's financial standing or employability.

e. Means of obtaining the information *(check all that apply)*:

☐ Field/Laboratory observation
x In-person interviews/survey *(attach questionnaire/ instrument)*

☐ Tissue/Blood sampling *(IBC Application must be submitted to Institutional Biosafety Committee)*
☐Telephone interviews/survey *(attach questionnaire/ instrument)*

☐ Measurement of motions/actions
☐ On-site survey *(attach questionnaire/ instrument)*

☐ Use of standard educational tests, etc.
☐ Examine public documents, records, data, etc.

☐ Mail survey *(attach questionnaire/instrument)*
☐ Examine private documents, records, data, etc.

☐ Medical records *(require HIPAA form)*
☐ Other means *(specify)*:

f. Will subjects be *(check all that apply):*

☐ Videotaped xAudio-taped ☐ Photographed N/A

(securing an additional signature is recommended on consent/assent/permission forms)

Explain how above media will be used, who will transcribe, and how/when destroyed:

The interviews will be digitally recorded. The researcher will transcribe the recordings.

g. Discuss the benefits of the research, if any, to the human subjects and to scientific knowledge *(if the subjects will not benefit from their participation, so state)*:

The participants may or may not benefit from their participation.

h. Outline, **in detail**, the risks and discomforts, if any, to which the human subjects will be exposed *(such deleterious effects may be physical, psychological, professional, financial, legal, spiritual, or cultural.*

Some research involves violations of normal expectations, rather than risks or discomforts; such violations, if any, should be specified):

The human participants will possibly be exposed to personal emotional discomfort or embarrassment because of the nature of the information they may give.

i. Describe, **in detail**, the means taken to minimize each such deleterious effect or violation:

Questions will be presented in a manner that allows participants to choose not to answer a particular question. Participants may stop the interview at any time.

7. Informed Consent

An informed consent form is usually required, unless subjects remain anonymous or a waiver is otherwise justified below. *(Templates and examples of Informed Consent, Parental Permission, and Child's Assent Forms are available at* http://www.umt.edu/research/irb/irbforms.htm *).*

- A copy of the consent/assent/permission form **must be offered to all subjects**, including parents/guardians of subjects less than 18 years of age (minors).

- Use of minors
    - All minor subjects (under the age of 18) must have written parental or custodial permission.
    - All minors from 10 to 18 years of age are required to give written assent.
    - Assent by minor subjects: All minor subjects are to be given a clear and complete picture of the research they are being asked to engage in, together with its attendant risks and benefits, as their developmental status and competence will allow them to understand.
    - Minors less than 10 years of age and all individuals, regardless of age, with delayed cognitive functioning (or with communication skills that make expressive responses unreliable) will be denied involvement in any research that does not provide a benefit/risk advantage.
        - Good faith efforts must be made to assess the actual level of competence of minor subjects where there is doubt.
        - The Minor Assent Form must be written at a level that can be understood by the minor, and/or read to them at an age-appropriate level in order to secure verbal assent.

- Is a written informed consent form being used? x☐ Yes *(attach copy)* ☐ No (*justify below)*

  To waive the requirement for a written informed consent (ICF), describe your justification:

- Is a written parental permission form being used? ☐ Yes *(attach copy)* x☐ No
  (If yes, will likely require minor assent form)
- Is a written minor assent form being used? ☐ Yes *(attach copy)* x☐ No
  (If yes, will likely require parental permission form)

The Principal Investigator agrees to comply with all requirements of The University of Montana-Missoula IRB, the U.S. Department of Health and Human Services Office of Human Research Protection Guidelines, and NIH Guidelines. The PI agrees to ensure all members of his/her team are familiar with the requirements and risks of this project, and will complete the Human Subject Protection Course available at http://www.umt.edu/research/irb.htm.

Principal Investigator's Statement

I certify that the statements made in this request are accurate and complete. I also agree to the following:

- If I receive approval for this research project, I agree to inform the IRB in writing of any emergent problems. I further agree not to proceed with the project until the problems have been resolved.
- I will not make any significant procedural changes to procedures involving human participants without submitting a written amendment to the IRB and will not undertake such changes until the IRB has reviewed and approved them.
- It is my responsibility to ensure that every person working with the human participants is appropriately trained.
- I will not begin work on the procedures described in this protocol until I receive notice of approval from the IRB.
- I will keep a copy of this protocol (including all consent forms, questionnaires, and recruitment flyers) and all subsequent correspondence.

Signature of Principal Investigator: ____ Date: ___________________

NOTE: I AM AWARE that electronic submission of this form from my University email account constitutes my signature.

Students Only (students must submit hardcopy of IRB application complete with <u>original</u> signature of faculty supervisor)

Faculty Supervisor: ____ Date: ________________

Signature: ____

Department: __________________________________ Phone: _________________
Email:________________________________

(My signature confirms that I have read the IRB Application and attachments and agree that it accurately represents the planned research, and that I will supervise this research project).

Appendix 2
SUBJECT INFORMATION AND CONSENT FORM

Study Title: Life Experiences of Young Women Who Have Children With Down Syndrome, Ages Two Through Five

Project Director(s):

Janice Nugent, Doctoral Candidate, University of Montana.
Dissertation Co-Chairperson: Gail McGregor, Ed.D. School Of Education, University of Montana, Research Professor and Project Director / Principal Investigator of the Rural Institute on Disabilities
243-2348
Dissertation Co-Chairperson: Morgen Alwell, Ed.D. School Of Education, University of Montana, Curriculum & Instruction
Asst Professor, Curriculum & Inst, 243-5512

Special instructions:

This consent form may contain words that are new to you. If you read any words that are not clear to you, please ask the person who gave you this form to explain them to you.

Purpose:

If you agree to take part in this research study, you will be asked a series of questions relating to your situation as a mother of a child with Down syndrome.

The interviews will take over several sessions, which will allow both the interviewer and interviewee to recall the first interview and ask further questions or clarify some issues. The interviews will take place at your home or a location of your choice.

The length of the sessions will be determined by your needs, but will not exceed two hours. Total interview time will be at least three hours up to as many as ten hours.

Risks/Discomforts:

There may be some discomfort for those contributing to this study, as personal and emotional issues will be discussed. Risk to participants is minimal. The discussions will cover personal and emotional topics that may lead to some personal discomfort. You may stop an interview at any time. You may ask to skip any question.

Here are some contact persons and websites designed to support parents of children with Down syndrome that you may contact if you want to discuss personal and emotional issues :

Benefits: There is no promise that you will receive any benefit from taking part in this study. The scientific knowledge base about the experience of mothers of children with Down syndrome will be increased and expanded. Possible areas of future research may be highlighted.

Confidentiality: Your records will be kept private and will not be released without your consent except as required by law.

Only the researcher and her faculty supervisor will have access to the files.
Your identity will be kept confidential. Pseudonyms will be used for you and your child.
The data will be stored on the researcher's personal computer or in a locked file cabinet.
Your signed consent form will be stored in a cabinet separate from the data.
The digital recording will be transcribed without any information that could identify you. The recording will then be erased.

Compensation for Injury

Although we believe that the risk of taking part in this study is minimal, the following liability statement is required in all University of Montana consent forms.

In the event that you are injured as result of this research you should individually seek appropriate medical treatment. If the injury is caused by the negligence of the University or any of its employees, you may be entitled to reimbursement or compensation pursuant to the Comprehensive State Insurance Plan established by the Department of Administration under the authority of M.C.A., Title 2, and Chapter 9. In the event of a claim for such injury, further information may be obtained from the University's Claims representative or University Legal Counsel. (Reviewed by University Legal Counsel, July 6, 1993)

Voluntary Participation/Withdrawal:

Your decision to take part in this research study is entirely voluntary.
You may refuse to take part in or you may withdraw from the study at any time without penalty or loss of benefits to which you are normally entitled.
If you decide to withdraw, you may leave the study for any reason.
You may be asked to leave the study if the study is terminated.

Questions:

You may wish to discuss this with others before you agree to take part in this study.
You may contact the Principal Investigator at any time: Janice Nugent, 728-2400 extension 5031, or 728-0823
If you have any questions about the research now or during the study contact: Dr. Gail McGregor at 243-2348 or Dr. Morgen Alwell at 243-5512
If you have any questions regarding your rights as a research subject, you may contact the Chair of the IRB through The University of Montana Research Office at 243-6670.

Statement of Consent:

I have read the above description of this research study. I have been informed of the risks and benefits involved, and all my questions have been answered to my satisfaction. Furthermore, I have been assured that any future questions I may have will also be answered by a member of the research team. I voluntarily agree to take part in this study. I understand I will receive a copy of this consent form.

____
Printed (Typed) Name of Subject

______________________________________ _________________________
Subject's Signature Date

Statement of Consent to be digitally recorded.
I understand that audio recordings may be taken during the study.
I consent to being audio recorded.
I understand that audio recordings will be destroyed following transcription, and that no identifying information will be included in the transcription.

______________________________________ _________________________
Subject's Signature Date

Appendix 3
Initial Interview Questions

1. Tell me about your family.
2. What was your knowledge of or experience with Down syndrome before your child was born?
3. Tell me how you learned of your child's Down syndrome.
4. Can you describe your feelings at that time?
5. How have these feelings changed?
6. Describe your child's health and physical condition during his or her first year?
7. What had you expected motherhood to be like?
8. How was it different than you had expected?
9. Did you have career or education plans before your child was born?
10. What are your career or education plans now?
11. How do you explain the changes if any?
12. Tell me about community, medical and educational supports you have experienced?
13. Tell me about personal, family religious or other support?
14. Can you think of supports you wish had been offered?
15. Can you describe some of the benefits and positive features involved with raising a child with Down syndrome?
16. Can you describe some of the difficulties involved with raising a child with Down syndrome?
17. What are the responsibilities of a mother of a child with Down syndrome?
18. What advice would you give to other mother's of children with Down syndrome?

Appendix 4

The Stories

Anne

Anne wears a delicate tattoo on her left wrist. The word “Brianna” is traced there in elegant script. The story of that name is part of Anne’s journey.

Anne’s parents divorced when she was four, an event that still carries hurt when discussed 22 years later. She developed a pattern of moving between her parents homes, living with her dad when she felt she needed support and stability and with her mom when she wanted more freedom. She spoke of:

> ...a lot of back and forth as a teen…I think my Dad was more stable…which was what I didn’t want at that time. (with a rueful laugh) I just wanted to do whatever I wanted to do…and so I lived with my Mom…But when I needed….like the whole pregnancy I needed the stable, loving…so I lived with my dad….Yeah Its interesting…my childhood.

She needed the stability of her father when she went through a difficult pregnancy when she was fifteen. She was ill almost every day. Too sick to go to school, she spent most days sleeping at her boyfriend’s house. Near the end of her pregnancy her doctor was having difficulty finding a heart beat and decided to do an amniocentesis. Anne was frightened and frantic. After the procedure, the doctor came in and told them that she had some good news and some bad news. The baby was the girl Anne had hoped for. The baby also had Down syndrome. She remembers hearing that if the baby lived it would be a vegetable. Medical people were telling Anne about possibilities of keeping her alive with extreme measures or letting nature take its course. Anne felt that this decision was presented in far too cavalier a fashion, as if it was an easy choice. She did decide to let nature take its course, but the process of that decision was very hard for her. Soon afterwards the baby went into further distress. Brianna died before she was born.

Anne finished high school, went back and forth between mom and dad and entered into another relationship, with her second pregnancy at age 18. After an easy pregnancy, her son Leon was born. She recalls that the only difficulty this time was getting an epidural, describing the process of getting the shot between two vertebrae as frightening and intrusive.

When Leon was about six months old Anne met Pat. He became close to Leon, developing a strong, nurturing relationship. Anne and Pat married. Anne started school at the University of Montana. The early stages of another pregnancy coincided with the early stages of her first semester at the University of Montana. She was again very sick and dropped out of school. In her words, “Yeah and I was pregnant with Sonny and it was horrible. Yeah. It was horrible and trying to go to school was horrible. And then I felt really guilty…that I couldn’t manage it.”

The pregnancy continued to be “horrible”. Near the end of the eighth month she felt different and asked for an ultrasound. At first her request was denied, but she did prevail and had one. Shortly after the procedure as she was grocery shopping she received a call from the doctor. She was told to drink lots and lots of water and come back in immediately. Her perception of something different was had been verified by the sonogram as a calcified placenta, with an extreme shortage of amniotic fluid. Anne faced the specter of losing another child. “So I am terrified and I am like ‘Come on people get it together what am I going to do? What are you going to do with my body?” But Sonny was born, calcified placenta, tiny chord and all, apparently healthy. Anne remembered the unpleasant epidural process of a spinal injection and had decided to deliver without an epidural. “The pushing was the part that I was like ‘Oh my God.’I didn’t know it was this bad.”

A few hours after Sonny’s birth, the doctor came in and told them Sonny had Down syndrome.

> She tried to say it in a very concerned way. Like we were. Like it was a sad thing. I think she even said like ‘I’m sorry.’ and I was like What? What? Don’t say you’re sorry. (Gestures a baby in her arms) This is my baby! Don’t say you are sorry.

Anne did not expect that news. “I had no idea, although it’s funny. I had no idea but as soon as he was born I was like Wow! He really looks just like his sister. I mean he just looked just like his sister.” Describing her emotions at that time, Anne said she was in shock.

> And I think I might have been sad too. I felt bad. I felt guilty too, real guilty. I felt guilty because it was my fault. This is weird to say, but still… I felt bad that… he had to be the way he was and that he had to suffer... and that I had …all because of something that I did, or whatever. Like I know it’s all irrational…but it’s easy for me to say I guess. But yah I was very much in shock.

Anne now understands that she had a fifty-fifty chance of having another child with Down syndrome. She hasn’t yet had genetic testing done, but doesn’t plan to have another child. “But I didn’t actually have to have the genetic testing done. It would have cost a lot of money and like blah blah blah. And I mean it wouldn’t have made a whole lot of difference.”

She nursed Sonny, finding him to be a very fussy baby. She was busy all the time. She opened up a home day care business, combining an income source with the opportunity to spend time with her two little boys. Sonny had the digestive problems that are often seen in children with Down syndrome, seeming to throw up everything he ate. When he was sixteen months old his health had deteriorated to the point that she had to close her business.

Anne and Pat had been in to the doctor many times, getting the answer each time that everything was normal. She did not agree and was frustrated.

> And then, when he was 16 months old, it had gotten so bad that he was like white, lethargic and dying! And in a lot of pain. He was in a lot of pain all the time. And we took him to the hospital and were like "We are not leaving until you figure this out. This is like a chronic condition and we are not leaving"...and so basically that's when they did figure it out. It took like a whole day. She was still trying to say that it was not a big deal.

It was a big deal. Sonny had a duodenal web, an actual intestinal blockage. His condition had been aggravated when Anne introduced solid foods, reaching a point of crisis. He had surgery and ten days of hospitalization.

Anne learned and grew through this experience. She came to trust herself more and more.

> The parents know. You've got to listen to the parents. And like we fired! We fired her and got a new pediatrician. It was necessary. And our pediatrician is

> great now. Not that she wasn't great. It is just that she wouldn't listen and dropped the ball...

Sonny thrived after his surgery. Anne kept up with speech and physical therapy in the home and cherished her weekly visits with her family support specialist. She considers her to be part of the family.

> Usually she would talk to me about what was going on and how she could help and what I am doing and stuff like that. Brainstorm things that I could be doing. Or should be doing. Or like resources, you know that might help with whatever. Like just basically there to support me. It's really great. It turned into like a friendship.

Leon went to Head Start and did well there. He is a great big brother to Sonny, started preschool when he turned three. He continued with his therapy appointments on the alternate days. Anne was busier than ever, keeping up with her family.

"It used to be me and Leon and Sonny and their dad, it used to be all of us. But now it's just the three of us." Pat and Anne divorced before Sonny turned four. This was very hard on her and she worries that she wasn't there for her family the way she should have been.

> But there were some really hard times where I didn't deal with it all that great. The kids, really not just Sonny, but Leon I don't know…he had a hard time with it. But now it's like, I don't know, they just adjusted really well.

Anne's brother is staying with her. She likes the fact that her boys have a male role model and that she has another adult to talk to. "He's the reason I get to shower, too."

She is very conscious of helping her children through the divorce process.

> And their dad is a great dad and he's also there and loving and nurturing and caring so they still have that, but not together. They still have that. It's still really hard. But they still have that. It's not like…unhealthy, which is what I had. It's a huge difference a huge difference. So they have adjusted quite well.

Anne currently cleans and paints vacant rentals, working for her uncle. He is able to allow her some flexibility. She prioritizes Sonny's meetings and therapies ahead of that work and, for the most part her uncle is fine with that. As she explains, "They are like 'Yeah, whenever you can get to it.' They know. They understand sort of. I don't think they 'understand'. But they understand." She finds a sense of achievement in taking a trashed apartment, cleaning it thoroughly and repainting. It is a necessary job and she feels proud of doing it well.

She is carrying the financial responsibility for her family at this time and is proud of making it work even if "barely…just barely." Anne plans to continue this job until her little boy gets into kindergarten, when she plans to go back to school.

> That's what not needs to happen is me going back to school when he is not in school yet. Because I need to be able to focus on it and Sonny's not able to…And his schedule is just…not enough time to focus. So I know that.

She has always planned to pursue a career that involved working with children and thinks that is her likely path, but, as she says "Who knows if it will end up being with children? I don't know like…I just know I want to go back…I think it will be ' fun' and it was not fun when I went. I am looking foreword to that." Anne continues to have busy days in a busy life. She finds support in her brother and dad, her friends and her own strength and optimism.

Candace

Candace is happy with her life. She has been honored and trusted with a child with Down syndrome. She is flattered and privileged that God sent this child to her. As she describes it,

> It's unbelievable to know that you are trusted with something so precious. I mean they are all precious but something that you ...didn't expect and something that you don't know how take care of. It's a great it's a great flattery.

Candace is close to her family. She lives next door to her sister. She thinks her family became closer than most because they grew up military brat style and moved almost every year. Her siblings became her friends and remain so.

> I moved around a ton and I liked that. I like meeting new people. I am close to my siblings. I was close to my family. Mainly I have lots of friends, but I am still really 'friends' with my mom and sister.

Her parents had her older brother when they were sixteen and seventeen. They both went to college while raising their children. They now work in a nearby town as special education teachers. "And so they are vibrant and really involved they are here all the time and like I say with my sister next door, they visit their grand kids all the time. It's really fun." With parents who are special educators, a sister who is a social worker and her aunt a special education administrator she is proud that she was the one entrusted with Max.

With all the moves came a variety of schools. She was in a peer buddies class, but really didn't have much contact with other students with disabilities. "They were there but they weren't there. I mean Zack was there, but he had his own special classroom. It was just him in that class. Isn’t that horrible, why couldn’t they be… isn’t that evil? “

Candace wanted to become a photographer and was able to attend photography school. She married early, at age twenty, and had a baby right away. Her introduction to motherhood was rugged. She had a very difficult pregnancy, feeling very sick all the time. The scent of grass made her so sick that she would even get sick when she saw the color green. Her baby, Ariel, was often sick and her care was challenging for the young woman.

> Ariel was in the hospital even more than Max was…She cried all the time…I said I will throw her out the window if I don’t get some help with her. Or I’ll jump myself because I am 20 years old myself and I didn’t know what to expect…We were constantly in the hospital with Ariel. Or I was constantly in the hospital with Ariel. My husband was on the road and so it was mostly just me and Ariel.

Candace’s marriage was a casualty of the endless crying, illness and stress. Ariel’s dad lives in a nearby town now, sees her often and they all get along well. Candace really hasn’t pursued her photography career. It became secondary to her calling of motherhood. She puts it like this,

> I will do my photography, God willing, because that is what I like to do. But I like to leave things open just because I am here for, you know what ever I need to be here for . So, if it’s for my kids that’s more joy than I even deserve. I know I have things that I want and I have plans that are tentative but I didn’t feel that I was missing out on anything. I mean a career can wait for me. For now I have kids and that’s good.

When Ariel was two Candace met and married her husband Dallas. Describing him, she says. “He really listens. He really is sweet and understanding.” Dallas wanted kids, but Candace was very reluctant because of all the difficulty she had with Ariel. They had been married for six or seven years when he was born.

> The reason I went for six or seven years that I would not have any more kids was because it was too hard and I was happy with just Ariel. The further I got from infancy with her the happier I was.

Her pregnancy with Max was again a difficult one. She remembers feeling different than she had with Ariel, and even sicker. She carried him to term. She tells it of the moments after birth.

> My husband was joking with me right after I had him and they were measuring him and weighing him and Dallas was watching as they wiped him off.
>
> My husband said he looked like a little Chinese baby, “Candace is there anything I should know?” Then I think he felt absolutely terrible. Horrible. He didn’t mean anything…But he did have a little puffy face and he was just so squinty eyed and so cute and he was very...limp.

Shortly after birth two things happened. The doctor told them that Max might have Down syndrome. Then Max started struggling to breathe and turned gray. His blood was too thick to go through his lungs and he needed a transfusion.

Candace could not get out of bed because she had received an epidural for pain control during the birth, something she still regrets. They took her baby from her. She urged Dallas to go with the baby and she lay there alone. After about twenty minutes she was able to reach her dad on her phone and told him about the health crisis and the possible Down syndrome. She was far more concerned about the blood condition. “I’d be like ‘Were not that old!’”

She eventually learned that the blood condition was not life threatening and that it would likely heal itself, as would the hole in his heart. She was frustrated at having to wait for three or five days to learn if he had Down syndrome for sure. She thinks it is ridiculous that they can’t tell the parents faster.

She was in an absolute panic, being emotional from just having a baby and nursing, but Dallas took it harder. “My husband cried and cried.” Candace doesn’t think he cried from sadness, but for the child that never was. He had talked her into having this baby and was envisioning a little boy who would eventually be a football or basketball player. “I mean you know things that Max won’t ever do.” He also wondered if Candace had done something wrong during pregnancy.

She didn’t feel like she could talk to anyone right away. She felt that things were kept super secretive. “I don’t know why people can’t talk about it. It’s a quiet thing. I felt like I couldn’t ask the nurse, ‘Do you know of any other moms who might want to talk to me?’”

She was in such an emotional state that she panicked when a nurse came in without a nametag, fearing that she was going to steal her baby. She thinks that emotional, hormonal state was part of the reason for her panic but she also thinks it was because she felt somewhat guilty because she had been frightened because the baby had Down syndrome and she did not know how to take care of him. “I was just like, can you imagine if I thought...’I don’t know what to do with this baby’ and then someone took your baby before you had a chance to settle in ?” That nurse helped calm her and Candace was able to tell her how she wanted to talk to other mothers.

She was overjoyed when a mother of a toddler with Down syndrome came in bearing congratulations, gifts and her little girl who was healthy: talking, walking and laughing. This visit helped her put a face on Down syndrome and she saw that it was a positive face.

Candace and Dallas were able to take Max home after two weeks, but they made three or four trips back to the hospital in that first year. He had RSV pneumonia and Flu. The hospitalization was easier than it might have been because he didn’t roll over until ten months and so was able to lie quietly with an IV and oxygen tubes. It wasn’t as bad as they thought it might be. They learned how to give him breathing treatments at home and have been able to discontinue these. His health issues were not as hard for Candace and Ariel’s had been.

Candace’s commitment to being a stay at home mom deepened. It was a necessity. Her dream of what a stay at home mom was had to change. She fits in ten hours of therapies and home training weekly and tries to make all of his awake time educational and therapeutic.

Candace has a family room that contains at least five large bins of toys. She has created a large mural of palm trees on one wall, with Halloween pumpkins instead of coconuts. The ceiling fan had become a giant mobile with lady bugs hanging from it, because they are stimulating for Max’s vision.

She was still nursing Max when he was two. She and Dallas were using birth control and so they were very surprised by another pregnancy. “We were really happy.

We were really happy. I cried because I hate being pregnant. I felt sorry for my self, but only for a minute."

Colette is an independent little girl. At one, it seems that she and Max are at similar stages. They are learning together. "She's my special helper." Still, Candace describes the dirty looks she gets when she has to leave one child in the car while bringing to other one in to an appointment.

Most of Candace's social life revolves around family. When she does something with friends it is always at their home. She doesn't see being a stay at home mom as any sort of entitlement. It is her duty to keep Max and Colette stimulated and learning all the time.

> I want to be in charge of him accomplishing his goals. I would feel so useless if I didn't get to help him reach his goals and if I didn't know how and we kind of just spent our days next to each other. I just think that's not enough. We see them more than anybody else and so we should work with them.

She is proud of him and enjoys helping him reach his potential. She loves to think of creative ways to teach them. She is happy and enthusiastic to tell about some of the many therapy ideas she has developed.

> Like there are lots of times Max likes to play by him self and I have to chase him and sit in front of...We have kind of figured a way for him to work in secret ways. [If I let him watch TV] I know he will stand up to watch it. I'm like "Let's get Max to stand up for 20 minutes and he will think he's playing alone."

Her family room contains more than the paper palm trees, the ceiling fan-mobile and all the toys. She proudly shows beautiful photographs that she has taken of family and friends. She has put her photography career on hold, but she does have a website and does some work, usually for friends, without pay. Her work is featured on the local Buddy Walk website, chronicling many of the participants.   As she says “I am in practice mode. I’m buffering my skills for later on. Someday we’ll emerge...maybe.”

Candace and Dallas visited a farm that provided both a home and employment to some persons with disabilities. She was delighted with the idea and can see a possibility of doing something similar.

Like many stay at home moms, Candace relies on Dallas for financial as well as emotional support. Dallas had just graduated in Radiology technology and was planning to work in a hospital setting. When Max was born he had to change that plan and continue working at Costco because some preexisting conditions would not be covered by insurance in a new job setting.

Sometimes the remarks of other people are hard for Dallas. Candace can deal with them in a more matter of fact manner. He is very happy when he sees older kids with Down syndrome who are doing well and are happy.

Candace feels that Max’s Down syndrome was harder for Dallas than for her. Although during the period of diagnosis he cried and cried, he has accepted it and moved on. Candace tells of a conversation with Dallas.

> “Candace it’s wonderful! Because, guess what, we don’t have to be those parents who…they say ‘Oh our baby isn’t a baby anymore.’ He’s still kind of like a baby you know. He still crawls and cries when he wants something.” So we like that we get to hang on to him and hold his little chubby hands... just a little while longer.

Parents of very small children know that they have a long way to go before the future arrives. Candace knows that Max may have a supported living arrangement, but hopes that he lives with her. If she is still in photography she thinks that he might have employment making frames for her. She knows that if he needed a home that her family members would fight over who got to have him. She wants him to feel like the blessing that he is and be wanted and needed. “Like I can’t imagine being a virgin and being told I am going to have the Messiah, but I can imagine God trusting me with Max which is something I couldn’t imaging a while ago…”

Kelly

In her early thirties, Kelly is calm and peaceful. She has a position as a paralegal for a respected law firm in a major Montana city. She grew up in a small Montana town in the late eighties and nineties. She didn't really have any experiences with other children with disabilities. As she said:

> My experience with kids with disabilities was way different from what it is now in school...You know they were always separated. There was a kid my age who kind of interacted with people. I think he just had some kind of slowness, but he still could hang out with you, but intelligence wise he just…He was in different classes. You just did not see him much. They weren't in classrooms with you. Some of them were, but I really didn't know if there was a certain intelligence level for all of them.

Perhaps because of lack of exposure, Kelly felt uncomfortable when she did see these children.   Again, in her words:

> You know I was almost afraid of saying hi to them or being around them because I didn't understand, or know…what they could understand and could comprehend. And I kind of equate that to older people who have dementia or something. You know...I am just afraid that I would say or do something dumb, I guess. It wasn't that I thought they were lower or anything. I just...if I don't know what someone's understanding level is I feel a little scared to communicate with them.

After high school she moved to a larger town and then went to a junior college. Her training whetted her interest in the law and she considered going to college and then to law school.

While in school she became pregnant, planning to graduate just before her baby was born. Almost two months before Nicki was due, Kelly developed pre-eclampsia. Her blood pressure skyrocketed and her liver almost ruptured. She had to have an emergency caesarian section. Her little girl was not mature and required hospitalization for 28 days in the neonatal intensive care unit.

Kelly went to work after Nicki was a little older and then moved again. She worked as a legal secretary and started college, with the goal of a Bachelor's degree and eventual law school. She was a student for two years, but missed family support in the juggling act of school, baby and work:

> Nicki went to day care and preschool and I didn't have anyone there to care for her… to just watch her...When Nicki would get sick, a lot of times I would bring her I would just set her up with a movie in a conference room so I could be near her.

Another move brought Kelly to her current location, the town she has lived in for over 10 years. Her mother and her sister have also moved there. She got a job as a paralegal and was pleased to find it challenging, with interesting responsibilities, possibilities for advancement and other benefits. She decided to make that her career.

After a few years she established a relationship and became pregnant. She was very concerned throughout her pregnancy about once again developing pre-eclampsia and delivering prematurely. Like most young women not in a risk group, Kelly didn't have testing done before Kyle was born:

> Do you test with an amniocentesis or something? I really didn't want to do that. I was afraid of that. And I was more focused on when I had Nicki I got pre-

> eclampsia and had her two months early and I had a lot of water retention and my blood pressure skyrocketed and my liver almost ruptured. So that's where my focus was…afraid that that was going to happen again. And it didn't and everything was just fine and so I wasn't even thinking of anything, that anything remotely like that could happen.

Kelly carried Kyle to term. She had considered having a *v-back*, which is a vaginal birth after having an earlier child by C-section. She chose not to do that after hearing of a friend who did the v-back and encountered complications that lead to a hysterectomy. The pregnancy went well:

> After he was born they immediately gave him to me to nurse and everything was fine and then they came and got him to do all the measurements and stuff ...The doctor came and said that he suspected that he might have Down syndrome, but he wasn't sure and he wanted to take some blood and send it... to test it.

Kelly felt that the doctor was insensitive when he told them. She said it wasn't her regular doctor. "I guess they were on their shifts or whatever."

She was soon to experience another insensitive professional. Kelly and Tom decided not to say anything to friends and family until they heard the results from the analysis of Kyle's blood. Her mother was visiting her and the baby in Kelly's hospital room when still another doctor came in and started talking about Down syndrome in front of Kelly's mother, creating a difficult, emotional scene. Looking back on it Kelly said "Not that it really mattered. But it was just something...It was a challenge, you know."

Kelly and Tom got through the next few days, but the waiting continued. As she told it:

> I had him on a Friday and they were supposed to call me Monday or something or Tuesday. And they didn't call me, the Dr. didn't and so I called her and she said, "Oh I thought someone would have called you already." And they told me that he did and …so it kind of... it made me mad.

Kelly and Tom started the journey that many parents follow when a child is born with a known disability. They were frightened, but they loved their child and wanted to do the best for him. "I felt scared. I didn't want to feel bad about it, but I did. It didn't make me not love him, so it was just weird."

> Her baby was healthy and had a good sucking reflex. He did have a hole in his heart, but it healed up on its own. "After we found out...It was hard but it wasn't. It was hard to think about and hard to plan, but we did."
>
> Their thinking and planning involved research on the internet, buying books and reading about Down syndrome. Kelly was frustrated by some of the books, wanting more information about milestones and what to expect with a baby with Down syndrome. She found that talking to another mother who had a child with Down syndrome to be useful, as was a small pamphlet given her by the same mother. She didn't want to know what he wouldn't do, or what a typical baby would do. Kelly was not interested in reading about the experiences of other mothers of children with Down syndrome, preferring more factual information. The personal experience narratives made her feel sad. She found much joy in her baby, but was sometimes surprised by feelings of sadness.

Most people couldn't tell that her baby had Down syndrome, but people who recognized the condition would flock around them. One day at she met a family that was very kind and friendly. The family included a man of twenty four who had Down syndrome. He lived pretty much on his own and had a job. She couldn't explain why, but the meeting really affected her and left her with deep sadness. She said "I don't know why and no one was being mean. They were just real sweet and I don't know it was really hard for me when that would happen"

Tom and Kelly's relationship was not to last. Though definitely not the only reason, Kelly feels that Kyle's Down syndrome played a role. Tom loved Kyle from the start and is good with him, but the fact of the Down syndrome was very hard on him. He became depressed and that was a factor in the end of the relationship. They have worked together in raising him and seem to approve of each other's decisions regarding Kyle.

Kelly is proud of how she and Tom worked hard to craft a schedule that has allowed Kyle to be cared for by parents and grandparents. Kyle has not had to go to day care. Tom drives him to and from school so that Kyle doesn't have to ride the school bus, although Kelly thinks that Kyle would like it and might be ready for that soon. She wants to be sure to protect Kyle from any kids who might be mean to him.

Kelly said that other people with children with Down syndrome had more difficulties that she and Tom did. "Some people have a lot of problems they have to go through." Despite this positive statement, Kyle did get sick a lot. He had problems with adenoids and with persistent ear infections and respiratory problems. He got sick more often when he started pre-school and had interactions with other children. In recent months Kelly has been dealing with two difficult health problems. One has been long term , the other is a frightening recent illness.

He has struggled with sleep disorders for some time. His inability to sleep at night contributed to his susceptibility to colds and such. It also made sometimes made him too sick to go to school, necessitating changes in the caregiver schedule for Kyle. In addition to these annoyances, his lack of sleep often made him irritable and hard to deal with. Kelly also lost sleep, getting up with him, or, “I‘d lay awake and try to figure out and listen to him breathe and ...what’s happening to keep him from breathing.” Tom and Kelly read about sleep apnea and considered that to be a possibility for Kyle. Kelly went with Kyle for a sleep study. He was bewildered and fought the procedure. Kelly, who tends to downplay most difficulties, described it:

> It was the worst night of my life…They did not explain to me what he was going to have to go through. They have to have these like forty probes stuck to him that night. If I had known, there is no way I would have…I’d be like ‘I don’t know if that’s going to work.’ I don’t know. It was just horrible.

Kyle has always wanted to be held and carried. Since he is now about sixty pounds, that has grown more difficult. Recently he wanted to be carried even more often than usual. He developed a limp, was sleeping even less and began to scream when he was picked up. Kelly had to take him to three doctors before she got a diagnosis. He has Leg Calf Perthes Disease. This involves a half moon shaped cartilage in his hip getting flattened out because of a block in blood supply. She is in a holding pattern now, waiting to see if Kyle’s hip heals or if surgery will be needed. She used her self deprecating humor and says. “But he works it. He gets me to carry him up and down the stairs.” The bedrooms are up the steps of her condo. She minimizes the question of back pain for her.

Tom's job as a chef kept him at work until late at night, but did allow him to take most of the unexpected care situations. Kelly's employers have been cooperative with her need for flexibility with Kyle. When describing the good features of her job she said "They have been good. They are fine with appointments and that and ...You know...with his speech therapy and that stuff, so yeah, I really like it there." She placed flexibility to cope with Kyle's schedule as the first benefit she described about her job.

Tom also has given Kyle's needs priority in career planning is a chef and has given up an opportunity to open a branch of his restaurant in his hometown to stay where Kyle is a kindergartner.

The change from preschool to kindergarten seems to have proceeded smoothly for Kyle, but it has been a source of worry and stress for Kelly. She doesn't understand how his actual learning time is divided between his "regular "classroom and his special education resource room. Kyle does not speak well, so she is left with unsettling questions about what his days are like. Some of his school experiences have made her sad, increasing her realization of how different he is.

His Christmas program was a difficult day for her. She had the earlier experience of watching her daughter singing with all the kids.

> Well he walks in late with his para educator and he is limping so bad. And this was in December before we really got all this information about what was wrong with him and he sat on the edge and he was just doing his own thing and not really into the group singing and it just about killed me… It was almost like, I don't know, like they are trying to include him, but he's not included. You know, I mean he's still separated from them for what

> ever reason. And he couldn't stand up the whole time because of his leg. And I...oh it was just horrible.

When she went to get him afterwards, he was happy and doing fine, giving her another rise on an emotional roller coaster. Actions and reactions of other children impact Kelly powerfully. She has found both teasing and extreme coddling to be very hard. She tends to avoid situations that might be difficult and as a result tends to just be with Kyle and build her life around him on the half of the week that he stays with her. She isn't comfortable with other mothers and their discussions of their children's activities and accomplishments. She limits her social life because of a need to protect Kyle and because his behavior can be unpredictable.

Recently a friend who works at the health department arranged for Kelly to be on an advisory council of parents of children with disabilities. This was an empowering experience for her.

Kelly is happy with her life. She has been able to have some great times with her daughter, including a recent trip to Seattle. That would have been impossible with Kyle, who, by screaming, is able to dominate much of the agenda, from their routes around town, to what music they listen to. He likes the Black Eyed Peas song, *Boom Boom Pow*, and songs from the hamster movie, *G-force*, not exactly Kelly's first choices. And, as she says, "When he's along I am on high alert".

Kelly loves to be with Kyle. She is proud of him. She downplays the difficulties and speaks of them with wry humor. She hopes one day to get married and to have a nice home. For Kyle?

I hope, you know one day, that he could have a job possibly and live on his own.

With still guidance from us you know. I saw somewhere where kids that have Down syndrome are now going to college. If that's something that he would want to d o then that would be kind of neat. I just want him to be happy and doing stuff that he likes to do and feel good about himself whatever that is.

Liz

Education, learning and a love of reading are key values for Liz, a thirty year old woman who loves her work as a chiropractor in a practice that she owns and founded five years ago.

. She lives in a Midwestern town that is filled with her extended family: grandparents, parents, aunts and uncles, brothers and sisters and fourteen cousins. .Her husband's career as a teacher reflects a shared value of learning. Both Liz and Josh attended graduate school, with Liz completing her education after their first child, a little girl names Avery, was born. "Yeah, we had decided that it was better to have kids when I was still in school, which was true. I went back when she was about ten months old."

Liz and Josh think things through and make considered decisions. They make plans and follow them. Avery's birth, early childhood and transition to day care worked out according to Liz's plans. She was able to nurse Avery for her first year, giving her the natural start in life that Liz knows children need. "As a chiropractor I am very, very natural. I only do unprocessed foods with my family. I planned to breast feed all my children for at least a year and that's what I did with my older daughter."

Chiropractors typically make adjustments to the spine or other parts of the body to correct alignment problems and enhance the body's natural ability to heal itself. Liz clearly believes in her work, extending it to her family. "Both my kids are adjusted once a week. And they are so healthy because of that."

Avery thrived with Liz and Josh, learning to read at age three and a half. She was in a day care with twelve children to one adult and this worked for her. She met many developmental milestones early, pleasing, but not surprising her parents. “But we knew you’d do it. Not that it wasn’t a celebration, but we knew she would do it.”

After thorough and careful planning, education and preparation they were living a life of joy in their professions and their daughter. They were to have an unplanned event, a surprise that changed their lives. They were due to have their second child, as planned, when Avery was about two and a half years old. Liz’s pregnancy was not all that different from her first pregnancy and she expected an extensive labor because of her prolonged experience with Avery. This was to be a different situation. At Liz described it:

> It was…we had gotten to the hospital and it was very stressful because they didn’t want me to come into the hospital yet. My husband called and said that we were coming in and it was still three weeks until our due date...They were like “just get in a warm bathtub.” And I told him we were not getting in the bath tub!...We went to the hospital...we were there nine minutes and I started pushing. Two pushes and he was out! And so we literally got to the hospital and fifteen minutes later he was born.

Liz enjoyed having the delivery room staff place her little boy on her chest right after birth. She had not been able to have that experience with Avery, who had swallowed meconium. Tate looked a little bluish, but he seemed fine. The nurses and midwife took him to clean him up and, looking at photos later, Liz saw that they looked solemn as they examined his hands and feet. Tate was taken away to be weighed and cleaned. Josh called Avery to tell her that she was a big sister and a doctor and the midwife came in, looking very serious. Liz continued the story:

> I get my husband off the phone and you get that feeling of dread. You know. You don't know what he is going to say and...the first question he asked me, he said, "I don't mean to be offensive, but did you drink alcohol at all during your pregnancy?" And immediately I said "No." and my heart is just pounding in my chest. I am...as a chiropractor I am as natural as you can be. I eat all organic food. I take the supplements. I didn't drink for three months before getting pregnant with him just to be sure that everything in my body was working well.

Liz told the doctor that she absolutely had not done anything that could harm the baby. He then said that their son had some characteristics of fetal alcohol syndrome, and some of the symptoms of Down syndrome. He told them that they weren't sure which one it was, but he didn't have a lot of the physical manifestations of Down syndrome and that his symptoms were applicable to fetal alcohol syndrome.

The doctor went on to ask about family history. With the exception of an aunt of Josh, who had some sort of developmental delay, but not Down syndrome, they couldn't think of any history. Liz and Josh had not had any prenatal testing. As their midwife had said, "You're young, healthy, no family history. Just do the ultra sound and you will be fine." The doctor later said that he was 99% sure it was Down syndrome, but that they would check further and get back to them. During that day Liz and Josh went back and forth, not seeing any signs of Down syndrome at first, but gradually coming to think that Tate did have it.

> I don't know…it was more of a shock than an emotional thing for us. We always knew that we would do what we had to do and my husband is very supportive and coming from the background that he does come from, with a mom a special

> education teacher, and being a teacher himself he has been exposed to it so much more. I think a lot of men just have a lot of trouble with it, you know the guys not knowing how to deal with it. Um... It was definitely the shock of our lives though.

Tate had difficulty with breast feeding and this situation is what Liz remembers most for the remainder of their hospital stay. She did note that "No one really acknowledged that he had Down syndrome after that. No one talked about it. I mean the nurses would come in and they wouldn't really ask about him, just do their stuff and then just leave."

She said that probably they were just trying to be considerate and unsure of what her reactions would be. But, as she said in a shaky voice,

> It bothered me that no one would teat him like I had seen my daughter treated in the hospital…to me it was like "You guys are afraid to talk to me." It made me feel like I should be ashamed of it. So I knew I shouldn't but that's kind of how it made me feel.

When Tate was about four days old, a social worked came in to see Liz. She didn't ask how they were doing, but offered a pamphlet that described a program that was offered in North Dakota. Liz corrected her and said their home was in Minnesota. The social worker said she would get a different pamphlet, but she didn't come back. "And so we left with literally no information… No one to help us. And so I told my husband, we have to figure out what to do. And we did."

They chose the physician who had diagnosed Tate as his pediatrician, thinking she would like to follow up with him. Their first visit was not auspicious. The doctor picked up Avery and carried her out of the room without asking Liz and Josh, saying:

> "I am getting her out of here so we can focus on what's important." Then she comes back into the room and she sits down and I am holding Tate not two feet from her says 'Well how are you guys doing? No one wants a Downs baby."

Liz knew that she meant to say that that they had had a big shock, but the way she said it was…" so offensive. So we never went back there and …the first couple weeks are a fog of experiences like that. But I can honestly say that since then we have not had a whole lot of negative experiences."

They participate in a family blog. Josh sent out a message on the day Tate was born:

> This was the biggest surprise day of our lives. We were surprised that Liz went into labor early; we were surprised that we had a son and we were surprised that we were given a baby that has Down syndrome.

Although they went home from the hospital without any information about Down syndrome, that situation did not last for long. A para-professional from Josh's school called right away and talked to them about educational supports. In Minnesota, the public school system is responsible for early intervention from birth on. Within two weeks Liz and Josh were connected with an early intervention teacher. She was the mother of a childhood friend of Liz and quickly became more than a teacher for Tate. She became a support for the whole family. "And that was another blessing too. We never knew that we would need her services. But to have her come was so comforting to us."

Tate has speech and language therapy and occupational therapy once a month from the schools, but did not qualify for physical therapy. Liz does not think those services are enough, but said:

> I have to strike a balance between being a school employee's wife and advocating for my son and the way we handled it was we have great insurance and we have speech, PT and OT therapies come into to complement what he was getting through early intervention.

Liz had very little experience with Down syndrome. She had a few friends in high school and college who worked as a caregiver for persons with disabilities. A few of their clients were adults with Down syndrome. She knew that persons with Down's syndrome had cognitive delays and as a chiropractor she was aware of their spinal issues, but she had no idea of all the other complications.

Speaking of her experiences attending public school in a small Minnesota town, Liz said, "I don't recall seeing any kids with disabilities in my classes. Ever!…I don't know… I don't know if um they ...I absolutely don't remember ever seeing them at school." She felt that Josh had a little more background, as a teacher and as a special education teacher's son. "I was raised to be very in a very accepting family. I have fourteen first cousins and six of them are adopted, and from different places with different cultural differences. But I was just never exposed to disability."

Liz thinks that maybe it was because she is trained as a scientist, but she spent the first three weeks of his life at her computer every waking moment that she could. She searched for everything she could find about Down syndrome.

> Literally that was what made me feel okay. And finally after three weeks, I was like, "OK I've had my fill of information and now I know all the *what if's* and now I can just love him as this little boy who happened to be given to us and has Down syndrome."

When Tate was about a month old she began to see his birth as a wonderful thing for her family. She saw that it was going to be a benefit for Avery and for all of them as a family unit.

> I didn't see it right away. We were told that but I didn't see it. It wasn't that we didn't want a child with Down syndrome, but I didn't see why we were given a child with Down syndrome. But, watching him grow and develop…taught me about things about myself that I didn't know.

She now knows that everything a child achieves is worthy of celebrating, and is not to be taken for granted. He has also made her aware of other people, with all their differences. Liz can pinpoint the time when she knew she had adjusted to and could accept a child with Down syndrome. Her brother was in Iraq when her son was born. She remembers that she said to her husband that was good that "… Tate has Down syndrome because now John didn't miss out on so much of the baby stage."

She enjoys being able to appreciate each stage longer, even though there are frustrations with that. He is more willing to snuggle than her daughter was and he is more social and outgoing. "He just warms people up in a way that's just amazing."

Liz is also happy that Tate doesn't have many of the health problems such as heart or gastrointestinal problems that often come with Down syndrome. He has only had one ear infection. They did have to struggle with pneumonia, though. They had six incidents during his first year. He wasn't hospitalized, although they did have to make many rushed trips into the emergency room in the middle of the night. "Because we would put him to bed with no symptoms, no cough or fever or anything and then an hour and a half later, we'd walk in and his breathing would be so labored."

Luckily Tate hasn't gotten any other infections. Tate's Down syndrome caused Liz to do some things differently with him that she has planned as a mother, omitting some things she knew were very important. Speaking of chiropractic, Liz says "If we keep the nervous system functioning well, boosting the immune system, you are going to get fewer infections...Both my kids are adjusted once a week. And they are so healthy because of that." Liz's reality was that she had to put off adjusting Tate until he was two and she could have x-rays to rule out atlantotaxial instability, which is excessive mobility of the first and second cervical vertebrae. 10%-15 % of children with Down syndrome have this condition and manipulation of the head could possibly cause spinal chord compression.

Liz takes a natural approach to life and is a strong believer in breastfeeding. She had planned to nurse each of her children for the first year. She did so with Avery. Tate's oral muscle tone was so weak that he couldn't nurse and had to be fed with a syringe for a very long part of his infancy. At first she tried to nurse him without any supplement until a lactation specialist told her that Tate was working so hard to nurse that he was expending more calories than he took in. After that she pumped breast milk and fed him with a syringe. She was glad to do it for his health, but missed the bonding, warmth and ease. She kept it up as long as she could, but knew when it was time to stop.

> I got to the point where we had gone camping and I was sitting in the pick up pumping, attached to the cigarette lighter. And it was hot in the middle of summer and I just got fed up. I couldn't do it any more.

Just as Liz was getting accustomed to having a child with Down syndrome, it was time for her to go back to work. Now that she owned her business she did not have the luxury of taking a long maternity leave. Finding day care for Tate turned out to be one of Liz and Josh's first big challenges. The care situation, with relatively few adults, that had worked well for Avery would never work for Tate. They found a center near their home that focused on enrichment. Liz told them that she couldn't predict what Tate's skill levels would be. "And they told us flat out...'we don't have a place for him at this time.'" They worked hard to find a good place and they are pleased with their choice. Their day care provider loves Tate and is willing to let all the therapists come into her home and work with him. Liz doesn't trust anyone outside of family to care for him if they go out in the evening because he can have some unexpected behaviors. Liz and Josh have lost some of their privacy and have found themselves sharing his upbringing with other people:

> You don't always want all these other people involved in raising your child to the extent that we have them involved. You know there are some Tuesday s that I just want to have time with my kids. I don't want to have a teacher or therapist over. I just want to have time with my kids. And just be mom…It can kind of get old. We are always grateful for the help and the services but it also can get to be a burden some of the time.

Liz and Josh didn’t expect to have to continue doing so much for their child at age two and a half. Tate doesn’t walk and has just recently started crawling. He still needs lots of help with feeding and is very far away from toilet training. They had planned to have another child by this time, but they know that Tate needs some more of their time and they are waiting a few years. One of the most difficult things for them has been their realization and acceptance of a different pathway. Their dreams and expectations had to change.

> The number one hard thing for me was…his dreams are going to be different. He might still play hockey but it will be adaptive sport hockey. He might still go to college, but he’s not going to be an MD. He might go to technical school and get a skill that will serve him well in his life. That was probably the hardest thing... coming to grips with the realities much earlier than we had expected.

Part of the draw that led Liz and Josh to move back to her hometown was the presence of old friends and family. She had troubles at first with facing her old friends as well as making new friends who shared the Down syndrome experience.

> At first I avoided my friends with typical children. We are similar ages and our kids are the same ages. I blocked them out. There was a whole lot of babies born at about the same time and Tate was one of them and at first it was very hard for me.

It was also hard at first to talk to parents of children with disabilities. She still didn’t know what to expect in terms of Tate’s development and seemed to realize that she had to learn about Down syndrome in a gradual way.

> I didn't want anyone to ask how I was doing because I didn't know how I would answer. I think wasn't sure if I would be emotional or not. I wasn't ready. I was okay with that. I would seek it when I was ready. I did seek out a lot of support online. There are some message boards out there for families of kids with Down syndrome and that was good for me. Because I didn't have to go meet some one and worry that what if I couldn't face the realities of having an older kid with Down syndrome.

Eventually Liz not only went to the support groups, but became a leader in her community in the area of persons with Down syndrome. She plans workshops, visits new parents and has been featured in a local parenting magazine. She has found that her work has broadened, especially after that article, as she welcomes more patients with disabilities as part of her practice. When Liz went back to work after her short maternity leave with Tate, she was glad to see her patients,

> But it was hard for me. It was like "Who should I tell?" and "How should I tell them?" and I didn't want them to hear that I had a son with a disability. First I wanted them to know that I had a son and that he was awesome and then that he had a disability and it was fine. I didn't want that to be how they identified him.

Liz is a smart, articulate woman. As she tries to balance family and career, she grows more and more comfortable in her role as Tate's mother. Liz knows that she was blessed with Tate, and that many other blessings have helped her cope. She said. "I know we have different challenges than other families but I also know that we have different blessings than other families that they can't experience."

She feels blessed by her early education teacher and her day care provider. She is perceptive enough to see blessings in some bumps along the road. She said that Tate’s difficulty nursing was “a little bit of a blessing... because it took my focus off. I had been so preoccupied with Down syndrome and then I focused on how are we going to get this kid to breast feed?”

In a few years Liz and Josh plan to have another baby, completing their family. She knows that Tate’s Down syndrome will be a blessing to that child also. Her hopes and dreams for all her children are similar.

I hope they fulfill their potential and they don’t get content to just be comfortable and just do something easy. That they choose to do what makes them happy in life and they have a career that is fulfilling that they choose and that they meet someone along the way, whether it’s a friend or a husband or wife or whatever the case may be just someone they enjoy spending time with someone who makes them happy