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**University of Alberta**

**Adopting Children with Developmental Disabilities: A Qualitative Approach to  
Understanding Adoptive Parents' Experiences**

by

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A thesis submitted to the Faculty of Graduate Studies and Research  
in partial fulfillment of the requirements for the degree of  
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## Abstract

Much has been written about the experiences of parents raising children with developmental disabilities. Historically, parenting a child with a disability has been viewed as a stressful and overwhelming experience. More recent research is expanding the areas of disability and family functioning to include positive aspects of parenting and to examine the experiences of parents who knowingly adopt children with a disability. New research is also looking to qualitative research methods to gain a deeper and richer view of family life for parents of children with disabilities. The present study serves to expand current knowledge by utilizing a basic interpretive qualitative approach to examine the experiences of parents who knowingly adopt children with developmental disabilities. Stories from five parents, four mothers and one father, were collected through in-depth interviews. Each individual story is presented and common themes are identified. Common themes include: (a) Adoption: A Lengthy and Overwhelming Process; (b) Connecting People Through Adoption; (c) The Need to Save: Dealing with Abusive Histories; (d) Knowledge, Choice, and Realism: Keys to Adoption Commitment; (e) Challenges, Demands, and Sacrifices; (f) Value of Support and Services; (g) Advocacy in the Face of Adversity; (h) Happiness and Personal Growth; (i) Respect, Faith, and Self-Awareness; and (j) The Value of Family – Normalization of Adoption. The implications of the research are discussed in relation to prospective adoptive parents, current parents, adoption professionals, and other health professionals working in the areas of family and disability. Suggestions for future research are also provided.

## Acknowledgement

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A special thanks to all the parents who were willing to share their stories for this project. I appreciate your honesty and your ability to provide such rich and moving portraits of life after adoption when a child has a disability. Without you, this would not have been possible!

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Adopting Children with Developmental Disabilities: A Qualitative Approach to  
Understanding Adoptive Parents' Experiences

Introduction: My Story

My interest in families and developmental disabilities began 16 years ago when I volunteered at a children's residential hospital. I became emotionally attached to many of the children who I met there. These children ranged from infants to adolescents, and their physical, emotional, and medical needs varied widely. One child in particular, Michael, captured my attention and made me wonder about my purpose in life. Michael was a young boy who had a severe developmental disability and required extensive medical and rehabilitative intervention. He was a 10-year-old boy of small stature but extra-large personality. His behaviour was extremely self-abusive, and he often would repeatedly bite himself, sometimes causing serious harm. He was not able to speak and this seemed to frustrate him on a daily basis. He was a challenge to work with, but I enjoyed his charm and buoyant personality. All of the struggles seemed worthwhile when he gave me a hug at the end of the day.

At the time, I was a high school student and unsure of my future path. I did, however, feel the desire to take Michael home. It was the first time that I felt strongly about caring for a child. This experience made me keenly aware of what I wanted for a career. I knew that I was meant to continue working in the field of disability and helping children in need.

That experience, in retrospect, has led me to the topic of my dissertation, although it has taken several years for me to arrive at this realization. I now know that my interest in adoption and disability is not solely academic, but also personal in nature. I have met

several children with disabilities without stable or consistent homes. Perhaps by writing and researching in this area, my work can serve not only to provide information to families, communities, and professionals, but also to advocate for children searching for places to belong.

Many changes have occurred in my life since I began this research. My initial interest in the topic of adoption and disability emerged from my desire to “save” the children I encountered in my professional endeavors. I felt I could make a contribution to society and my community by adopting or fostering a child. I felt that parenting or fostering a child would be a fulfilling experience and that, given my own skills and experiences, it would be a possible task. As time passed, priorities in my life changed. I married a man who had little experience with children, let alone children with special needs. After we were married, I became pregnant with our own child. Little did I know that my world perspective was about to change.

I remember thinking about how I would react if I found out that my healthy baby girl had a disability. During my own pregnancy, the only wish I had for my unborn child was that he or she would be healthy. The thought that my child could be ill or have a disability crossed my mind, but I thought that it would “never happen to me.”

Once my daughter was born, the shocking reality of parenthood came crashing down on me. Being a parent is the most difficult job I have ever encountered. I struggled with learning to be a mother, and I continue to learn that parenting does not get any easier as children grow older. At the time that I began my dissertation research, I was not a parent and felt that my life path would lead to adoption and care of a child with a special need. Once my daughter was born, I realized how difficult parenting was and could not

fathom caring for another child. I also experienced intense emotions that I call the “mother bear” syndrome. I began to feel intense love, protectiveness, and caring for my daughter. I felt I would endure anything to ensure her safety and happiness in life. I began to truly understand for the first time how it must feel to hear that one’s child is ill or in pain. My only wish was for my child to be happy and healthy.

Even now, as the parent of a preschooler, the challenges of parenting are still overwhelming at times. After meeting and talking with parents who have children with disabilities, I realize that perhaps my life calling has changed. I no longer have the desire to adopt or foster another child. After looking deeply at my own capabilities, I have come to recognize that adoption and fostering is not realistic with my goals for my marriage, my family, and me.

Conducting this research has helped me realize my own abilities as a parent. This journey has also led me to understand some of my beliefs about parenting a child with a disability. During the course of my research, my ideas and preconceptions about parenting and disability have changed. I now understand that parenting is difficult, challenging, and often overwhelming. I can only imagine that these challenges are greater when a child is ill or has a special need. I now also understand that parenting can be the most rewarding experience in a person’s life. These rewards are evident regardless of whether a child has a special need. These two notions were prominent in my thinking throughout the research process. I have used these notions to channel my work to capture both aspects of parenting, the challenging and the rewarding.

Previous researchers have been interested in the topic of parenting and the experiences of parents who have children with special needs. Much has been said and

written on the topic, often with a focus on stressful life events. The majority of research has focused primarily on birth parents rather than adoptive parents. Given my background and interests, I felt it would be interesting to explore the topic of parenting from the perspective of adoptive parents. In my mind, their experiences may provide additional information for other parents, professionals, and those with an interest in adoption and fostering. I certainly have learned a lot about myself through this process.

My discussion will begin with a review of previous literature. I feel it is necessary to first explore the literature about birth parents and then issues that affect parents who adopt children with disabilities. Following this, I will discuss how the current study was constructed and the method utilized. The results will be presented in the form of stories for each of the parents interviewed. Commonalities and differences will be discussed in terms of themes and sub-themes identified. Discussion of results in terms of previous literature as well as benefits, limitations, and areas for further study will also be addressed.

## Literature Review

I will begin this review of the literature by exploring several key areas associated with birth parents of children with disabilities. These include family adjustment, parents' initial reactions to the diagnosis of their child, parenting challenges and rewards, and the resources and supports that families feel are important. The next section will discuss literature pertaining to adopting children with disabilities. Prior to discussing issues of disability in adoption, it is important to examine other core issues in adoption that can be evident for many families. These include the experiences of loss and rejection, the role of openness in adoption, as well as other variables associated with special needs placements. These other variables include age of children at time of placement, children who have experienced abuse and/or neglect, and cultural differences/transracial adoptions. The final section will provide some information about current adoption trends in Alberta.

Prior to beginning a discussion of previous literature, it is necessary to clarify terms and definitions used throughout this study. The parents of the current study adopted children with developmental disabilities. As used here, the term "developmental disability" refers to a chronic and severe mental and/or physical impairment that will likely require specialized care over the long-term (Prucho, Hicks Patrick, & Burant, 1996). The disability is evident during childhood and results in functional limitations in self-care, receptive and expressive language skills, learning, mobility, self-direction, and capacity for independent living. The term "special needs" is used in the current study to highlight issues related specifically to adoption. The term "special needs" in the field of adoption implies that a child will need extra support over and above the support needed by other children. This support could involve extra medical, educational, psychological,

or community resources (Dumbleton, 1996) and can encompass multiple factors (i.e., older children, ethnic minorities, sibling groups, as well as children with developmental disabilities), believed to make adoption more difficult (Eheart & Power, 1991; Reilly & Platz, 2003). The term “special needs adoption”, therefore encompasses factors that may or may not include developmental disability. It should be clearly noted that the literature review is written with original definitions and terminology presented by previous researchers, as this ensures a more accurate presentation of previous findings.

#### Introduction: Family Adjustment When a Child has a Disability

Much has been written about family adjustment and coping when a child is born with a disability. Historically, family and disability research has focused on the negative aspects of parenting a child with a developmental disability. In the 1970's, research in the area of disability focused on the child with the disability as a source of stress for the family (Fotheringham, Skelton, & Hoddinott, 1972). According to Korn, Chess, and Fernanday (1978), “the handicapped child is viewed as a source of their (parent's) guilt and interpersonal discord, as over-demanding, an embarrassment to the parents and to the other children in the family, and a serious economic drain that results in a wide range of family sacrifices” (p. 309). These strong negative views of disability no longer dominate research. However, the negative tone, according to some, has not completely diminished. Helff and Glidden (1998) conducted a review of family adjustment research over the previous 20 years. They found that the majority of these research studies were written about family adjustment in negative terms. Although this negativity has decreased over the last two decades, they argue that there has not been a corresponding increase in positivity. It was concluded that research still tends to focus on the stress that a family



may experience when a member has a disability. Families are still often viewed as victims. A consequence of this negative orientation is that “if we approach research from a negative perspective, we will, of course, be more likely to find negative results” (Helff & Glidden, p. 458).

New research now acknowledges the positive and life promoting experiences of families of children with disabilities. A recent article by Hastings and Taunt (2002) reviewed existing published research on the positive impact that a child with a disability can have on family functioning. They were able to draw several conclusions about family experiences including that families do experience positive perceptions and joyous moments when raising a child with a developmental disability. These positive experiences were noted to include 14 key themes. These themes were: “(a) parents receive pleasure and satisfaction in providing care for their child, (b) their child is a cause of joy and happiness, (c) parents gain a sense of accomplishment in having done one’s best for their child, (d) parents share love with their child, (e) their child provides parents with a challenge and opportunity to learn and develop, (f) parents report having a strengthened family and/or marriage, (g) parents gain a new or increased sense of purpose in life, (h) parenting has led to the development of new skills, abilities, or new career opportunities, (i) parents report becoming a better person (i.e., more compassionate, less selfish, more tolerant), (j) parents feel increased personal strength or confidence, (k) families have expanded their social and community networks, (l) families report increased spirituality, (m) parenting has changed one’s perspective on life, and (n) parents now make the most of each day and live life at a slower pace” (p. 118).

A second conclusion noted by Hastings and Taunt (2002) was that families also tended to report negative and stressful experiences when raising a child with a disability. It was also noted that families of children with disabilities experienced more stress than other families rearing children without disabilities. However, evidence also supports the notion that families of children with disabilities report no difference or even more positive experiences than other families without children with disabilities. Given this information, it is important to examine, in more depth, the existing research on families coping with a child with a disability. The following will examine the negative, stressful, as well as positive experiences.

#### Birth Parents: Initial Reactions

Finding out that a child has a disability can be very difficult for some parents. As with any unexpected news, parents can feel overwhelmed, saddened, and unsure of the future for both their child and their family. Initial reactions by parents to their child being diagnosed are often described in the literature as negative, frustrating, challenging, and life shattering (Barnett, Clements, Kaplan-Estrin, & Fialka, 2003; Kausar, Jevne, & Sobsey, 2003). For example, “to be told that his or her child has a serious disability is one of the most painful experiences in a parent’s life” (Shea, 1984, p. 265). According to Cahill and Glidden (1996), some parents who have a child with a disability “vividly remember the day their child was diagnosed” (p. 97) and sometimes re-live these feelings of sadness that they initially experienced. One mother described the “feeling in her stomach of dread and fear that remained for weeks and that still, after all these years, returns when she talks about ‘that day’” (Harris & Powers, 1984, p. 208). Many parents “feel doomed to live forever with the feeling of unspeakable loss” (Whelan & Hudson,

1987, p. 106) and the realization that “life will never be the same for them” (Harris & Powers, 1984, p. 208).

According to previous researchers, the initial weeks following a child’s diagnosis can be filled with shock, disbelief, and sadness (Gupta & Singhal, 2004; Kearney & Griffin, 2001; McAndrew, 1976). Some parents speak about the loss of the “normal” and “expected” child (Barnett et al., 2003; Cahill & Glidden, 1996; Howard, 1978; Shea, 1984; Whelan & Hudson, 1987) “and in its place is a child with apparent and frightening problems and unknown prospects for the future” (Turnbull & Turnbull, 1990, p. 108). According to Barnett et al. (2003), the time of a “child’s birth may be mixed with stress and despair” (p. 184). These feelings of sadness can re-emerge at significant life events, such as birthdays, starting school, or if the child fails to meet social norms and developmental milestones (Howard, 1978). According to some, the recovery from grief is a process of “updating, rebuilding, and replacing hopes and expectations with the realities of what a child can accomplish” (Barnett et al., 2003, p. 186).

Other research suggests that some parents feel overwhelmed with the concept of disability and what to expect when their child is diagnosed. One researcher described a parent’s “sense of normalcy as rudely shaken” (Harris & Powers, 1984, p. 209). Some parents have little knowledge of what “normal” child development is and their existing knowledge of child development does not usually include a handicap or disability. Therefore, for parents of children with disabilities, it can be difficult to discern what their own child’s development should look like (McAndrew, 1976) and parents have deep concern for their child’s future (Kearney & Griffin, 2001).

Barnett et al. (2003) provide a list of common parental reactions to news of a child's disability. Feelings were noted to include devastation, shock, denial, confusion, sense of loss for the hoped-for child, guilt, shame, and a shattering of dreams and expectations. They also noted that some parents react with strong anger toward professionals, experience decreased self-esteem, and must cope with increased strain in their marriage and family relationships as well as disruption of family routines.

Barnett et al. (2003) reported that parents must come to terms with the meaning of their child's diagnosis, not only for themselves, but also for their child and other family members. Parents must move past intense negative emotions in order to experience the positive feelings of joy, pleasure, reward, and connection to their child. Part of this process involves acceptance of both the child's condition and their own emotional responses to the disability.

In addition to feelings of loss and sadness, some parents have reported feeling guilt and self-blame for their child's disability (Barnett et al. 2003; Carr, McKeever, & Yoshida, 1997; Nixon, 1989). Parents may feel genetically responsible or fear that their previous actions, either as parents or during pregnancy, may have contributed to the problems now apparent in their child. Given their feelings of guilt or responsibility, some parents have a strong desire to find a cure for their child's disability at the time of diagnosis (DeMyer, 1979; Larson, 1998) or fear having additional children in the event that they too will have disabilities (Whelan & Hudson, 1987). Professional interventions are often required to assist in promoting parent and child adjustment with families raising a child with special needs. Factors such as distress, uncertainty of the diagnosis, preoccupation with guilt or anger, avoidance of feelings, and isolation from support were

noted by Barnett et al. (2003) to hinder a family's ability to cope and adapt in a positive and functional manner.

A study by Juvonen and Leskinen (1994) examined parents' perceptions of responsibility for their child's disability both at the time of diagnosis and following time to watch their child's rehabilitation. Guilt was noted to be associated with the onset of the disability. As guilt decreased over time, the parents' sense of hope and acceptance of the disability increased. Hope was reported to be a strong predictor of parents' acceptance of their child's disability and to lead parents to be able to experience happiness, joy, and gratitude.

#### Parenting Challenges

Raising a child, regardless of disability, can be a challenging endeavor in today's society. Parents of a child with a disability often face additional challenges on a daily basis. These challenges include, but are not limited to, increased childcare demands, cognitive and behavioural difficulties associated with the child, financial limitations, dissatisfaction with their child's educational placements, lack of time for family recreation, leisure, and holidays, lack of information about services and supports, and less time for parents to spend quality time with each other or other children in the family (Bailey et al., 1999; Boyd, 2002; Dyson, 1991, 1997; Failla & Jones, 1991; Larson, 1998; Lessenberry & Rehfeldt, 2004; McAndrew, 1976; Perry, Sarlo-McGarvey, & Factor, 1992; Philip & Duckworth, 1982; Sanders, 1993; Scorgie, Wilgosh, & McDonald, 1996; Turnbull & Turnbull, 1990; Whelan & Hudson, 1987). A study by Roach, Orsmond, and Barratt (1999) found that parents of children with Down syndrome experienced high

levels of parent-related stress and more difficulties related to health problems, role-restriction, and depression compared to parents of children without a disability.

According to some researchers, the greatest source of stress for many parents seems to center on concern for their child's vocational and social future and how their child will cope when they, as parents, are no longer able to care for them due to aging, illness, or death (Adams, Wilgosh, & Sobsey, 1990; Failla & Jones, 1991; Heaman, 1991; McAndrew, 1976; Turnbull & Turnbull, 1990; Weiss, 1991; Whelan & Hudson, 1987). Some parents also encounter difficulties finding resources, gaining information, and finding appropriate and skilled professional help (Bailey et al., 1999; Farmer, Marien, Clark, Sherman, & Selva, 2004; Hendrickson, Baldwin, & Keith, 2000; Weiss, 1991).

The level of stress a family experiences can depend on many factors. These factors can include (a) the ambiguity of the child's diagnosis and prognosis, (b) the severity of the disability, (c) whether the child with the disability requires life-long care, (d) whether the disability leads to social stigma or isolation, (e) the rarity of the disorder, and (f) the availability of community and social supports (Bristol, 1984; Bristol & Schopler, 1984; Lessenberry & Rehfeldt, 2004). Greater stress and family strain may also hinder a family's ability to access needed supports and services (Farmer et al., 2004). Individual family factors such as socio-economic status and culture can also affect family adaptation. A recent study by Farmer et al. (2004) found that families of ethnic minority status and lower social-economic status indicated a higher level of unmet family needs, including less access to health / dental care, respite care, and preschool / daycare services for their children.

The nature, type, and severity of the disability can affect the family's reaction and subsequent adjustment (Holroyd & Guthrie, 1986; Turnbull & Turnbull, 1990). Family life can be more adversely affected when the child has a more severe and pervasive disorder (Bouma & Schweitzer, 1990; Cummings, 1976; Donovan, 1988; Farmer et al., 2004). Perry et al. (1992) found that stress is associated with whether the disorder is progressive and if there is little hope for significant treatment gains. Farmer et al. (2004) found that mothers who rated their child as having a more severe and debilitating condition reported greater needs for services, information, and strategies to utilize when interacting with their child. Research also portrays parents who have a child with a more severe disability as more pessimistic about their child's future. These feelings of pessimism can increase as the child grows older and the parents must make alternative placement decisions (Lessenberry & Rehfeldt, 2004; Rimmerman & Portowicz, 1987).

When examining stress and adaptation in families, researchers have conducted many comparison studies. Families of children with developmental disabilities have been compared to families of children with medical needs, asthma, and children without disabilities. Based on this type of research, researchers postulate that many families who have children with disabilities experience more stress than families who have children without disabilities. Results, however, are inconsistent.

Some researchers conclude that parents of children with disabilities experience more marital problems, more disruptions in daily living, and more life stress than parents of children without disabilities (Beckman, 1991; Bristol, Gallagher, & Schopler, 1988; Perry et al., 1992; Roach et al., 1999). Mothers of children with disabilities also are

reported to have higher levels of depression compared to mothers of children without disabilities (Miller, Gordon, Daniele, & Diller, 1992).

Other studies show that families with a child with a disability do not differ significantly from families who have children without disabilities in terms of family functioning and life stress (Dyson, 1991, 1997; Horton & Wallander, 2001). Some results even suggest that families caring for a child with a disability have less stress since they cope more effectively with stress and have experience at mobilizing resources and support networks (Trute, 1988).

In recent research, hope has been identified as a moderating variable, decreasing the negative effects of stress on family functioning. A study by Horton and Wallander (2001) found that perceptions of hope and social support in mothers of children with physical disabilities lessened the effects of stress and maladjustment. Similarly, a study by Kausar et al. (2003) found that hope served as a positive transformational process that assisted parents of children with disabilities to reframe their outlook on life and better cope with parenting challenges and stress.

Researchers also compare family stress and functioning among families who have children with different types of disabilities. A study by Holroyd and Guthrie (1986) examined stress among parents of children with physical illnesses. Stress patterns were different among parents, and these patterns were consistent with the nature of the child's illness and the care required by family members. An interesting result was that stress was higher among parents when their child's physical illness incorporated mental retardation.

A study by Bouma and Schweitzer (1990) compared stress among mothers of children with cystic fibrosis, autism, and those with healthy children. The results showed



that mothers experienced stress differently depending on the type of their child's disability. Mothers of children with autism exhibited more family stress and stress related to the stigma attached to the term "autism" than mothers of children with cystic fibrosis exhibited related to the term "cystic fibrosis." Overall, it was concluded that families with children with psychological or mental problems experienced more family stress than families with children with physical problems. The reasons for this were believed to be a result of societal attitudes regarding disability, child characteristics, behavioural issues, and parental feelings of shame and guilt.

One recent study by Baker et al. (2003) examined parenting stress over time for parents raising children with intellectual disabilities. They found that children with intellectual disabilities were rated by parents as having a higher degree of behavioural difficulties compared to non-delayed peers. Parents of children with intellectual disabilities also reported experiencing increased levels of stress. This stress, however, was related more to behavioural difficulties rather than disability issues of their children.

A longitudinal study by Seltzer, Greenburg, Floyd, Pettee, and Hong (2001) compared parental well-being for parents of children with developmental disabilities, mental health difficulties, or no disability. The results indicated that by mid-life (age 50), parents of the children with developmental disabilities had adapted positively to life. Parents of children with mental health difficulties, however, exhibited poorer physical and mental adaptation, and showed higher levels of depression compared to the other parents. This result was explained by these parents having less time to adjust to their child's disability since the mental health problems tended to occur later in their child's

life. Another possible explanation may be related to the fact that mental health problems are less predictable and have uncertain projections and life courses.

A large body of research exists that directly compares maternal and paternal experiences for parents of children with disabilities. Within this realm of study, the research results are often inconsistent. Part of this inconsistency may be related to the reliance on maternal reports of their husband's experiences. A study by Trute and Hiebert-Murphy (2002) found no differences between mothers' and fathers' appraisals regarding the impact of their child's developmental disability on the family. A similar study by Turkel, Crossman, and Rimmerman (2003) found that parents' perceived similar levels of stress related to their children's development, child-related stress, and marital interactions.

Beckman (1991) and Wolf, Noh, Fisman, & Speechley (1989) found that mothers experienced more depressive symptoms, more health difficulties, more life restrictions, and decreased feelings of self competence compared to fathers. A study by Moes, Koegel, Schreibman, and Loos (1992) showed that mothers of children with autism exhibited greater stress and were at a greater risk of depression than fathers. The authors concluded that the reason for this finding was related to the fact that mothers were often the primary caretakers and saw their child's disability as a reflection of themselves. Fathers, on the other hand, viewed themselves in terms of their careers outside of the home. Therefore, their self-worth was tied to different experiences.

Similar research by Kraus (1993) found that mothers tend to experience more stress in relation to parenting and dealing with behaviour problems whereas fathers experience more stress in relation to the child's temperament and their own relationship

with the child. Some mothers also report that stress was associated with excessive caregiving demands and a lack of spousal support (Beckman, 1991; Roach et al., 1999).

Relatedly, a mother's life satisfaction can be enhanced when the father assumes a more active role in childcare (Milgram & Atzil, 1988).

A study by Lemanek, Jones, and Lieberman (2000) examined psychological distress among mothers and fathers of children with Spina Bifida. Results indicated that mothers reported decreased psychological distress compared to fathers. The study noted that different coping styles between mothers and fathers played a role in their findings.

A recent study by Hastings (2003) examined levels of stress and depression in mothers and fathers of children diagnosed with autism. Results indicated no difference in overall levels of stress between mothers and fathers sampled. However, mothers reported more anxiety than fathers, specifically in relation to their child's difficult behaviours and the father's level of stress. These same factors had little effect on the father's reported levels of anxiety. These results were partially interpreted in light of the fact that mothers continue to be responsible for a majority of care giving duties compared to fathers. Additionally, mothers often rely on their spouses for support. If fathers are unable to give this support, due to their own increased levels of stress, this was deemed to have a negative effect on mothers.

### Positive Parenting Experiences

In addition to research that examines the challenges that a family may face, more and more research is examining the positive aspects of parenting a child with a disability. Disability in the family does not always lead to serious family consequences, stress, grief, or sorrow (Rodrigue, 1989). One author stated that, "all humans are imperfect...no child

is inherently disappointing...[and] all children can be a source of pride” (Sobsey, 1996, p. 8). According to some authors, the number of studies that examine positive benefits of disability in the family are still too infrequent (Stainton & Besser, 1998). The positive findings may also be “minimized, ignored, or explained away as denial or ‘false hope’” (Sobsey, 1996, p.7). Despite this tendency to minimize positive experiences, research does show that challenging life events, including raising a child with a disability, have the potential to elicit transformative experiences resulting in personal growth (Larson, 1998; Palus, 1993).

Research is beginning to emerge that shows that life challenges can have positive and life changing benefits for well-being. Repeated stressful events may result in future stressful events as being experienced as less distressing (Aldwin, 1994). Stress can lead to transforming people’s perspectives, which allows them to cope more effectively with future stresses. Transformation is a term used to designate outcomes when a person feels significantly and permanently changed. This change can result in the person’s personality being extended or reduced in either a positive or negative direction. Ultimately, transformations entail a change in a person’s values, beliefs, attitudes, and views of themselves, others, and society (Palus, 1993; Sobsey, 1996).

Studies that incorporate positive life transformations as a result of raising a child with a disability are important for several reasons. These studies offer a balanced view of family life. They do not dismiss the challenges that parents face. They do describe some family experiences as life altering and stressful. However, they also illustrate how life can be changed for the better and that challenges can be overcome. This is a powerful message for families who are new to the experience of disability in their family.

A recent study by Kearney and Griffin (2001) examined the experiences of six parents of children with significant developmental disabilities. They found that these parents experienced many difficulties in daily living. One theme that these parents portrayed was sorrow. Sorrow included many aspects including fear for their child's future, feelings of powerlessness and helplessness, and frustration with family, friends, and professionals. Despite feelings of sorrow, these families also experienced great joy in relation to their child. Their personal and emotional lives were strengthened, they felt intense love and pride for their child, and were able to rejoice in the "small things." These families experienced life transformations that made them stronger.

A study by Krauss and Seltzer (1993) examined coping strategies among older mothers of children diagnosed with cognitive delays. This study found that despite hardships in parenting, these mothers experienced great life satisfaction. The initial diagnosis caused them to re-think and re-define their family situations. Once acceptance of the disability occurred, they were able to reinterpret the meaning of their life situations and see the events in their lives as a means to grow personally and spiritually. Their children helped them transform and they were able to view life differently.

A study by Abbott and Meredith (1986) found that parents raising a child with mental retardation had reported that their family had "grown stronger, closer, and more unified" (p. 374) as a result of their experiences. Parents who "defined their situation in a positive way, accepting the child as they did their other children" (p. 374), and who emphasized their child's positive attributions, adapted well to having a child with disability. Mothers in a study by Byrne, Cunningham, and Sloper (1988) discussed ways that they had changed for the better. These mothers became less materialistic, less

self-centered, gained a better appreciation of what was important in life, became more self-confident, and placed less value on appearance and ability.

A qualitative study by Stainton and Besser (1998) was the only study found that examined only positive aspects of raising a child with special needs. This study found that raising a child with special needs can be a source of joy and happiness and can lead parents to more purposeful and meaningful lives. Parents reported that they experienced an increase in personal and social networks as well as increased spirituality, family unity, growth and strength. They also gained a more tolerant and understanding attitude toward all human differences.

One study by Scorgie et al. (1996) specifically examined parental transformations when a child has a disability. These researchers interviewed parents of children with disabilities regarding their experiences and feelings surrounding life, parenting, and disability. The authors found that families raising a child with a disability experienced three kinds of transformations. These included personal (who they were), relational (how they relate to others), and perspectival (how they view the world) transformations. Scorgie found that families felt personally changed, gained personal strength, changed how they related to other people, and learned to celebrate life. Scorgie and Sobsey (2000) found that 80% of parents surveyed, who are also raising children with disabilities, experienced similar positive life transformations as those parents initially interviewed by Scorgie et al. in 1996.

A recent study by Kausar et al. (2003) examined the role of hope in families of children with disabilities. This qualitative study found that raising a child with a disability led families to experience emotional strength, personal growth, and meaning in life.

These families experienced hope through deep care and compassion for their child, a realistic understanding of their child's disability, a focus on their child's abilities, personal transformations, unified family, social support, and strong spiritual beliefs.

These factors helped these families cope with the stresses and difficulties of raising their children.

Spirituality is one theme that emerges frequently in the disability and transformation literature. For some families, religion and faith can help them make sense of their children's disabilities and can provide elements of support and strength (Kausar et al., 2003). A study by Skinner, Correa, Skinner, and Bailey (2001) found that faith was a significant source of support for many Latino families. Faith brought solace, strength, hope, and a feeling of being closer to God. Many stated that their faith increased after the birth of their child with a disability and that this fostered a "personal transformation around disability" (p.311).

Researchers have examined the role of religious conviction for parents of children with disabilities. Most studies support the notion that faith and religious conviction have a positive effect on family adaptation (Krauss & Seltzer, 1993). An article by Glidden, Rogers-Dulan, and Hill (1999) explored the roles of ethnicity, culture, and religion for parents rearing children with disabilities. They commented that religious support groups could provide invaluable support to families including moral, social, financial, emotional, and educational assistance. They also contended that culture and ethnicity are variables that interact with religious convictions and that the interplay between these variables is important to consider when examining coping and adjustment among families.

### Family and Social Support

We all rely on support of friends and family, particularly during difficult times in our lives. Social support is equally important for some parents who have a child with a disability. Many families rely on community, professional, and informal extra-familial support to cope with the demands of caring for a child with special medical, emotional, and psychological needs (Antosh, 1990; Trute, 1988). For many people, social support can greatly reduce many negative effects of stress (i.e., depression, anxiety) and can lead to better coping strategies. For example, studies by Gill and Harris (1991) and Gray and Holden (1992) found that mothers of children with autism were significantly less depressed and stressed if they had more available social support. A study by Abbott and Meredith (1986) found that parents raising a child with mental retardation adapted well, provided that the parents had a secure marriage, were involved with parent support groups, and had strong religious beliefs. Positive belief systems and a non-critical and supportive family network can serve to decrease stress for some parents (Frey, Greenberg, & Fewell, 1989).

A study by Akkok (1994) examined parental experiences regarding children with disabilities in Turkey. In spite of the limited professional services for families in Turkey, most families functioned well, despite the increased demands of caring for children with disabilities. This result is explained by the Turkish culture in which mothers rely heavily on extended family for the care of their children. This support system leads to decreased caretaking demands for mothers and has a positive impact on parenting competence and self-esteem.



Several researchers have examined the role of both formal and informal services to families of children with disabilities. A recent study by Law, King, Stewart, and King (2001) evaluated the effects of belonging to a parent-led support group for parents of children with disabilities. This qualitative study found that mothers attended group meetings more frequently than fathers. The main purpose of the group membership was emotional support, information, education, and advocacy. Parents noted that support groups were able to provide camaraderie and a sense of belonging, a means to cope, to gain information, and strategies to deal with disability issues. They viewed group meetings as a way to organize ideas and collectively advocate for change.

A study by Hendriks, DeMoor, Oud, and Savelberg (2000) evaluated parental well-being following the participation of their child in a therapeutic toddler class for children with motor disabilities. Mothers and fathers reported that they felt more connected to other parents, more empowered, and gained insight into their child's abilities following 10-months of class participation. The program was noted to have had a greater impact on the well-being of mothers compared to fathers, specifically regarding feeling physically in shape, planning social tasks, and having more time for self-care and relaxation. Fathers appeared to have gained more insight into their child's abilities compared to mothers.

Informal support has also been found to be equally, if not more instrumental, to assisting parents of children with disabilities. A literature review by Boyd (2002) found that low levels of social support provided to mothers of children with autism were linked to increased depression and anxiety. For many mothers of children with autism, informal support systems, including spousal and family assistance, were more effective at

decreasing stress than were formal support systems. A recent study by Trute (2003) found that emotional support provided by grandparents is more effective at buffering parental psychological adjustment and stress than grandparent instrumental support (i.e., money or practical help). It may also be true that a parent's perceived level of support may be more instrumental than actual available support (Farmer et al., 2004).

Despite the known importance of social support for families, parents often need additional support from friends, family, and professionals. Some families have stated that their extended family and friends had difficulty accepting their child with a disability and were not supportive at the time of their child's diagnosis (Cahill & Glidden, 1996). Other families have stated that members of the extended family are supportive financially but less supportive emotionally (DeMyer & Goldberg, 1983). Some stated their family was embarrassed or afraid and did not know how to relate to their situation. For these reasons, some families turn to parent support groups that can provide camaraderie, understanding, and a sense of partnership in dealing with issues surrounding disability (Law et al., 2001; McAndrew, 1976). Parent support groups can provide unconditional support, information, and perspective. Also, these groups can provide parents with a more positive view of disability (Kausar et al., 2003).

Parents are beginning to express the importance of external support from employers. A study by Freeman, Litchfield, and Warfield (1995) examined how some families balance work and family responsibilities and how employers can improve their employee family needs. The majority of families expressed the need for supportive work environments and policies related to family life. Support at work that was deemed

important included flexible hours, time off for medical appointments with the child, and comprehensive benefit packages.

One finding that seems to permeate the research on family and disability is the negative experience that some families encounter when dealing with professionals.

According to Gray (1993) there is a “lack of fit between the expectations of parents and professionals over the nature of the diagnosis, services available for treatment, and the emotional significance of the illness” (p. 1037). Some professionals expect families raising children with disabilities to be stressed, grief-ridden, and experiencing negative outcomes (Sobsey, 1996). A study by Bebko, Konstantareas, and Springer (1987) found that professionals rated parents as more stressed than parents rated themselves.

Additionally, some professionals hold pessimistic views of the child’s ability to learn and advance. This pessimism may be part of the reason why parents view some interactions with professionals in a negative light. A study by Larson (1998) noted that mothers often felt that doctors’ remarks were “impersonal and failed to respect their child’s humanity” (p. 869). Relatedly, a study by Perrin and Lewkowicz (2000) found that physicians often underestimated the child and family needs of parents of children with chronic medical conditions, despite rating the severity of the child’s disability worse than parents did.

Anger and frustration towards professionals is not an uncommon finding. Some parents blame medical professionals for lack of information regarding disability issues, failing to adequately help their children, inability to provide referral information, and failing to meet the needs of their families (Hendrickson et al., 2000; Larson, 1998). Some parents feel that their children’s educational progress was slowed due to professional misinformation (Coyné-Cutler, 1984). “Collaboration between professionals and parents

may be strained when family's discourse is viewed as unrealistic, overly emotional, exceedingly optimistic, and confusing by professionals" (Larson, 1998, p. 865).

Additionally, some parents view professionals as unhelpful, non-supportive, lacking in empathy and sensitivity, and lacking the ability to communicate information in layman's terms (Clarkson, Shelton, Bray, & Ballard, 1996; DeMyer, 1979; Kausar et al., 2003).

For the most part, parents also perceive professional distance as a lack of empathy and understanding (Gray, 1993; Larson, 1998; Scorgie et al., 1996).

### Adoption and Disability

As illustrated, there is an abundance of research that examines the experiences of parents who have a child with disability. It is now time to consider the experiences of parents who adopt a child with a disability. Adoptive families differ from birth families in a number of ways, including: (a) their ability to prepare for the arrival of a child with a disability into their homes and lives (Goetting & Goetting, 1993); (b) their knowledge that they are not biologically responsible for the child's disability, which may result in fewer feelings of guilt, denial, or shame (Davis & Montgomery, 1981; Eheart & Power, 1991; Glidden & Bush, 1990); and (c) screening of adoptive parents prior to a child entering their home which may affect their ability to adapt and cope with the child's disability. One must also consider the fact that adoptive parents are actively seeking parenthood whereas some biological parents may not be. An area that deserves further notice is the nature of adoptive parents' unique life experiences.

Parents, children, and families formed by adoption have unique challenges and tasks to overcome. Research has examined the psychological impact of adoption of families and the resulting core issues for adopted children. Resolving these issues is often

cited as being a life-long process, not only for adopted children but also for adoptive parents and families (Smit, 2002). Core issues are often identified as including feelings of loss, grief, rejection, identity struggles, and difficulties with intimacy and attachment (Neil, 2000; Smit, 2000). Factors such as openness at the time of placement may also impact on adoption outcomes and affect the core issues that adopted children face. These core issues will now be discussed in more detail, followed by a discussion of special needs adoption.

### Core Issues of Adoption

#### Loss, Grief, and Rejection

Adopted children often experience feelings of loss (Neil, 2000). Loss encompasses the loss of birth parents, siblings, and other connections to the biological family. Loss also includes loss of history, medical information, culture, and family traditions (Smit, 2002). Children may wonder why they were placed for adoption and these questions have been noted to re-surface as the child ages and gains increased cognitive awareness of the adoption and their feelings (Neil, 2000). Grief is a natural response to loss and grieving these losses has been viewed as healthy adaptive development for adopted children (Smit). Children must come to terms with why they were placed for adoption and to cope with the family they lost. Some children will experience feelings of rejection and feel responsible for the birth parent's decision to place them for adoption. They may feel "bad, defective, unlovable, and unworthy" (Smit, 2002, p. 147). Children may fear repeated rejection from their adoptive family, peers, and other important persons in their lives. Smit noted that helping adopted children feel a sense of belonging is important to diminish these feelings of rejection.

### Identity and Intimacy

As children reach adolescence, they must begin to make sense of who they are and gain a sense of self-identity. For children who are adopted, Smit (2002) noted that the tasks of adolescence involve exploring the meaning of being adopted and connecting the adoption to one's sense of self. When missing information about one's past is evident, connecting one's sense of self can be difficult. Cultural differences can also be difficult to analyze and incorporate into one's identity. Smit also noted that identity struggles may affect a person's ability to develop intimate relationships with others. Support is often needed to assist older adolescents and young adults through this process and to resolve adoption-related issues.

### Openness in Adoption

Research in adoption is beginning to look at the concept of openness in the adoption process and its impact on an adopted child's resolution of core issues of loss, rejection, and identity. Open adoption allows birth families to be involved with the adoption process and to interact with adoptive families. As noted by Silverstein and Roszia (1999), open adoption serves to "minimize loss and maintain and celebrate adopted children's relationships and connections" (p. 638). The reality of many adoption placements is that some children have memories of living with their birth families and that subsequent removal from these homes can be traumatic. This is especially evident when the rights of birth parents have been terminated due to violence, abuse, and/or neglect. Openness in adoptions can help children cope with grief and loss they may feel and to acknowledge their membership in new families. Continuing contact with siblings, previous foster parents, and extended family can nurture their identities and keep them

connected with themselves, their cultures, and their heritages (Silverstein & Roszia, 1999). For adoptive parents, open contact with birth families can answer questions, provide a more complete history, and help prepare them for their role as new parents.

A study by Sykes (2001) examined the impact of continuing contact with families of origin on the experiences of adoptive parents. The study noted that many adoptive parents initially believed that open contact with birth parents might pose a threat to their parental authority. Concerns were also raised when birth parents' behaviour and communication toward their children was inappropriate or confusing. Several adoptive parents felt that being in control of the contact helped alleviate their fears. Some parents felt that contact with birth parents helped confirmed their role as parents and enhanced their feelings of parenting competence. Many adoptive parents felt acknowledgement that their home was the best placement for the child. Contact also helped their children gain a better understanding of their past. For some adoptive parents, contact with birth parents was viewed as stressful, fearful, and exhausting. This was most evident when parents felt that birth parents posed a physical or emotional threat to themselves or their child. Some parents expressed anger toward abusive parents, while others felt empathy. Some adoptive parents reported feeling the need to compete with birth parents for their child's affections. Overall, continuing contact with birth parents over time was noted to develop into greater empathy for birth parents and to assist in developing more complete and flexible past life stories for children.

#### Special Needs Adoption

The term "special needs" in the field of adoption implies that the child will need extra support over and above the support needed by other children. This support could

involve extra medical, educational, psychological, or community resources (Dumbleton, 1996). Special needs adoption, therefore, encompasses many factors that are believed to make adoption more difficult, including children over the age of 5, ethnic minorities, sibling groups, and children with emotional, behavioural, medical, or developmental disabilities (Eheart & Power, 1991; Reilly & Platz, 2003). Special needs adoption has increased in the last decade. The number of healthy babies available for adoption has decreased due to increased abortion rates, increased use of effective birth control, and the growing social acceptance of single-parent families. Tatara (1993) (as cited in Sullivan, Freundlich, & Donaldson, 1999) reports that there has been a steady increase in the percentage of children with special needs awaiting adoptive placements. There are authors who estimate that between 30 and 50 percent of children awaiting adoption have a developmental disability (National Adoption Information Clearinghouse, 1999). In response to the reduction in healthy babies available for adoption, prospective adoptive parents are beginning to consider special needs children as a means to having the family that they desire (Barry, Barth, & Needell, 1996; Brooks, James, & Barth, 2002; Eheart & Power, 1991; Davis & Montgomery, 1981; Glidden & Pursley, 1989; McCullagh, 1985; Reilly & Platz, 2003; Todis & Singer, 1989; Westhues & Cohen, 1990).

A recent study by Brooks et al. (2002) examined adoptive parents' preferences for certain characteristics of children eligible for foster or adoptive care. Characteristics examined were race, age, and whether a child was diagnosed with a disability or special need. Results indicate that prospective parents preferred young, Caucasian children without special needs. Results also indicated the following: (a) 82% of all parents reported that they would be willing to adopt a foster child; (b) large percentages of



parents were willing to adopt biracially (88%), Latino (83%), Native American (81%), Asian (81%), and African-American (64%); (c) most parents preferred to adopt a child as an infant (94%), however many were also willing to adopt children aged 1-2 years (85%), 3-5 years (71%), 6-12 years (45%), and over 13 years (25%); and (d) 75% of parents were willing to adopt a child with special needs, including sibling groups and children exposed to substances prenatally. An in-depth discussion of factors that constitute “special needs” including child age, race, and disability, will now be presented.

### Age and Adoption

Older age of a child at the time of adoption has been found to have an impact on the child’s subsequent adjustment and feelings of his/her adoption experience (Howe 2001; Howe, Shemmings, & Feast, 2001). Children adopted as infants have often experienced more continuous care and less disruption in caregivers prior to adoption placement. Children relinquished as infants tend to have good starts in life and are often well functioning at the time of placement (Neil, 2000). Older children placed for adoption are more likely to have experienced multiple caregivers and suffered pre-adoption abuse, neglect, and /or rejection (Howe, 2001).

A study by Howe et al. (2001) examined adopted adults’ experience of adoption, with age of placement as a key variable. Results indicated that 66% of those children placed after the age of two reported feeling different from their birth families and older age placement increased the risk of feeling that they did not belong in the family. In general, older age at placement was associated with increased negative and mixed emotions regarding the adoption experience.

Results of a similar study by Howe (2001) found that age at placement was associated not only with the adopted person's experience of feeling unwanted but also with rates of contact with both birth and adoptive parents. Results indicated that older children placed for adoption reported feeling a lack of belonging in the family and did not feel loved by adoptive mothers. They were also less likely to remain in contact with both birth and adoptive parents.

One study by Neil (2000) examined the reasons why young children were placed for adoption and the implications for subsequent psychological development. Neil examined three groups of children. The first group of children were relinquished as infants (those children given up for adoption before or around the time of birth). Given these children's ages at the time of the adoption placement (with the majority younger than 6 months), most attached successfully to new caregivers and were at a lower risk of future developmental problems. Most had very little contact with birth parents and most, as adults, did not desire to locate birth parents or family. The second group of children was children placed for adoption due to complex reasons, including parents feeling unable to cope, pregnancy as a result of rape, or parents unable to care for their child. Some children were placed for adoption, while siblings remained in the family home. Most children in this group had experienced multiple caregivers and had some resulting attachment difficulties. Many children in this group were noted to experience feelings of rejection, loss, and grief. The third group of children was children who were removed from their family's care as a result of abuse and/or neglect. Most children had lived for some period of time with birth families. It was noted that these children and their birth families experienced the highest amount of loss and disadvantage. Additionally, 25% of

these children maintained open contact with birth relatives after the adoption. Neil discussed the implications of openness for these three groups of children.

Recommendations for adoptive parents included: (a) openness and honesty when discussing birth family history, (b) telling the facts surrounding the adoption in a sympathetic and realistic manner, and (c) post-adoption supports to manage openness issues with birth parents, especially for older children with intact birth histories.

#### Adoption of Children with a History of Abuse and Neglect

As stated earlier, older children placed for adoption are often victims of abuse and neglect (Howe, 2001). Research has noted that children who were abused or who exhibit externalizing behavioural problems were more difficult to parent and at a higher risk of adoption termination (Coyne & Brown, 1986; Dance, Rushton, & Quinton, 2002; Donenberg & Baker, 1993; Eheart & Power, 1991; Groze & Gruenewald, 1991; Howe & Fearnley, 2003; Rosenthal, 1993; Smith & Howard, 1994).

Research is beginning to explore the developmental, social, and cognitive effects of abuse on children placed for adoption and to provide valuable support to adoptive parents of these children. Children with a history of severe neglect, abuse, and/or multiple caregiver placements are at risk of developing gaps in their social development, leading to difficulties in their ability to form bonds with adoptive families (Hughes, 1999).

Hughes examined the experiences of parents who adopted children with significant attachment difficulties, following the experiences of abuse or trauma. Hughes discussed the importance of a match between the child and the adoptive family when a child has shown difficulty making attachments to others. He commented, “the decision to adopt a child with significant attachment problems is one that should be made only with the full

knowledge about the child and after much deliberation” (p. 551). Post adoptive supports that Hughes noted as important included support groups, respite services, and in-home support from mental health and family support professionals.

New research is emerging that highlights important factors when adopting children who have experienced abuse and neglect. A qualitative study by Henry (1999) examined five themes of resilience and their impact for adopted children who have experienced abusive home lives in the past. One theme identified by Henry was labeled “loyalty to birth parents.” For many children, joining a new family may resemble a loss for them, especially when they have been removed from previous homes. A loyalty to previous family, despite the existence of abuse, is often present for these children. This was reported by Henry to be very difficult for adoptive parents to understand. Henry noted the importance of this theme to assist adoptive children in grieving their previous families and to help establish bonds to their new homes. A second theme identified in the study by Henry was labeled “invisibility to the abuser.” Children who have experienced abuse often survive these experiences by isolating themselves from the abusers and attempting to distance themselves from danger. As these children enter adoptive placements, these behaviours of withdrawal or distance toward their new families can be evident and also difficult for adoptive parents to understand. Adopting a child with a traumatic past often requires adoptive parents to be patient and receive extra support and professional assistance during the initial transitions and joining of two family worlds.

A study by Smith and Howard (1994) examined the effects of previous sexual abuse on the adoptive adjustment of children. Results indicated that children who experienced sexual abuse had more disruptions in later adoptive placements, exhibited

greater behavioural difficulties, had trouble attaching to new caregivers, and experienced frequent moves between caregivers. The authors noted that the traumatic impact of sexual abuse often led to sexual acting out in children, feelings of powerlessness, betrayal and anger toward the birth family, grief, low self-esteem, and self-destructive behaviours as a result of shame. It was noted that the issues related to sexual abuse trauma and grief can hinder a child's separation from the birth family and subsequent attachment to a new family.

A study by Dance et al. (2002) examined rejection by birth parents and a child's subsequent adjustment to adoptive placement. Results indicated that children subjected to emotional abuse, specifically those children singled out by birth parents and rejected, experienced great difficulty bonding with new families.

Another factor that affects the adoption of children with special needs is prenatal substance abuse and its effects on a child's learning and development. A study by McCarty and Waterman (1999) interviewed parents who had adopted children with prenatal exposure to alcohol and/or drugs. These children were also racial minorities and many had lived in several previous foster placements. It was noted that 50% had also been victims of abuse, neglect, and/or trauma. Results indicated that adoptive parents generally experienced positive outcomes following the adoptions and noted many rewards to parenting, over and above what they initially expected. It was found that the initial transition of the child into the home was most difficult, with many parents reporting difficulty dealing with their children's behavioural outbursts, moods, inability to adapt, and a mismatch between the children's behaviour and parental expectations. It

was also noted that parents felt supported by external support systems. Adjustment generally improved over the first year of the adoption.

### Transracial Adoption

Adoption of children of a different race or culture has been noted as a type of special needs adoption. Transracial adoption remains a controversial issue (Feigelman, 2000; Hollingsworth, 1994) and a discussion of the moral implications is beyond the scope of the current study. A discussion of its effect on adoptive placement does warrant some consideration.

An article by Vonk (2001) provides an extensive literature review of transracial issues for adoptive parents. Specific constructs of racial awareness, multicultural planning, and survival skills in relation to transracial adoption were reviewed by Vonk. He noted that parents of adopted children of different cultural backgrounds needed to engage in a developmental process to understand their own values, biases, and assumptions about their child's race and culture of birth. This process of self-reflection is helpful to parents seeking to meet their children's unique racial and cultural needs. In summary, Vonk concluded that, "parents who are sensitive to and aware of race, ethnicity, and culture are thought to be more able to help their children cope successfully with related issues. Racial awareness may help parents understand the importance of recognizing their child's race and of fostering their child's identification with his or her race" (p. 250-251).

In addition to racial awareness, Vonk (2001) discussed the importance of multicultural planning. He defined this as the "creation of avenues for the transracially adopted child to learn about and participate in his or her own culture of birth" (p.251).

Adoptive parents should strive to provide avenues for their children to be exposed to and involved in their birth culture. Vonk discussed the importance of survival skills for adoptive parents. He stressed the importance for adoptive parents to prepare their children to cope successfully with racism and to develop strong and positive self-images.

A recent article by Vidal de Haymes and Simon (2003) explored the experiences of children and families who adopted transracially. It was found that parents often felt that others questioned their motives for the adoption and frequently felt unsupported by their communities. Adopting transracially made families more visible in the community and this often resulted in heightened curiosity and questioning from others. Adoptive parents also reported various reactions from family, including support, initial resistance, as well as persistent rejection. This study also found that parents and adopted children experienced some difficulty finding acceptance in both white and black communities, schools, and neighborhoods. As a result of their adoption experiences, most became more aware of racial issues and experienced personal transformations of their perspectives. Many parents reported feeling more open to multicultural issues and made efforts to ensure their children became aware of their birth heritage. Parents also reported a need for additional support and services specifically related to cultural issues and greater links to other parents who have also adopted transracially.

A study by Feigelman (2000) found that a large majority of parents who adopted interracially reported having close and warm relationships with their adopted children and 75% reported high satisfaction with their adoptions. A key finding showed that white adoptive parents residing in predominately white communities reported that their children experienced increased discomfort compared to children who lived in more integrated and

racially mixed neighborhoods. The authors recommended that transracial adoptive parents may want to consider relocating to more culturally mixed communities as a means to assist in their children's adjustment post adoption.

#### Adoption of Children with Disabilities

More and more studies are examining families who adopt children with special needs, including studies of children with developmental disabilities. According to Phillips (1998), "until 25 years ago, the idea that disabled children could be placed for adoption was totally inconceivable and unheard of...they were labeled as 'unfit' medically and if their parents could not cope with them they spent most or all of their childhood away from their families and in some form of residential provision" (p. 157). There has also been the "assumption that seriously handicapped children are extremely hard to parent and less desirable to potential adoptive parents" (Coyne & Brown, 1985, p. 607). People sometimes question the "wisdom or motive of a family who would seek out the responsibility of rearing a handicapped child" (Davis & Montgomery, 1981, p. 296). Even some adoption agency professionals question the motives of parents who seek a child with special needs (Wimmer & Richardson, 1990) and parents may even be viewed as suspect (Phillips, 1998). The growing visibility of children with disabilities living happy lives in the community and the increase of positive portrayals of families of children with disabilities may be making adoption of these children more attractive. Despite this, children with disabilities have a difficult time securing permanent home placements due to the fact that there are still too few appropriate and willing families to care for them (Phillips, 1998). Additionally, some adoption agencies may be ill equipped



to handle issues in relation to disability and adoption (Reilly & Platz, 2003; Wimmer & Richardson, 1990).

The incidence of adoption placements breaking down (adoption disruptions) has been reported to be higher when the child has a disability compared to healthy infant adoptions (Westhues & Cohen, 1990). There are several mediating variables that affect the quality of post-adoptive placements. These include the family's commitment to and preparation for the child, how the child's characteristics and personality match parental expectations and preferences, parental personality, family dynamics, and family support systems (Glidden & Bush, 1990). Adoptions are at risk of termination if adoptive parents adopt older children (over the age of 5), if adoptive parents do not receive adequate background information about the birth family, or if adoptive parents lack external support (Festinger, 2002; Rosenthal, 1993). Longitudinal research on adoption outcomes indicates that adoptive placements are more likely to be sustained if fathers are involved with childcare, if marriages are strong, and if the adoptive parents choose to adopt due to their own infertility (Westhues & Cohen, 1990). When a child has a disability, adoption disruption rates are found to be unrelated to the type of disability, medical needs, speech difficulties, problems with mobility, or language/learning disabilities (Coyne & Brown, 1985). Disruption rates have, however, been shown to be related to problems such as aggression, defiance, or destructive behaviour exhibited by the child (Coyne & Brown, 1986; Festinger, 2002; Groze & Gruenewald, 1991).

A study by Festinger (2002) examined adoption dissolutions for a random sample of children adopted in New York City in 1996. Results indicated that adoption dissolution was an infrequent occurrence. The study did find that a majority of families experienced

challenges and struggles during the post-adoption period. Many parents in Festinger's study reported a need for additional support, services, and information regarding special needs adoption. Assistance was deemed necessary in terms of after-school services, educational programming, homecare, clinical services, health services, housing, and legal assistance.

### Types of Families who Adopt Children with Special Needs

Many adoptive families who specifically choose to adopt a child with a known disability had previous experience with disability (Davis & Montgomery, 1981; Goetting & Goetting, 1993; Marx, 1990). The families either knew the child through a previous foster placement situation or had previous experience working with other children with disabilities (Brown, 1988). Many adoptive parents report that their previous experience with disability enabled them to successfully care for and adopt a child with special needs (Dumbleton, 1996). Some adoptive parents are recruited from the larger community and did not previously know the child through a work or foster parent relationship. Most of these parents, however, specifically request to adopt and care for a child with a disability (Coyne & Brown, 1985, 1986).

According to adoption agency staff, the ideal adoptive parents for children with special needs are mature, flexible, family-centered, religious, experienced in dealing with children, able to handle stressful situations, and have a strong desire to adopt a child with a disability (Coyne & Brown, 1986; Davis & Montgomery, 1981; National Adoption Information Clearinghouse, 1999). The majority of adoptive families are warm, caring, accepting of individual differences, and have a clear understanding that their child may not attain certain skills and achievements regarded as desirable by societal standards

(Coyne & Brown, 1986; Unger, 1988). They also tend to value home and community (Marx, 1990). Many prospective adoptive parents view themselves as having strong parenting skills and the ability and knowledge to parent a child with challenging behaviours and needs (National Adoption Information Clearinghouse, 1999).

#### Reasons to Adopt a Child with a Disability

Studies by Glidden (1984, 1986) examined pre-adoption motivation in families living in Britain. The results indicated that the majority of families who adopted a child with special needs adopted due to biological infertility, religious conviction, or personal or professional experience with children with disabilities. Studies by Nelson (1985) and Todis and Singer (1989) found that the main reasons for adoption were having a previous attachment to the child through a foster-parent relationship, not being able to adopt a “healthy” child, concern about the needs of children not adopted, feelings that they could make a difference in a child’s life, and a view that the child would mesh well with their current way of life. Also, many families felt proud that they were contributing to the well being of a child.

Studies by Goetting and Goetting (1993) and Marx (1990) found that many adoptive parents felt a “calling” to care for a special child. Many adoptive parents viewed adoption “as an opportunity to do something for someone else, to nurture children already living who are entitled to a family, and to replace the one lost to them” (Davis & Montgomery, 1981, p. 293).

Now that we have an idea of what the core issues of adoption may include and a better understanding of special needs adoption, we can begin to examine life experiences for adoptive families of children with disabilities. Key areas highlighted for birth parents

of children with special needs are also salient for adoptive parents of children with disabilities. Specifically, what are their experiences when the child first enters their home, how do they adapt and cope with daily life, and what supports do families view as important?

#### Parental Reactions When a Child is First Adopted

What adoptive families experience when a child with a disability enters their homes may differ from the experience of birth families. Previous literature portrays birth families reacting with sadness, shock, and disbelief to the birth or diagnosis of a child with a disability. Families, who choose to adopt a child with a known disability, make a conscious decision to accept the reality and responsibilities associated with the child's special needs. They are aware that the child has a handicap and many have information and strategies to cope with the child's abilities prior to the child's entrance into the family home (Glidden, 1984, 1986). Some adoptive parents have the opportunity to choose the kind of child that will fit into their lifestyle. Birth families usually do not have this choice. Being prepared for a child with a disability can enable positive adjustment and can make the positive aspects of parenting more readily apparent (Glidden & Bush 1990).

There are also adoptive families who do not consciously choose to adopt a child with a disability because the diagnosis occurs later. A study by Crittenden, Waterbury, and Ricker (1985) examined birth and adoptive parental reactions to the diagnosis of hearing disabilities in their children. They found that birth parents experienced more severe grief and depression compared to adoptive parents. They found that all birth parents in their study experienced grief reactions, which the authors described as anger, blame, denial, depression, and sorrow when their child was diagnosed with a disability.

Adoptive parents' reactions were less severe. This finding was interpreted as a result of the decreased guilt that adoptive parents experience. Adoptive parents know they are not biologically responsible for their child's disability and may experience less guilt and subsequent depression than birth parents.

Research in adoption disruptions indicates that there is an increased disruption rate for families who find out that their child has a disability after the adoption takes place compared to families who knew about the disability prior to the adoption (Barth & Berry, 1988 as stated in Glidden, 1991). This finding further supports the notion that choice and preparedness are important factors in special needs adoption and can also explain why many birth parents (who often learn about the disability after their child is born) experience difficulties. Related research by Rosenthal and Groze (1991) examined adoption outcomes for parents who adopted children with physical handicaps compared to children with mental retardation or serious medical conditions. Parents reported experiencing fewer positive outcomes when their child was diagnosed with mental retardation or a learning disability. This result was interpreted as providing support for the importance of information and preparation for adoptive parents prior to the placement of any child into the home. Often children with cognitive or learning delays have needs that are less visible than children with physical disabilities. Needs that are not as visible are therefore more difficult to predict and prepare for, which leads to additional parenting stress.

Parents who adopt children may not experience as much guilt or shame regarding their children compared to birth parents. These families can attribute problems to external situations or the children's past and this serves to alleviate much of the guilt (Todis &

Singer, 1989). A study by Glidden (1986) found that adoptive parents do experience an initial crisis but this crisis is usually short-lived and parents adjust well to the demands of raising a child with a disability. Most families expected that the outcome would be more stressful than their actual experience and the majority said that they would like to adopt another child with special needs in the future.

Relatedly, research on families who adopt numerous children with disabilities report that with each subsequent adoption, parents experience fewer crises and less stress. Families who adopt more than one child with a disability also tend to be highly organized and are able to effectively utilize support services and resources (Todis & Singer, 1989). Also noted is that families who adopt more than one child with a disability are often very visible in the community and this can be a source of prejudice and discrimination against them. This bias can be an additional source of stress for these families (Todis & Singer, 1989). A recent study by Glidden, Flaherty, and McGlone (2000) examined adjustment in families who adopted five or more children compared to families who adopted four or fewer children. Results indicated that parents of larger families were coping as well or better than parents who adopted fewer children. Parents generally reported positive family coping despite increased child caring responsibilities associated with having additional children within the home.

As noted earlier, studies examining birth families have investigated how the type of disability affects family coping and adaptation. Researchers in the field of adoption are also interested in how type of disability affects coping and functioning for adoptive parents. Glidden and Cahill (1998) investigated family functioning for adoptive parents of children with Down syndrome compared to parents who adopted children with other

developmental disabilities. Interest in this topic was spurred by research suggesting that children with Down syndrome are easier to parent than children with other types of disabilities. Results indicated that all families, regardless of their child's handicap, evidenced healthy family functioning five years post-adoptive placement. Type of disability did not appear to play a role in family adaptation.

### Challenges and Rewards for Adoptive Parents

There are difficulties and challenges that can occur when parents adopt a child with a disability. These include behaviour and parenting problems, stress, financial concerns, difficulty coordinating services, and frustration with delays and uncertainty in the adoption process (Festinger, 2002; Glidden & Bush, 1990; Groze & Gruenewald, 1991; McCarty & Waterman, 1999; Phillips, 1998; Reilly & Platz, 2003). Other obstacles include difficulty helping the child disengage from the past, problems uniting different family cultures and backgrounds, time and childcare demands, discipline problems, and helping siblings understand and cope with the adoption (Vidal de Haymes & Simon, 2003; McGlone, Santos, Kazama, Fong, & Mueller, 2002; Mullin, 1999; Phillips, 1998). Impairments in the adoptive child's developmental progress can also be a source of pain and frustration for adoptive families (Rosenthal & Groze, 1992). A study by Marx (1990) found that the most common difficulties faced by adoptive parents are (a) obtaining professional help, (b) fear for the child's future, (c) negative reactions from others, (d) difficulty finding appropriate childcare, and (e) feelings of pessimism from professionals. Research by McGlone et al. (2002) found that increased parenting stress was related to increased workloads of raising a child with extra needs and subsequent lack of time for parents to spend together as a couple. Bather and Berry (1988) (as cited in McGlone et

al., 2002), identified sources of stress for adoptive parents to include misleading expectations, lack of support, financial burdens, lack of nurturance of marital relationships, and difficulty adjusting to new parenting roles.

Some believe that adopting a child with a disability is a difficult endeavor. “Families face enormous challenges and strains in adopting a special needs child” (Groze & Gruenewald, 1991, p. 581), and many adoptive parents must sacrifice their careers and lifestyles for the new child in the family (Ward, 1996). Phillips (1998) described her negative experiences with a local social services department when a family she knew requested to adopt a second child with a disability. This adoption request was denied on the grounds that it was believed to be an “impossible and foolish task for any family” (p. 158).

A recent study by McGlone et al. (2002) examined stress among adoptive parents of children with special needs. Results indicated that parents reported higher than average stress levels associated with child characteristics, parent-child interactions, family and parental adjustment, and services following the adoptions. Increased stress was also noted when adoptive children displayed externalizing behavioural problems (i.e., violence, tantrums, and hyperactivity), internalizing behavioural concerns (i.e., self harm, excessive fears, and lack of self confidence), and/or chronic medical problems.

A study by Glidden and Bush (1990) compared maternal adjustment to disability for adoptive and birth families. The results indicated that birth mothers showed higher levels of depression than adoptive mothers did at the time immediately after the initial diagnosis or adoption placement. Adoptive mothers reported higher levels of family pride, less family conflict, and more marital happiness. Birth mothers reported more



family disharmony, more concern and stress regarding the care of their children, and more limitations on family opportunities.

Longitudinal research is emerging that examines post-adoptive functioning for families over time. Glidden and Johnson (1999) examined post-adoptive adjustment in adoptive families of children with disabilities 12 years following the initial adoption placement. Families reported a balance of stress and reward, but generally perceived their experiences as positive. Of this sample, 50% have adopted at least one additional child, which is another indicator of positive family experiences. Glidden (2000), using the same sample of adoptive parents, also examined long-term adjustment for adoptive families. Results indicated that the families surveyed experienced positive adjustment. Parental variables including age, level of education, and socio-economic status had no effect on adjustment. Characteristics of the adopted child also did not affect level of parental adjustment. Additionally, it was reported that parents who adopted more than one child with a disability also experienced positive outcomes.

Another longitudinal study conducted by Glidden and Schoolcraft (2003) examined and compared depressive symptoms of birth and adoptive mothers of children with developmental delays. Results indicated that both birth and adoptive mothers level of depression was low at an 11-year follow-up after placement or diagnosis of their children. These results were interpreted to provide additional support for the notion of positive long-term adjustment when rearing children with disabilities.

A recent study by Flaherty and Glidden (2000) compared family adjustment of both birth and adoptive mothers and fathers of children diagnosed with Down syndrome. Results indicated that birth and adoptive parents presented as adjusting positively to the

demands of parenting a child with Down syndrome. This study did find that birth mothers initially experienced elevated levels of depression at the time their children were diagnosed. This was interpreted as a predictable finding, given extensive previous research with similar findings and the fact that birth parents do not have the ability to prepare for or make the choice to parent a child with a disability. The impact of post-partum depression for birth mothers was also deemed to explain the initial elevated levels of depression. Both birth and adoptive parents who were sampled showed equivalent long-term functioning and low depression scores, indicating that parents, over time, adjust positively to caring for children with special needs.

As shown in previous research, adopting a child with a disability can be a joyous and life-fulfilling experience for many parents. Families who successfully adopt a child with special needs demonstrate that children with disabilities are adoptable and that “no matter how challenged they are, they have special love to give” (Gail, 1990, p. 3). Many adoptive parents report becoming happier, more compassionate, less materialistic, and having more meaning in their lives as a result of adopting a child with special needs (Goetting & Goetting, 1993; Nelson, 1985). Mothers of adopted children with special needs reported many positive benefits to their experiences. The majority of mothers in a study by Glidden (1996) reported that they had become more patient, happier, developed additional friendships, improved their relationships with their spouses, and had become better people overall. Parents also often reported experiencing great joy as a result of their experiences and felt enriched in their family lives (National Adoption Information Clearinghouse, 1999).

Todis and Singer (1989) completed a qualitative study that examined stress management for families who adopted between 2 and 30 children with disabilities. The results indicated that management of daily household tasks and childcare routines were not perceived as stressful to these families. These families tended to view their adoption experiences in a positive light. According to Todis and Singer, many adoptive parents experience positive rewards from their adopted children. Most feel gratified when their children learn and progress. Parents often gain self-esteem and pride in their roles as caretakers. A study by McDonald, Propp, and Murphy (2001) found that parents often reported both stresses and rewards as a result of their adoption experiences. A majority of parents sampled reported that their adopted children made valuable contributions to their lives and families.

A predominant focus of adoption research tends to highlight the experiences of parents. Less is known about the impact of adoption on siblings, specifically when the adopted child has a disability. Some early research supports the notion that special needs adoption can have a positive impact on siblings within the family and sees families as a whole growing stronger and closer (Marx, 1990). More recent research is emerging that addresses the difficulties that siblings experience when a new child enters the home. McGlone et al. (2002) found that many siblings experience some difficulty adjusting to a sibling with a disability and often feel that they receive less needed attention within the family following the adoption. Keck and Kupecky (1995) (as cited in Mullin, 1999) reported that family life can change after the adoption of an additional child. Parents often report having less energy and attention for siblings and some siblings have difficulty adjusting to changes in daily routines. Mullin (1999) reported that many

siblings feel vulnerable following a special needs adoption and experience emotional distress when faced with confusion of a new family, lack of choice in the adoption process, and dealing with potential behavioural difficulties of the adopted child. Common occurrences in siblings were noted by Mullin to include sadness, acting out behaviour, anger, and resentment. Positive outcomes were noted to include bonding between siblings, learning to share, and the development of new coping and problem solving skills. Mullin reported that helping parents and preparing siblings for the adoption could serve to aid in family adjustment and support the entire family through the adoption process.

#### Support for Adoptive Parents

Families who choose to adopt children with disabilities may need help and special services available to them. Many adoptive parents depend on financial subsidies and extensive support from adoption agencies over a long period of time for successful post-adoptive outcomes (Coyne & Brown, 1985; Farmer et al., 2004; Smit, 2002). Despite this need, there is often a lack of counselling and psychological services available to these parents (Barton, 1998; Festinger, 2002; Groze & Gruenewald, 1991). Marcenko and Smith (1991) found that most adoptive parents were dissatisfied with educational and counselling services for their child. These families reported the need for increased respite services and support groups and additional post-adoption follow-up.

Support and contact with other families in similar life situations is often valued and desired. As one adoptive parent stated, “just knowing that you are not alone ...can make all the difference” (Archer, 1996, p. 60). Many parents often desire to meet with

other parents who have children with special needs, adopted or not (Dumbleton, 1996; McDonald et al., 2001).

Research suggests that some adoptive parents are not provided with sufficient information regarding respite care and support services (du Porto & Phillips, 1996). A family who adopts a child with disabilities may need more background information regarding the child, additional time to prepare for the child entering the family, more services and respite care, access to support groups, educational programming for their child, financial subsidies, and assistance with behaviour management in the home (McDonald et al., 2001; Reilly & Platz, 2003; Rosenthal & Groze, 1992). The services most families view as important include funding, pre-adoption counselling, knowledge of the child's disability, and support from other families (Todis & Singer, 1989).

In addition to community and family support, many adoptive parents had positive experiences with professionals and adoption agencies during the time they were adopting their child. Many felt the agencies were able to provide needed information and long-term support. Despite these positive aspects, these same parents still noted a need to be given more information regarding their child's biological background and desired that financial subsidies be easier to access (Nelson, 1985; Reilly & Platz, 2003; Rosenthal & Groze, 1992). Many adoptive parents felt that agency staff were knowledgeable about medical aspects of their children's condition but lacked a clear understanding of disability and development (Coyne & Brown, 1986; Reilly & Platz, 2003; Wimmer & Richardson, 1990). Other parents of adopted children with special needs have reported that there is a lack of information from adoption agencies regarding disability and the child's background, lack of a consistent treatment approach from professionals across various

disciplines (psychology, social work, etc.), and that parents often face numerous bureaucratic barriers when dealing with professional services, school boards, and community programs (Dumbleton, 1996; Nelson, 1985; Phillips, 1998; Ward, 1996).

The most common complaints from adoptive and foster parents regarding professionals and adoption agency staff were long waiting lists for services, lack of individualized services, financial concerns, and difficulty obtaining respite services (Hudson & Leaser, 2002; Nelson, 1985). Parents also view professionals in the adoption agencies as having little insight into how a child with special needs can affect family and home life (Kramer, 1999). Additionally, most stress occurred when dealing with medical and educational professionals (Todis & Singer, 1989) as well as professionals who held negative views of their child's potential (Marx, 1990).

A study by Kramer (1999) specifically examined the supports utilized by adoptive parents. The adoptive parents studied were participating in a community living program, whereby they were placed in a neighborhood alongside other foster/adoptive parents, volunteers, therapists, and received extensive and continual community support and access to resources. Findings indicated that these parents relied on a variety of formal and informal support systems including adoption professionals, health and medical professionals, teachers, family, and friends to cope with the demands of adopting a child with special needs. A majority of these parents raised concerns about their children's development, education, health, behaviour, and birth family histories. Many felt satisfied with professional support and access to needed services, referrals, and information to solve problems they encountered. One significant finding was that among most of the families studied, spousal support was sought for most problems encountered. Over and

above the professional services available, families found support from family, friends, and their own faith, as most helpful.

### Current Adoption Trends in Alberta

Information pertaining to current adoption trends in Alberta was obtained via the Alberta Children's Services Website, put forth through the Alberta Provincial Government (<http://www.child.gov.ab.ca/whatwedo/page.cfm?pg=index>). Adoption through Alberta Children's Services refers to the adoption of children who are in the care of the Children's Ministry. Children available for adoption range from healthy infants to those with various medical, physical, developmental, learning, and emotional needs. The adoption process through the Alberta government involves several steps including an application process, document and records check, attendance in a pre-adoption session, and a home study or home assessment. Prospective families are matched to existing children. Birth families have varying levels of involvement, depending on the needs of the children and families. Factors to be considered during the matching process include the kind of child a family is willing to accept, wishes of the birth parents, and results of documentation and home study assessments. Children are matched through a centralized process and applicants willing to consider a child with special needs are generally given priority. Children with special needs include sibling groups, older children, or those with disabilities. These children are in the permanent care of Children's Services and most live in foster care prior to the adoption placement. Children's Services often utilizes media services (i.e., Wednesday's Child Program on television, website profiles, newspapers, recruitment fairs, and adoptive parents newsletters) to promote the placement of children with special needs.

As noted in the Alberta Provincial government website (<http://www.child.gov.ab.ca/whatwedo/page.cfm?pg=index>), the number of children with special needs placed for adoption between April 1, 2003 and March 31, 2004 in Alberta totaled 294. A total of 78 were under the age of 2, 103 were aged 2-5 years, 70 were aged 6-10 years, and 43 were over age 10 years. The total number of government adoptions was 43, including 8 infants, 294 special needs, and 124 international adoptions. The number of private licensed arranged placements and private direct placements between April 30, 2003 and March 31, 2004 totaled 145. Private adoption agencies in Alberta included in the survey were Adoption by Choice, Adoption Options, Catholic Social Services, Christian Adoption Services, and LDS Family Services.

Supports for permanency offered through the government helps adoptive parents attain needed support, training, respite, and services to assist in post-adoption issues. Assistance involves financial help, parental relief, counselling, and information to link parents to support groups and community services.

#### Summary and Purpose of the Research

The current project examines the experiences of parents who adopted children with developmental disabilities. I have chosen to qualitatively examine the experiences of parents who knowingly adopted children with disabilities. I hope to capture both positive and challenging aspects of adoptive parents' experiences. Topics of interest include (a) responses to disability by adoptive parents, (b) reasons to adopt, (c) relationships with family, friends, and non-adopted children, and (d) social, familial, and professional support systems these parents view as important. Other topics were identified and examined as they arose through interactions with parents during the course of the study.



I have always admired the families who adopt and raise children with developmental disabilities. Part of the reason for exploring this research topic is to understand the experiences of families who live with children with disabilities and how or if this experience has changed their lives. I am hoping that information I gain will ultimately help me grow personally and professionally. I am also hoping to expand knowledge in the area of special needs adoption. It is also my hope that parents of children with disabilities and couples considering adoption will gain additional knowledge from the stories of the parents who participated in this study.

The preceding review of the literature covered a wide array of topics and key issues related to parenting, disability, and adoption. An understanding of the research examining birth parents raising children with disabilities provides a framework for understanding the experiences of adoptive parents. For both types of parents, daily challenges, stresses, and strains are evident. Also evident, are the joys and rewards that parenting can provide. Both types of parents report a strong need for social, community, and professional support to cope with issues of disability.

The existing literature on adoption also covers a wide array of topics and themes. The themes discussed are all linked to the experiences of the parents interviewed in the current study. The review briefly discussed core issues of adoption (i.e., loss, rejection, and openness) that many families, regardless of whether the adopted child has a disability, must overcome. Relatedly, special needs adoption encompasses many child characteristics including age, race, life history, and disability, which can affect parenting experiences. The participants in the current study included families who adopted a child with a developmental disability. Looking closer at the families in the current study, these

children also possessed many other qualities that would classify their adoptions as special needs. The review of the literature in all these areas will have hopefully provided a deeper understanding of the experiences of the families in the current study and enrich the stories presented.

## Methodology

Most previous research in the area of family and disability has employed a quantitative methodology (Hendrickson, 1999). Specifically, studies have often focused on quantitative measures of stress, family adaptation, coping, and psychological dimensions of depression and anxiety (Rodrigue, Morgan, & Geffken, 1990). Qualitative research, however, allows us to study the nature of everyday life and experiences. It provides information on the meaning of experiences and on how people construct meaning in their own lives (Page, 2000). Qualitative research enables researchers to meet the needs of the participants by allowing their voices to be heard (Rogers, 2000) and by exploring people's experiences within their own unique social and cultural context (Metz, 2000). Qualitative research is rich, holistic, can provide thick descriptions of a phenomenon, and reveal complex social and cultural experiences (Asay & Hennon, 1999).

According to Lee, Mitchell, and Sablynski (1999), there are four characteristics of qualitative research. They are: (a) research occurs in natural settings, (b) information is derived from the participant's perspective, (c) designs are flexible to allow for the research to match the research situation, and (d) the methods, analyses, and instrumentation are flexible to fit the data. Additionally, qualitative research is descriptive, value laden, and views experience as a whole (Evans, 1998). Merriam (2002) also described qualitative research as having four components or key characteristics: (a) that research aims to comprehend the meaning people have of their experiences, (b) that the researcher is the primary means for both the collection and analysis of data, (c) that

the process of inquiry is inductive and builds to expand current knowledge, and (d) that the data are presented in a rich and descriptive form.

Given these characteristics, qualitative data are useful to provide description, interpretation, and exploration of phenomena within family research. Qualitative data in family research allow for a real-life glimpse of the phenomena and can provide rich and deep understandings of what families experience on a daily basis (Asay & Hennon, 1999).

Qualitative studies are useful to determine the impact of raising children with disabilities from the perspective of the parents and allow parents to describe their experiences in their own words. They can provide a refreshing and deeper description of family functioning and families have the opportunity to provide insight into different and new aspects of parenting. By allowing parents to discuss issues of importance to them, researchers can gain a new perspective on how families cope with raising children with disabilities and to determine which experiences are salient for them. For example, a qualitative study by Evans (1998) examined the experiences of deaf children in education. Previous research in the area relied heavily on quantitative methods and resulted in many findings of deficits in the language development of children with hearing loss. Evans' study used a qualitative design and found many positive aspects of the children's language competencies that were previously not addressed. Another study by Daniluk and Hurtig-Mitchell (2003) employed a qualitative approach to understanding the lives of infertile couples' experiences of adoption. In-depth narrative interviews and a phenomenological approach to the data analysis allowed for a deeper understanding of parenting experiences.

### Basic Interpretive Qualitative Research

For the current investigation, I have chosen to utilize a basic interpretive qualitative approach. According to Merriam (2002), a basic interpretive qualitative study aims to understand how participants understand and provide meaning to an experience or phenomenon. This approach captures aspects of phenomenology and accepts that people understand their own experiences based on the meanings they provide. Symbolic interaction also influences the basic interpretive qualitative approach by examining how a person constructs meaning through interaction with others and society. In essence, people construct meaning as they live and interact with others (Crotty, 1998). The goal of a basic interpretive study is therefore to “understand how people make sense of their lives and their experiences” (Merriam, p. 38). Specifically, a researcher aims to understand “(a) how people interpret their experiences, (b) how they construct their worlds, and (c) what meanings they attribute to their experiences” (Merriam, p. 38). This is achieved through data collection, examination of recurring patterns and/or themes and rich and holistic descriptions of findings. This kind of qualitative inquiry is useful in family research to truly understand parents’ experiences and feelings regarding their lives and children.

### Participant Selection

The participants for this study are parents who have adopted children with developmental disabilities. I have chosen to look at parents who have knowingly adopted children with disabilities for three reasons. First, I am interested in the notion of choice and how this affects family adaptation and personal parenting experiences. Second, I wish to explore the reasons why people choose to adopt children with developmental

disabilities. Finally, I am interested in the way parents prepared for the entry of this child into their homes.

For the purpose of this dissertation, the definition of developmental disability will be taken from the United States Federal Developmental Disability Act of 1984. This definition provides a broad view of disability with a focus on multiple needs and specialized care over the long-term. The definition is:

Developmental disabilities, according to Public Law 98-527 of the Developmental Disabilities Act of 1984, are severe and chronic disabilities that (a) are attributable to a mental or physical impairment; (b) manifest before the age of 22; (c) are likely to continue indefinitely; (d) result in substantial functional limitations in three or more areas: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living or economic self-sufficiency; and (e) reflect the need for a combination and sequence of special, interdisciplinary or generic care, treatment, or other services that are life long or of extended duration (Prucho et. al., 1996, p. S284).

The children represented in the current study are connected by the fact that they all have a developmental disability that will entail a level of caregiving support over and above the support needed when raising a child without a disability. For all of these children, that level of caregiving support may entail life-long assistance and access to services to assist with daily needs. It should also be noted that this sample of children also possessed characteristics that would define their adoption as “special needs”, over and above merely having a developmental disability. For instance, many of the children were older at the

time of their adoption, were part of sibling groups, were ethnic minorities, and/or had experienced abuse and neglect.

Parents were recruited through adoption and fostering agencies within Edmonton and Alberta. The recruitment process involved the researcher attending an adoption and fostering recruitment fair held in Edmonton. A meeting was scheduled with two adoption counsellors working for the Alberta government. A letter describing the study was given to the adoption counsellors and this letter is provided as Appendix A. Due to issues of confidentiality, names of parents who adopted children with special needs were not permitted to be disclosed directly to the researcher. The adoption counsellors gave the letter to several parents known to them who had adopted a child with a disability. Parents who viewed the letter and who were interested in participating were invited to contact the researcher for additional information. Through this process, five parents contacted the researcher and volunteered to participate.

Criteria to participate included that the parents: (a) knowingly adopted a child with a developmental disability, (b) have been an adoptive parent of the child for a minimum of 2 years, and (c) were willing and eager to share their life experiences. Since the study examined experiences, it was important that participants had been adoptive parents for a minimum of 2 years. This time frame ensured that parents had sufficient opportunity to experience living with and caring for their children to a fuller extent.

The number of participants available to be part of the study depended on the availability and willingness of parents. In qualitative research, the number of participants interviewed also depends on theoretical saturation and redundancy. If additional information from participants no longer leads to new learning, data collection and

participant recruitment will end (Lee et al., 1999). Only four mothers and one father volunteered to participate in the current study. Two of these five individuals were a married couple. The five participants were ultimately chosen for their willingness and eagerness to share their life experiences raising children with disabilities. Separate interviews were utilized for the married couple interested in participating since it is important for participants to feel free to describe their personal experiences and to protect their confidentiality.

### Data Collection

Key areas related to adopting children with disabilities were identified in order to construct an open-ended interview guide. The guide covered potential topics of interest as determined by a review of previous literature in the areas of adoption and disability. The guide was flexible and questions changed for each participant as the interview progressed. The guide, however, began with a standard opening question, "Tell me about your thoughts, feelings, and experiences related to your experience of adopting a child with a developmental disability." The guide included key areas and questions for the interviewer to introduce if topics were not naturally raised by the participants. These areas included reactions when children were first adopted, reasons for adopting children with special needs, beliefs about how they or their family has changed, stressful as well as positive aspects of their experiences, outlook for the future, social support networks, and interactions with professionals. Additional topics and questions were asked as appropriate and as new information from each participant emerged. A final question, "Are there any other areas that I have not covered that you feel are important to add to the



interview?” was also asked. The interview guide with tentative questions for each area is included as appendix B.

Three phases of interviewing were implemented for each participant. The first was a structuring interview in which participants and I met to discuss the nature of the study and to gather background family information. This meeting also served as a time to build trust and rapport with the participants. The participants were given a written description of the purpose of the study and were informed of issues related to confidentiality. Participants were also asked to sign a consent form to participate. The study description and consent forms are included as appendix C and D respectively.

Once the initial structuring interview was completed, the data-gathering interview was initiated. For all participants, the first two phases of interviewing occurred on the same meeting day. The initial question was posed and the interview followed based on the participants' experiences. The interview was conducted by the researcher/author and was audio taped for later verbatim transcription. Each interview lasted between 1 and 2 hours and took place in a location convenient to each participant. During the course of the data collection, individual time was spent with each participant developing rapport and working toward a trusting relationship. The author kept in contact with the participants through mail and phone updates. Time was spent with two parents attending a community conference. Phone conversations occurred several times with several parents and information was obtained regarding family updates.

The third meeting was a collaborative interview with participants, occurring through mail, e-mail, and/or a phone conversation. Following completion of the initial data analysis, participants were provided with a draft of their respective stories. They

were instructed to read their story and provide written or verbal feedback regarding the themes generated. They were invited to critique, change, or add to the data. The time between the data gathering interview and the collaborative interview was roughly 2 years. A 2-year lag between the initial interview and the collaborative interview occurred for several reasons. One year was needed to complete all interviews, recruit additional participants, and transcribe the data. A second year was utilized to analyze the data. It should be noted that the data analysis occurred over a one-year period on a part-time basis in order to accommodate the family and career needs of the researcher. Once the initial data analysis was completed, the writing of the participant stories occurred and these stories were shared with four of the five participants. Due to the time frame between the first interview and the collaborative interview, one participant could not be located as a result of a change in residence. A collaborative interview was not completed for this parent. Formal written feedback was not obtained for any of the parents, as many lacked time to provide this in-depth critique to the researcher. Feedback was obtained verbally from Claire, Margaret, and Pauline. Based on feedback from these parents, the current study allowed them to tell their stories and they felt pleasure with having a record of their experiences. No changes were made to the data analysis following the collaborative interview. Parents who provided feedback noted that their stories accurately reflected their thoughts and experiences at the time of the interview. Parents acknowledged that they continued to hold the same views regarding the challenges of parenting, rewards, and views of children and disability. Three parents provided some updates regarding their families and this information will be provided once all stories have been told.

### Data Analysis

A key concept of qualitative research is that designs and methods are flexible to allow the researcher to match the research situation to the data obtained (Crotty, 1998). Part of conducting qualitative research is to understand various methodologies and evaluate how each can contribute to the particular study and research questions. Crotty also suggests that once we evaluate methodologies used, we can begin to “forge a method that will meet our particular purposes in this research” (Crotty, 1998, p. 14). Throughout the process of investigation inherent in the current study, information was taken from several methods of examining the data. Combinations of data analysis techniques were used to ensure a fit between the data and subsequent results. These included techniques from Stevick, Colaizzi, Osborne, and Keen as cited by Moustakas (1994), Colaizzi (1978), and Osborne (1990). The process of analysis will be described in detail throughout the remainder of this chapter.

The process of analysis involved several steps beginning with the verbatim transcription of the interviews with each participant. Not only was attention paid to the context of the words spoken, but also to the participants’ rate of speech, emotional expressions, pauses, and body language (Poland & Pederson, 1998). This was the first level of interpretation (Lapadat, 1999). Each transcript was then read in its entirety several times to gain an overall sense of the participants’ experiences of the phenomenon.

Statements of significance (meaning units) were highlighted and extracted from the verbatim transcript. These meaning units were chosen based on their ability to illuminate important aspects of the phenomenon. These meaning units were then clustered into groups based on identified topics or themes. Redundancies were eliminated

and themes were grouped and/or regrouped over time to ensure proper identification of themes and topics of importance. Once these themes or topics were identified, a story was written for each participant incorporating these areas of importance. Careful attention was made to include verbatim quotes and the examiner's interpretations. Credibility of the data analysis was ensured by using and referring to the initial verbatim transcription. Returning several times to review the transcriptions and audiotapes throughout the process was important to ensure the accuracy of themes identified and to assist with refining existing, and exploring new, interpretations of the data.

Following completion of each individual story, four of the five participants were then provided with their respective stories to validate their content. This procedure was used to enhance the trustworthiness of the results and helped ensure the fit between the data analysis and the participants' actual experiences. Once each description was validated, the theme clusters for each participant were compared and contrasted to each other and a search for shared themes occurred. These shared themes were then described in detail, highlighting the similarities and/or differences between participants.

#### Internal Validity, Trustworthiness, and Generalizability of Results

Several steps were undertaken by the researcher to ensure rigor and trustworthiness of the following results. Qualitative research aims to understand a person's perception of reality. It is important to understand that reality rests on interpretations made by the researcher and that reality is forever changing (Merriam, 2002). To ensure internal validity in the current investigation, strategies of member checks, peer review, and submersion in the data were utilized. Four participants were provided with initial interpretations of the data and were asked to provide feedback

and/or corrections to ensure the accuracy of the researcher's interpretations. Peer review occurred throughout the research process, as professional colleagues were involved in the review of the data at several stages throughout the research process. Additionally, the researcher spent an abundance of time investigating and attempting to understand more about adoption and disability by spending time with parents, attending conferences, and researching the process of adoption through government agencies.

Reliability is often defined as the replicability of the research findings. According to Merriam (2002), "reliability is problematic in the social sciences simply because human behaviour is never static, nor is what many experience necessarily more reliable than what one person may experience" (p. 27). In qualitative research, reliability focuses more on whether results make sense and how the end results show consistency with the data initially collected (Merriam, 2002). In essence, researchers are interested in consistency, dependability, and trustworthiness of the data. The researcher used several strategies to ensure the trustworthiness of the results. Detailed notes were kept throughout the research process, which provided explanation as to how themes were generated. Steps were also taken to ensure a fit between the end results and original transcriptions of the data.

Generalization, or external validity, is conceptualized as how results can be applied to other life situations. For the current study, a small and convenience sample was utilized. It should be noted that participants volunteered to participate in the current study. They independently contacted the examiner upon learning about the purpose of the study. It should also be noted that participants were associated with their respective adoption agencies and have been strong advocates for disability and adoption in their

communities. In qualitative research, it is the reader and not the researcher who determines the generalizability of results (Page, 2000). Readers utilize the results from their own perspectives based on their own cultural and social framework (Carpenter, 1999). Ultimately, the readers determine how the findings relate to their own lives (Evans, 1998). According to Merriam (2002), “readers themselves determine the extent to which findings from a study can be applied to their context” (p. 28-29). This process is assisted through use of rich and thick descriptions of the phenomenon. Through these descriptions, readers will be able to determine if their own life situations are similar and/or different than the participants’ and glean their own meaning of the experiences discussed. It is hoped that the stories presented in the results section will provide readers with the means to relate to the families and learn through their experiences.

#### Ethical Considerations

The participants in this study were informed regarding issues of confidentiality and the requirements of participation. All participation was voluntary and participants were able to terminate their involvement in the research at any time without penalty. Pseudonyms were used for participants and their families throughout the research process to protect participant anonymity. Goodley (1999) raised the issue of whether it is ethical for researchers to interview persons with few available supports in their lives. Specifically, the researcher is viewed as a support person who enters the life of the participant and then leaves, leaving the participant with no additional resources. Given this potential complication, parents were provided with information on community resources in the event that they felt the need to access help and support outside of their immediate circle of family and friends. Parents were also given information on accessing

counselling services should the research process lead to life stress or emotional discomfort. During the course of the data collection, individual time was spent with each participant developing rapport and working toward a trusting working relationship. Based on feedback from parents involved, the current study allowed them to tell their stories and they felt pleased with having a record of their experiences.

### Participant Stories

The following are the stories of five parents, one father and four mothers, who adopted children with developmental disabilities. They involve the stories of four families as one couple agreed to participate. Each story is told separately, since all individual experiences are considered unique. Each participant talked about his/her experiences with adoption, his/her difficulties and joys of parenting, and how his/her children have affected his/her life. Each story begins with a brief discussion of who each parent is. It is hoped that the reader will have a sense of each person's struggles, values, and experiences. These stories are not meant to provide a documentary of these parents' lives and experiences or a chronological ordering of events in their lives. These stories are meant to provide the reader with examples of the parents' joys, experiences, challenges and opinions in reference to their adoption experiences. These stories provide a glimpse of what life raising an adopted child with a disability could entail. I appreciate the parents' candor, honesty, and willingness to share their personal experiences.

The following stories are presented in terms of themes that emerged from each participant interview. These themes summarize key experiences and provide some insight into the life of each parent. Each story is unique and the content of each is dependent on what the parent felt was important to discuss. Themes for each participant may be similar or entirely different from those for the other parents. Following the presentation of each story, a thematic analysis will be presented. The thematic analysis will explore the commonalities and differences evident between and among the stories.



### Tammy's Story

Tammy is a 58-year-old mother of four children. Her husband, Noah, is 65 years of age and works as a civil servant. They have two biological daughters who are now 34 and 27 years old and two adopted daughters who are 32 and 15 years old. Diane, their second adopted child, aged 15 years, has severe disabilities including Cerebral Palsy, Blindness, Epilepsy, and Hydrocephaly. Tammy is an active volunteer and president of a community family support agency. She spends several hours per week helping other families, both adoptive, birth, and foster, with advocacy, support, and parenting. She is also actively involved in fostering children and has done so since 1987. Tammy is currently a foster parent to a teenage boy with severe behavioural difficulties. Tammy dedicates most of her time toward parenting and home schooling her daughter Diane.

Diane was first placed with Tammy and her family as an infant foster child. Diane lived in two previous homes and spent much of her first year of life hospitalized in intensive care. At the time of the foster placement, Diane was very ill and not expected to live. Diane remained with Tammy and her family and they adopted her at the age of 5 years. When Tammy adopted Diane, her other children were young adults and were actively involved in helping with parenting, chores, and Diane's daily care. The adoption has been a life-changing event for all involved. The following are the themes and sub-themes that emerged from my discussions with Tammy regarding her experience adopting and raising Diane.

#### Understanding and Empathy for Biological Parents – Lack of Guilt with Adoption

Tammy has dedicated much of her adult life to advocating for parents of children with disabilities, both birth parents and those who adopt. Given Tammy's work and life

experiences, she has some insight into the lives of biological parents who struggle to cope with having children with severe disabilities. Tammy commented that she “can understand why people place their children in foster care when they have special needs kids.”

Tammy talked openly about some of the strains, struggles, and stresses of parenting children with developmental disabilities. She was quick to note that these struggles are present in the home, regardless of how the child came to live there. In Tammy’s views, there is one major difference between birth and adoptive parents and their ability to cope with parenting a child with developmental disabilities. In her view, adoptive parents...

*don't have the guilt of a biological family who had either messed up or through no fault of their own, given birth to a special needs child. [Raising Diane] was much easier for me compared to all those biological moms (who went to the same programs as I did) that had all that guilt of 'if only I'd done this differently.' So that [lack of guilt] is a definite asset to adoption.*

#### The Pull to Adopt – It was the Child’s Decision

Tammy talked about the time when Diane first came into her life. When she first heard about Diane, she talked about feeling obligated to try to care for her. Diane was a young, fragile baby who had already experienced trauma and abandonment. Other attempts at foster placement had failed and Tammy believed that she could give Diane the care and nurturing that Diane desperately needed. Tammy and her family decided to take Diane as a foster child. Once Diane came into their lives, the decision to adopt was made for the family. In her mind, she...

*didn't decide to adopt. She (Diane) made that decision. She just jumped out and grabbed us by the heartstrings.*

Diane was in the home for 5 years prior to the official adoption. During the time when Diane was a foster child, she had many visits with her biological mother. According to Tammy, it became clear that Diane's needs could best be met with Tammy and her family. Tammy became very attached to having Diane as part of the family and was not prepared to say good-bye to her in the event that the fostering relationship ended. Tammy and her family had previously experienced having to part with other children they had fostered and were not willing to do this again. Tammy described herself as...

*almost possessive. I think the whole family felt that way as well. It wasn't a matter of if we were going to adopt. It was when. We were going to do it come hell or high water.*

#### Fear of the Unknown – Coping with Medical and Multiple Needs

Despite her experience working with foster children, the care of a child with several severe needs was initially a fearful endeavor for Tammy. She reported that raising and caring for a child with significant medical needs is a unique challenge, often based on the unknown. Tammy talked about when Diane was first placed in the home:

*They told us just to take care of Diane's basic needs. We didn't expect her to live and [doctors told us] not to get too attached because if we got too attached and she passed on, it'd be very traumatic and hard to get beyond that.*

Caring for Diane was described as “exciting and scary as hell. It was scary because she had seizures and because we didn't know what her future was.” Diane was hospitalized repeatedly, often on a weekly basis until she was 5 years old. She experienced several near death situations and survived. Tammy views Diane as a true fighter with tremendous spirit.

Tammy has had several foster children live in her home, several of whom exhibited behaviour problems that were difficult to manage. Upon reflection, Tammy

noted that children with medical needs were easier to cope with than children exhibiting behavioural difficulties. According to Tammy, Diane's needs were unique yet she was able to cope with these needs with the support of professionals and family. For Tammy, she has more difficulty managing children whose behaviour is out of control.

Tammy is aware of the impact of Diane's disability on her own life. She is also cognizant of how children with multiple disabilities experience additional struggles in their own lives. Tammy believes that...

*kids with Cerebral Palsy have enough struggles. When you add blindness to that, it really alienates them. It almost puts them out there as a single star, so to speak. I'm not saying they are not still shiny, but it limits their worlds so much. It's very difficult.*

Dealing with multiple disabilities is difficult for parents but also for the person with the disability. This fact is sometimes overlooked.

#### Dealing with Medical Professionals

Tammy recounted that she spent an inordinate amount of time advocating for Diane. Tammy has needed to be an advocate for Diane and has found this to be a challenging, frustrating, and exhausting experience. At times, she felt unsupported by medical professionals, educators, adoption services, and the community.

When Diane was first introduced into Tammy's home, the message from the medical professionals was that this placement was temporary, given Diane's serious medical concerns. Despite negative and pessimistic views from professionals, Diane flourished in the family home. Tammy stated:

*It wasn't like we were taking care of this broken doll. There was a real live human being in there and she was responding to everything we said and did. I think medical professionals are not quite as smart as they think they are.*

Diane experienced several near-death experiences. Tammy needed to be an advocate to ensure Diane's proper medical care. Tammy recounted:

*In 1992 Diane had a shunt revision and they put the valve in backward. The neurosurgeon put the valve in backward! 10 days later she presented like she had a stroke at home. She couldn't make any sense. She was all mumbly, jumbly, and weepy. We took her in and they did an emergency surgery. Upon completing the emergency surgery, they brought her back to the room. I said 'she isn't right.' They said, 'she's fine, you're just being paranoid.' I said 'no, she's not right. Phone the neurosurgeon. Tell him she's not right.' They phoned the neurosurgeon twice. He refused to come up. Finally in desperation, I begged a student intern to please take a look at my child. I thought she was having seizures but they weren't the kind of seizures I'd ever seen before. I wasn't that familiar with those kinds of seizures. And sure as heck, she was having seizures. They took her down and they had closed the second operation on a bleed and she was bleeding into her cerebral fluid and she almost died. They put her on the table to do the CAT scan and she coded.*

#### Educational Hardships and Misunderstandings

The education system has also been a source of stress for Tammy and her family. Tammy commented that "education is the biggest frustration in my life." Despite the numerous medical emergencies and traumatic experiences, Tammy noted that that "wasn't nearly as hard or difficult as all the bureaucratic bullshit that I had to put up with." Tammy talked about how Diane was hospitalized weekly as a young child. These hospitalizations often resulted in expulsion from educational programs due to lack of consistent attendance. Tammy needed to be actively involved in having Diane re-admitted to needed programs and services. Tammy commented:

*I don't know whether I would have the energy to fight all those battles again. It's all the fights that you have that are hard. It was very difficult.*

Tammy reported that she constantly needed to advocate for Diane to be part of specialized programs. She remembers...

*often being criticized or condemned if Diane was ill. We'd get letters saying that because of your irregular attendance (due to hospitalizations), you no longer*

*qualify (for special programs). We've been extremely criticized by the school system for missing a large portion of time at school.*

As Diane got older, Tammy needed to constantly advocate for small changes within Diane's school environment. She said, "It was difficult to get them [the school] to cooperate and do those little extra things." For example, enlargements on the blackboard, reflector tape in the hallways, or seatbelts on the school bus. Tammy talked extensively about the funding that Diane received from the education system. Given Diane's severe needs, the school was given money to assist with Diane's programming and to make modifications in the school environment. Tammy voiced her frustration when she stated that...

*although Diane got the most grant money, she was the good kid. The quiet one. She got very little one-on-one aide time. She got none. And she was funded the highest of any of the children because of her disabilities. So that was frustrating.*

Tammy recounted another story that reflects her level of frustration with the school system:

*Diane had seizures. The [school] didn't recognize when she was starting a seizure. She's the type of child that when she's in a seizure she stops breathing. She had a little bit of what they call sub-clinical symptoms, so you wouldn't see anything but the eyes jerking a little bit and she'd be very very quiet and you'd see a little bit of activity in the pinky on the left hand. And it would just go like a heart beat; bump, bump, bump. But the school wouldn't recognize that or they would ignore it or whatever. She'd get into a grande mal seizure and she'd stop breathing. You'd have to get an ambulance and she'd have to be intubated and all kinds of things. And yet, you could tell them that but they still didn't get it. Maybe it's over protectiveness but they just didn't get it.*

Another example involved the busing system:

*They had no seat belts [on the school bus]. Here's a kid, when you go around the corner and she doesn't have a seat belt on, she's sitting on the edge of the seat and she falls on the floor. She doesn't have that control on the left side so, flump, she's on the floor. There was no consideration for that. They told me that it was impossible for them to get a seatbelt. I could order a special car seat once they had some organization that would pay for a seat belt. It was ludicrous.*

### Community Isolation and Prejudice

Community isolation and prejudice has been another source of frustration.

Tammy explained that “People don’t understand children without sight and I found it very difficult for people to comprehend the extent of her disabilities.” As a result of parenting a child with developmental disabilities, “You find out who your friends are. Some people are not as tolerant and the community as a whole is not as tolerant of people with differences.” She commented that...

*you can't get anybody to look after your child because everybody in the community is scared of your kid. They're different. They appear different. They walk different. They talk different. So you can't get respite and relief.*

As a parent of a child with a developmental disability, learning to be self-sufficient is a key lesson.

### The Need for Self-Education and the Ability to Think Outside the Box

Tammy’s advocacy efforts have led to many positive and creative outcomes for Diane. Tammy often found herself engaged in self-education not only to become more aware of existing services but to determine alternative means to help Diane progress with daily living. Tammy was able to utilize creative and relatively simple solutions to enhance Diane’s quality of life. For example, she taught Diane to chew gum in order to increase Diane’s jaw strength and mouth movement. This exercise resulted in Diane having the muscle control needed to learn to speak. She encouraged Diane to drink cola to ensure proper bowel movements. She advised the school to put reflector tape on posts in the hallways so Diane could better view the posts and walk independently at school without bumping into them. The solutions resulted from Tammy’s self-education, persistence, problem solving, and creativity. In Tammy’s experience, having a child with

a developmental disability often requires one to think differently and change one's normal perspective.

### Toll of Parenting – Age, Physical Strain, Time Limits, and Money

Parenting a child with multiple disabilities is not an easy task. Several factors have made parenting more difficult for Tammy, including Tammy's age, physical limitations and financial constraints.

Tammy reported that age was a significant factor in the decision to adopt Diane. She remarked:

*God, I'm still parenting and pushing 60! Having already been an adopted parent, it wasn't hard for me to adopt. Where I was worried was thinking about if I was going to be able to cope with this child for as long as she needs me.*

Given all of the struggles and bureaucracy, Tammy noted that being younger at the time of the adoption might have made things a little easier. In her view, her age was also a barrier to the adoption process. There was some government resistance to allowing Tammy and her family to adopt Diane given that Diane would require long-term care and there was the possibility that foster care would be needed at a later time. Age also plays a role in how Tammy is able to manage the daily physical routines required when a child has severe disabilities. Diane is now an adolescent and continues to require an abundant amount of physical assistance with bathing, dressing, and daily routines. These chores are becoming increasingly difficult for Tammy to manage on her own. Recreational activities are also more difficult. Tammy regrets that she...

*hasn't got the energy to haul her up the hill and go tobogganing any longer. I don't have the energy to do that anymore. I can't take her swimming anymore. She's too big and too strong and it's too much effort. It tires me out.*



Given Diane's diverse physical needs, time is also a stress factor. All daily routines take longer and there is often not enough time for other activities. Tammy does not always have time for her own needs and self-care.

Financial difficulties are also a significant concern for Tammy and her family. Given Diane's needs, many adaptations, home renovations, special shoes, wheelchairs, and other accommodations are often necessary. Applying for funding is often a difficult process and can be demeaning. Tammy was often expected to ask community agencies for financial support prior to receiving government assistance. She mentioned that...

*when I needed things like a wheelchair and a standing frame, the government told me to go out and try and get it from community organizations, men's groups, and those kinds of things. I had to get three letters of rejection before they would consider supplementing us. My husband had a heart attack. He was out of work for a period of time when some of these big expenditures were coming up. I wouldn't sell her out in the community so therefore we didn't qualify. I was not going out and telling everybody her story. She's smart enough to know that people are talking about her. She would probably not like it. She would probably resent it.*

As a result of these convictions, Tammy often did not qualify for funding for Diane.

Tammy recounted that it is very difficult to "raise this kind of child and get them the wheelchairs and special shoes that they need."

As a result, Tammy and her family have made many life sacrifices to provide for Diane's needs. Tammy's husband made the decision to change occupations due to the need for him to be more involved in the daily care of Diane. Tammy stays home to school Diane during the day. These life decisions have resulted in additional loss of income, which has added to the financial difficulties experienced by the family. Tammy found that social services and post-adoption supports did little to help with the financial burdens.

### The Need for Personal Strength, Strong Character, and Flexibility

Tammy described herself as an “above average parent who works well with children.” She also labeled herself a “perfectionist, overachiever, and a good nurturer.” These were the qualities that Tammy felt were important when raising a child with a developmental disability. Tammy also has a strong belief in family.

*I don't think that there's really any throw-aways out there or that people should be institutionalized without an attempt at family. I think that family comes first and foremost, whether it's a family chosen by the child or a child that's chosen by a family.*

Tammy's outlook on life has changed as a result of her adoption experiences. Tammy commented that she has developed “huge tolerances for differences” and her whole family has been involved in advocacy and educating others about disability. She has noticed changes in her children and husband in terms of their outlook and philosophy on life. She remarked that, “It's been a very rewarding experience having Diane as part of our family.”

### The Value of Respite and Support

Caring for a child with a severe developmental disability can be a demanding and exhausting endeavor. Tammy remarked that, “In order to stay fresh and be able to cope, you have to have some breaks from the child.” Family support and the ability of the family to work together as an integrated team was noted as an important coping strategy.

Within the immediate family...

*everyone pitched in and everybody helped. My daughters used to take turns singing to her and walking and they did a lot of interactive play. We had a lot of adults and a lot of energy and a lot of young people who were helping out.*

Spousal support was also viewed as essential, with Tammy's husband doing at least half of the parenting. The family was home schooling Diane, and Tammy relied on

family and spousal support to ensure that Diane's educational needs were being met. Since the entire family was involved and working as a team, the improvements Diane made resulted in "encouragement for the rest of the family as a whole."

In addition to family support, respite support from the community was seen as an essential service not only to enhance personal well-being but also to ensure the healthy functioning of the entire family. Despite difficulties accessing services, Tammy felt reassured to know that "there's somebody always available to help when you need it." This could be family, friends, neighbours, and/or professionals. In addition to the importance of respite care, professional support was also viewed as essential. Tammy commented, "My best support person is my physiotherapist who provided little tips on all kinds of things." The school system, despite inherent difficulties, also provided some needed educational support.

#### Belief in her Child's Abilities – Hope, Joy, and Miracles

Despite the existence of severe and multiple disabilities, Tammy saw in her daughter a bright, vibrant, motivated, and intelligent child. She described Diane as an "amazing kid with a terrific sense of humour." When Diane was very young, Tammy recalls being told that Diane "would be a vegetable," that she would never walk or talk. Despite these negative expectations, Tammy believed that Diane could learn. The family was able to see many gains within the home. Diane was able to learn to walk, gain control over bodily functions and also learned to speak. Diane experienced severe medical complications as a youngster and survived, making her a medical miracle. Tammy recalled when...

*Diane had an external drain in her brain for 21 days. Most people don't live after 10 days. She's just an amazing kid. And a lot of this is her own motivation and her own will to live.*

Diane has certainly proven the professionals wrong and has beaten the odds in terms of her capability to live and ability to learn. Given these strides, Tammy has hope that Diane can lead a fruitful and productive adult life. Diane's learning and progression occurred because of the hard work that took place in the family home. All members of the family were actively involved and engaged in Diane's learning. Tammy recalled a discussion with Diane's pediatrician who remarked that Diane "came as far as she did because of the stimulation in the family." Tammy remarked that watching Diane learn was a remarkable and rewarding experience. She said:

*You can't begin to imagine the elation and joy of having a child that is supposed to be a vegetable be able to do things. The more she did, the more encouragement it was for the rest of the family. It was a very exciting process.*

Even small accomplishments resulted in laughter, tears, and elation. It seemed that progress also provided hope. Tammy said, "If we could get through on that area (i.e., walking), then we should be successful with some of the other things that we were working on."

### Learning what is Important in Life – Knowing Your Limits and Adapting to Life's

#### Challenges

According to Tammy, having a child with a developmental disability forces one to look at what is most important in life. Even small choices can make a huge difference. Tammy recounted her decision to allow Diane to use a soother until the age of 7 years. She had heard that using a soother could help children with Cerebral Palsy learn to speak. She thought...

*'to hell with her teeth.' I can fix that afterwards. It's more important that Diane have the opportunity to speak if she is capable.*

To Tammy, family is the most important thing in her life. Family comes first over all else and any decisions that involve family are easy for her to make. She commented that, "My house could go to hell and back, I didn't care. The kids needs always came first."

With all choices comes a period of adaptation. Having a child with a developmental disability requires flexibility and finding other ways to enjoy life.

According to Tammy, having a child with a disability can...

*limit the places you go but that doesn't mean there are not good places to go and nice people to see and good places to eat dinner. You just have to adapt.*

Tammy also noted that knowing one's personal limits as a parent is also important. Tammy described herself as an overachiever and perfectionist. Diane is currently home schooled and Tammy has struggled with placing too many expectations on Diane to succeed. Views of high achievement often hindered her ability to be an unbiased educator when home schooling her daughter. Over time, Tammy was able to see her own faults and become flexible in her approach to how she spent her time teaching Diane. Insight into one's abilities and being flexible, according to Tammy, is very important when raising a child with a developmental disability.

#### Concern for the Future - Realization of Own Mortality

Having a child with a severe developmental disability requires a life-long commitment. Tammy confided that she often worries about whether or not she will be able to care for Diane for as long as needed. Many questions arise as she views her own mortality: "Who will care for Diane when I am gone? How will Diane's financial needs

be met?" In addition to Tammy's realization of her own mortality, Tammy is concerned about Diane's eventual move outside the family home and into group care. She wonders, "Are they going to have the same kind of compassion and care? Are they going to do as good a job?" It was reassuring for Tammy to learn that there are programs and group homes available for Diane and her unique needs. Tammy's concerns for the future mostly revolve around housing and financial needs. There are few doubts in Tammy's mind that Diane will find productive employment in the future, especially given her unique skills and talents. In Tammy's mind, Diane will lead a fruitful and productive life.

### Pauline's Story

Pauline is a single mother of five adopted children. Pauline was once married, but divorced after the adoption of her second child. Pauline is a strong advocate for persons with disabilities as well as adoption in her community. She volunteers several hours per week with a local adoption agency. She also teaches government courses pertaining to the adoption process and prepares new parents for their adoption experiences. Her professional background is in nursing.

Pauline's first adopted daughter, Jane, is now 26 years old. She has multiple disabilities, including Cerebral Palsy, Schizophrenia, Developmental Delays, Pervasive Developmental Disorder, and Asthma. Pauline then adopted Katie, now 24. Katie also has several disabilities, including Fetal Alcohol Effects, Microcephaly, and Attachment Disorder. Katie also experienced abuse as a young child. Jordan was adopted next. He is currently 17 and diagnosed with Cerebral Palsy and Seizure Disorder. Pauline adopted a fourth child, 11-month-old Noah, who was diagnosed with Down syndrome and a severe heart defect. Due to Noah's serious physical difficulties, he required open-heart surgery. Noah did not survive and died at the age of 1 year. He remains a prominent part of Pauline's family. Pauline's most recent adoption was a girl named Emily, now 11 years old. She has been diagnosed with Fetal Alcohol Effects.

Throughout the last 12 years, Pauline has not only adopted five children but has also been actively involved with fostering numerous other children with severe and multiple developmental disabilities. There are currently 27 children, some of whom are now grown and have families of their own, who still consider themselves part of

Pauline's family. Pauline maintains an open-door policy in her home and always welcomes those youngsters in need of love, support, shelter, and family.

Given Pauline's life and work experiences, she has extensive knowledge about the process of adoption and the issues and life challenges associated with adopting and parenting children with developmental disabilities. Pauline talked extensively about the issues and life challenges surrounding all adoptions, regardless of whether the child has a disability.

### Tasks and Challenges of All Adoptions

Adoption, regardless of whether the child has a disability, is a process with unique challenges and adjustment. Pauline feels that...

*if you adopt any child, you are usually going to have some issues, disability or not. I think that one of the biggest things to deal with is kid's past baggage and not with a disability. Issues could include abandonment, past abuse, interest in the birth family, and/or relatives not accepting this child into the family. This list is infinite, given that all persons are unique and have different life experiences and expectations.*

Pauline believes that adopting a child with a disability, who has not experienced severe trauma or abandonment, is sometimes easier. Pauline commented that...

*you do better adopting a child with challenges as opposed to a normal child who has been 'messed up' or who has gone through abuse or moving between foster care.*

Adoption can often lead to unexpected surprises and life transitions. For example, Pauline talked about meeting a biological relative of her adopted child at school. For some adoptive parents, new issues are continually surfacing, often when least expected. Pauline recounted one story about the difficulties that can occur within families:

*I met one lady who runs an adoption agency. She went through a lot of stuff with her adopted son, who was another race and all those things. And that wasn't an issue. But he got married and he and his wife had a baby. And she had infertility*



*issues her whole life. So suddenly your child can have children but you can't have children.*

Pauline's talked about the complication when her children have never met their own birth families. She commented that some of her children wonder about their birth parents or create fantasy parents as a way to cope with the unknown. According to Pauline, it is important that all potential adoptive parents are aware and prepared for how to help their children cope with not knowing their biological families. It is also important for adoptive parents to be prepared in the event that their children wish to find their biological families.

#### Adoption as a Normal Way to Have Children

Pauline respects birth parents who are able to say that they cannot care for their children. That insight into one's own capability is something that requires courage and self-sacrifice. Pauline believes that birth parents should feel pride in allowing their children to have better lives. Adoption is a way for children to grow up in families that can care for their needs. It is also a way for couples to have children that they otherwise would not be able to. According to Pauline, adoption should be considered a natural way to gain a family. She recalled one story about a man named...

*Mr. Smith. He went on to talk about the wonderful people who go the extra way to adopt children. And of course I got up and said, 'you know, this isn't about that. I want people to think of it as normal. I don't want it to be hush, hush.' Katie brought up, at her day program, that she was adopted and people immediately got all quiet and moved on to other topics. And I think, 'why?' I want it to be a normal way of having children.*

#### Importance of Commitment

According to Pauline, the success of adoption seems to rest on one key factor: commitment. Parents need to be committed to the children they adopt. Pauline

remembers the adoption of her first child. She was married at that time and adoption personnel felt that she and her husband “were the ideal couple; an engineer and a nurse and all this experience.” Looking back, Pauline does not view her experience and occupation as the main factors as to why her adoption experiences were successful. For her, she was committed to each child. Pauline openly supports any couple or person who wants to adopt, as long as they are committed to the child and are able to care for the child’s needs. In her opinion, a child must match the house and the lifestyle of the family. Pauline’s children were matched to her home. Her children fit. Her house is a whole as a result of the children in her family. She explained:

*I have 27 people, kids, whatever you want to call it, that belong to our family. That can be through respite care for people with extra needs, teenagers who literally have walked into my door, children we’ve babysat on a long-term basis. I can think of one child who was cocaine addicted, a child with Down syndrome, or teenagers with family issues, alcoholism in the family, sometimes there was abuse. Sometimes the parents don’t feel ready to parent the child at home anymore. So I end up with them. And they all fit.*

#### Parenting as a Choice – Fulfillment of a Life Goal

According to Pauline...

*adoption is a chance to make a difference for a child. If you really want children and you want to have a chance to feel that you’ve really made a difference in someone’s life, this is your chance.*

Pauline is making a difference in the lives of numerous children. She is able to provide comfort, home, family, and security. She is providing children with self-esteem and the chance for meaningful lives. Pauline is committed to providing a family to children who would otherwise not have this opportunity. She has made the choice to help and be the kind of parent that she is today. She commented how parents often ask, ‘How can you do it?’ Pauline responds by reminding people that this is “her life choice.”

Pauline is aware of her own personal limitations. Despite choosing the life of being a parent to 27 children, she knows that there will come a time when she can no longer care for all her children. She hopes that in the event that she can no longer parent these children, there will be government resources and assistance to help. Pauline commented that...

*the government has an obligation to pay. I didn't make them so the government can pay later on when they need to. I've saved them big bucks in between. If I didn't adopt these children, most of them would be in foster care. I've done my best. I know very well that it's highly unlikely they would have had another family. Which of course is why I end up with crisis adoptions. That's part of what I do. I want the kids the other people don't want. Because I believe those children have value. And I'll make other people want them.*

Pauline's early life experiences enabled her to become familiar with issues related to disability. As a child, she had interactions with people with disabilities. She also read many books throughout junior high school about families who adopted numerous children, which led to the idea that she wanted a similar life. Her background in nursing made it easier to understand some of the parenting demands that would be placed on her when she brought her first child home. Even as more children were added to her family, there were some moments that were overwhelming for Pauline. Pauline recalled that...

*Noah was 1 month in the neo-natal intensive care, from intensive care straight home. Not on a unit. Not anywhere else. When I got to the hospital they already had my name on his bracelet. And two of the doctors told me he was going to die. It was very scary.*

Throughout the last 12 years, parenting has become easier. Pauline was able to learn and make educated life choices. She chose to always care for children who needed her. Pauline proclaimed, "I'm doing what I always wanted to do." Pauline often has people approach her and describe her as an incredible woman, overwhelmed with her

ability to live her life with so many children. Pauline feels that she is fortunate to have been able to choose her life...

*as opposed to parents who have a child born to them. They have all the grieving for what they expected. I don't have that grieving. For me, it's not difficult.*

### Challenges, Demands, and Sacrifices

Raising children with developmental disabilities is no easy task. This seems to increase when the number of children within a family home increases. Pauline commented, "The first child was easy. Two children were hard and after two it's easy. You've already done it." It seems that the first child involves a lot of new learning. The addition of a second child makes more demands on one's time and energy. Once that point is reached, the addition of subsequent children becomes easier because one has learned to be organized and knows what to expect. There are fewer surprises.

There are some physical demands associated with parenting children with developmental disabilities. These physical challenges depend on the needs of the individual children. Pauline talked about sleep deprivation as an on-going concern. She remembers, "With Noah, it was sort of everything at once. You're feeding every 3 hours and don't have time to really think." Pauline has learned to cope with lack of sleep. She admitted that she sleeps...

*off and on and all over the place. Jordan says I sleep all the time but that's because he wakes up at 5:30 and I have to attend to him. I usually sleep from about 2:00 to 5:30, sometimes more. I cared for one child who used to live with us and he actually thought I was magic and didn't sleep at all. But I actually do. After a while, your body gets used to it and then goes along.*

Physical challenges are more evident when children have numerous physical needs. Pauline commented that...

*basic things like wheelchair accessibility are difficult. Things I never thought about when I brought home a physically challenged child. No one talked about wheelchairs, curbs, snow, and people who don't shovel.*

Having children with limited mobility makes caregivers learn to be more mobile.

One's body learns to cope with physical challenges. Pauline recounted one story:

*A friend of mine who had a son with challenges recently got married. And she said, 'if you get married and you go on a honeymoon, take your kid.' For 2 weeks they were away and she came home and she couldn't lift her son anymore. And she set her back off and she had to have physiotherapy and chiropractors and everything else. So, if you work out every day you get used to it. It's like a relative once told me, about the farmer who could lift a cow. He could lift the cow because he lifted it every single day.*

Time is always a factor when parenting a child with a developmental disability.

The need to be organized is key to making sure one has time to do all the things that need to get done. Pauline has learned to be organized not only for herself but also others assisting in the home. Pauline pointed to her calendar and asked:

*See that calendar? [The large calendar is filled with colored markings]. That's the first week. If someone ever moves my calendar, we're in deep, deep...*

When Pauline first starting adopting children, she had feelings of fear and apprehension, specifically related to the fragile medical needs of her children. She remembers, "With Josh, I was panicked that first night I was alone with him. I was really scared." Even after 10 years, Pauline commented, "I'm not worn out yet."

In addition to dealing with the physical demands of parenting, Pauline has had to adjust her life to cope with challenging behaviors and unexpected life events. Several of the children she has adopted were sometimes difficult to manage within the home. She recounted:

*There was a lot of child proofing. Jane was a going concern. She's a little demolition derby. She dislocated a lot of dolls and so a lot of stuff that I had thought would be nice for a little child ended up getting moved out very quickly.*

*We had to remove light bulbs because she bit the light bulbs off and she would eat them.*

Pauline commented that dealing with Jane's behaviour was easy because she really wanted a child. She really "wanted a kid and that was that. It was just what I did to have her in my home."

The choice to adopt led Pauline to make several sacrifices. Giving up of some of life's little things is always part of being a parent. Pauline made the choice to live in her neighborhood, due to the support and assistance she feels and receives from her community. Being around aboriginal people is also very important for Jane, so living in a community rich in aboriginal culture was also important for Pauline and her children.

#### Ability to Cope – Faith, Time, and Creating Alternative Solutions

Pauline's first parenting experiences were difficult. There was limited knowledge about Fetal Alcohol related disabilities when her first children were adopted, resulting in a lot of trial and error regarding parenting and dealing with difficult behaviors and situations. Over time, she has learned to cope and adjust and better understand how to parent effectively.

As time passed, Pauline also learned to accept things as they are. She learned to "accept that things are in place and things happen for whatever reason." She also came to realize that one cannot "cure" a child. Pauline's view of the world had always been one of "children having to fit into the world." Now she can see that the "world has to adjust to accommodate everybody."

Having a child with a disability creates many challenges that often require creative solutions. For example, one daughter was afraid to speak. Instead of trying to overcome that fear, they began using sign language. This proved to be a more effective

means of communication for her. Pauline is also aware that daily routines are altered when children in the home have disabilities. She stated:

*I know how chaotic my house sometimes looks. But there is a reason why the toilet paper is in the kitchen with the door shut and never in the bathroom. Those kinds of little things.*

There are ways of making life easier for Pauline that are based on trial and error, experience, and creative thinking. Life creates challenges and we adapt. Pauline described her father's habit of carrying loose change in his pocket whenever he went to the mall with her daughter. One of her daughters always enjoyed throwing her shoes in the water fountain at the mall and "my dad had no problems walking around with change in his pockets and paying boys to fish Jane's shoes out of the fountains."

#### Coping with Multiple Roles and Living up to Family Expectations

Living up to external expectations can be difficult. Pauline must be a parent, professional, and an advocate for her children. She commented, "I'm a parent, but I'm a professional and an advocate. I make that very clear." Pauline has a strong personality and is able to advocate for the best care for her children. When dealing with professionals, Pauline makes a stand that she is educated and well informed about her children's needs. Pauline's background in nursing has also been an asset for dealing with medical professionals. She has earned the respect of the doctors she interacts with. She proclaimed:

*I do know what I am doing and nobody pushes anything over on me. I approach the doctors on the fact that I know what I am talking about and I know my stuff and they know their stuff. Then they'll sort of behave themselves.*

Her relationships with professionals are one of a team approach, working together for the best needs of her children.

Others in her community have recognized Pauline's hard work and dedication to children with disabilities. Her success and dedication to children in her home has led to the adoption of additional children. After several years of service, people come to her when a child needs a safe and loving home. Others now acknowledge the positive impact that Pauline has on the lives of children in need.

Pauline discussed having to live up to social, community, and professional expectations in regards to raising her children. She also talked about needing to meet the expectations of her own family. She views her life as very different from the life that her parents and siblings expected her to lead. As a younger woman, Pauline...

*never completely thought about adopting a mentally challenged person because I came from a highly academic family. I'm a complete horror to my family because I live in a low-income neighborhood and have 27 children! None of them homemade.*

Pauline does feel supported by her family, specifically her father who is always worried about how she will be able to cope physically, emotionally, and financially. She remarked, "I never tell my dad we're getting another kid until they show up. I know he'll just worry." Pauline has learned to deal with life as it comes. In her mind, everything has a way of working out.

#### Dealing with "The System" – Importance of Advocacy

Pauline is a strong advocate for her community and the children she raises. She voiced some concerns and frustrations in regards to fighting for her own rights and for the rights of her children. One area of frustration has been finding appropriate educational placements for her children. She believes that "the school system is probably an on-going hassle for a lot of parents." When her children were younger, Pauline talked about accepting the programs that were offered and doing her best to ensure her daughter's



needs were being met. Now, she talks about advocating for what her children need and not accepting a program that is not appropriate. She remarked:

*Now, I would make my own program. Make sure you know that you can shop around. If you are not finding success with something, look for something else. Always look for other options.*

Pauline has dedicated much of her adult life to making changes to how adoptions take place and ensuring that her children have a voice. She is actively involved in training for new parents and “fighting the system.” She was once told that she could not adopt a second child with a developmental disability because she was a single parent. Having come full circle, she is now the first person who is asked to take children with multiple needs. Pauline remembered one psychologist asking her to take a child. She recalled his asking, ““Can you please go to social services and get this kid into your home. We’ve seen the difference. We know you can do it.”” Through her spirit and beliefs, Pauline has changed how others view adoption, and her work has made important changes to government policy and procedure. Pauline remarked that she was the first foster parent to be involved in a joint guardianship agreement in Northern Alberta. Joint guardianship means that a Provincial court allows a foster parent to have legal status regarding a child who is in permanent care of Child Welfare. It also allows foster parents to share responsibility and decision making for this child.

Part of Pauline’s advocacy involves ensuring that her children have voices. Pauline actively works to break the cycle of abuse and educate others about disability and teach others that children have value as human beings. Pauline strongly believes in birth parents and children having a say in where the children live. She respects that parents can

make healthy choices for their children and can provide valuable insight into the needs of their children.

Pauline recalled one story of a birth mother who was unable to care for her child. This child later came to live with Pauline. Government policy at that time was to send the child to a relative. The biological parent of this child voiced her concerns but they were disregarded. Pauline recalled:

*The youngest daughter that we adopted had Fetal Alcohol Effects. She was functioning at a normal level with Attention Deficit and was sent to relatives to save the government money. And they couldn't cope with the patience you need for Attention Deficit and caused a severe brain injury. So she was in a coma for a year...My child was brain injured by family. A social worker wrote that on paper. She didn't think those kin had the patience to deal with special needs children. But the government saved money and they sent her there, to relatives, anyway. In some cases kinship care and brothers and sisters and that is wonderful. But in some cases if there's a problem we have to look at the whole picture. In her case, her birth mom, who we still see at times, had said 'don't send her there'...And so now she has Cerebral Palsy and has to wear a helmet all the time because if she falls one more time she'll die. She's actually a happy child because she doesn't remember what happened to her. She fits in well with our family. She functions ahead of most of the people that live with us. And so therefore she has a lot of self-esteem about who she is and what she is able to do.*

Pauline works hard to ensure similar incidents do not happen for other families.

### Importance of Community, Social, and Family Support

“I think it helps to know other people in similar circumstances.” Community spirit, friendship, and support are very important to Pauline. In her view...

*everybody has to support people. It's the reason why we worked for 9 years and gave up a lot to live in our neighborhood. Because everybody's lives come into everybody else's and everybody helps out.*

Her community has been very supportive of her family, with this support the main reason she chose to live where she does. She stated, “If I open up that door too fast, people come flying out to see what's wrong with the kids.” Pauline is also a very social

person. She describes herself as having a lot of friends. She talks to others in her neighborhood and this quality has been passed to her children. They have learned to “ignore people who ignore them and to keep on talking to those who will listen.”

Social and government support are also valuable services for Pauline to ensure she has help and assistance when needed. She believes that...

*the birth parents who have children with special needs created the supports that I have in my life and I'm very grateful for them. Because of them there is a world for the adopted children.*

These supports include in-home services, respite care, and extra money to help pay for needed care, aides, and other necessities. Pauline has a high level of in-home support to assist with the daily care of her children. She is grateful to have committed people working in her home and they also become part of her large and extensive family. Pauline declared:

*There's a lady who's been involved without family since before I adopted my son. We adopted at 3 and he's now 17. People commit to us in the same way. A lot of people felt that they would never work in a group home again but they will still work for me. We have people who would like to work for us and basically have to wait.*

This has been a tremendous support for all her children.

Family support is also very important to Pauline and has been instrumental in assisting her life and her dream for her children. Given that there are 27 people or children who belong to her family, there are many advantages of this large family support. All of the children who Pauline has cared for are...

*extra family and will always be related to my adopted children. My children have more people than a lot of families do and are not as isolated. We are out there. Somehow we're out there. We have a lot of extended family.*

Another positive aspect has been that her children are comfortable when their siblings care for them, rather than when strangers come to the home. This is especially relevant when Pauline is needed to care for medical emergencies involving her children or children in her care. She remarked, “My kids are not freaked out if the kid that they live with looks after them. They are more freaked out when other people come in [to the home].”

### Personal Growth – Life Changes

Pauline views herself as a caring person. Her values about life and children have not changed since she became a parent. In fact, it seems her values and ideals are what led her down her chosen path of life in the first place. Pauline sees herself as more outgoing than she used to be. She is more involved in her community and is a more active spokesperson both personally and professionally. Life experiences can change how one views life and the decisions one makes. The death of her son, Noah, changed Pauline deeply. She recalls how her life was changed as a result of Noah’s death:

*I think I became more patient with Noah. And Noah dying really taught me how to value every child, every moment, regardless of how crazy they make me. So I think that was probably the turning point. Before that I think I wanted a lot more success for my kids.*

It took several years for Pauline to learn not only her own limitations but also those of her children. Her intentions at first were to provide family to children in need but also to help them learn and achieve success in their lives. She commented, “I think initially when people got to taking children home and stuff, you really want success all the time.” Pauline’s family, as mentioned earlier, is full of high achievers. Pauline described feeling a lot of pressure to be a successful parent and to make a significant contribution not only to the lives of her children but also to the system surrounding

adoption, disability, advocacy, and government policy. It was a life lesson to realize her own personal limitations. Pauline explains what she has learned since she first began adopting children:

*You really have to realize that some of these children are going to plateau. In some places you still won't be going anywhere. Other things will make a difference. Not everybody can be fixed completely and that's a real hard thing to get around.*

For Pauline, there are no miracles in raising a child. One can only do one's best and work with what has been given. Part of this life lesson is also learning to focus energy on what and who is most important. She feels that...

*you are not committing to taking on every single child when you adopt. You are committing to take on your child or children. You are not taking on the whole world. It is very difficult to be in a high-achieving mode when you are raising a child.*

A skill that Pauline learned was to view happiness as a construct on it's own. Happiness is not measured by the skills that are learned or mastered. It is not measured by success. Happiness is what to strive for everyday, regardless of what life deals to you. She believes that life is good "when the kids are happy." Pauline lives and works to make her children happy and to enjoy life.

Lastly, Pauline commented that becoming a parent, either through birth or adoption, is a life changing experience. Many people think that adopting a child is simple and once they have a child they can move on with their lives. Having children, regardless of whether they are adopted, brings about new issues, challenges, sacrifices, and changes in perspective. Pauline declared:

*Life is never the same and I think that's one thing that if you haven't had kids before, it may be a little shock for people.*

Belief in the Value of all Children

Pauline has a strong belief in the value of all children, regardless of gender, race, or disability. Pauline accepts high-risk children into her home and children at risk of illness or who have significant medical, physical, or cognitive delays. If Pauline did not take these children into her home...

*it's highly unlikely that they would have had another family. I take the kids other people don't want because I believe those children have value. And I'll make other people want them.*

Pauline's adoptions are usually crisis adoption, those children who need an immediate home as a result of circumstance. Pauline is able to provide a safe and secure home for these children and the outcomes are remarkable. Pauline remembered:

*A woman came to me after watching my youngest daughter and said, 'I'd take her home anytime.' And I thought, 'yeah right.' She listed in the social services book for 3 years and nobody took her home. But now she's outgoing, she's secure, she's confident, and she's cute. Now people want her.*

Pauline's children have all learned and grown into unique individuals. Part of their success is Pauline's belief in ability, not disability. She also focused on what her children knew how to do. She strongly believes that...

*people really should never think that just because someone's got extra needs or whatever, or can't talk, that they don't know what's going on. They know lots of stuff.*

Pauline has been able to work with her children's strengths and capitalize on their abilities. Pauline talked about one of her daughter's inability to communicate. Once she was able to teach her sign language, she remarked how she "couldn't teach her signing fast enough." It was then that her daughter was able to communicate and recount some early life memories. A previous diagnosis of severe mental handicap seemed inaccurate based on what her daughter was able to communicate and information she was able to

learn. She believes that, “People forget that just because one area of the brain is damaged, it’s not the whole person.” There is so much that we can learn and so much that can be accomplished by focusing on the abilities that all people have. Pauline advocates strongly in her work and life to overcome the negative stereotype that people with disabilities cannot learn and achieve greatness in life.

### Claire's Story

Claire is a mother of two adopted twin boys, both diagnosed with Fetal Alcohol Syndrome. Claire's most recent employment involved caring for the elderly living in nursing care facilities. She also spent 15 years developing programs for seniors and organizing hospice services. Doug, her husband, works as a mechanical engineer. They could not have children of their own as a result of infertility. They decided that adoption was a good choice for them to have children, something they desperately wanted. Claire and Doug researched adoption thoroughly and began their search for a child when living in Ontario. They attended several adoption fairs, seminars, and conferences. During the time they were searching for information, Doug was offered an employment opportunity in California. They felt that moving to the United States would hinder their chances of adoption. They decided to move to Alberta from Ontario to seek employment and pursue their dream of having children. Upon moving to Alberta, they met the twin boys, Samuel and Justin.

Claire and Doug adopted the twins when the boys were 5 years of age. Samuel and Justin previously lived in a foster home, however were removed due to allegations of abuse. Claire is now a stay-at-home mother so she can provide full time care for her children. She is actively involved with family services as a home support coordinator and assists other families, both natural and adoptive, who have children with developmental disabilities.

### The Reality of Adoption - Knowing What You've Signed up For

Claire and Doug entered the adoption process well informed and open to accepting a child with developmental disabilities. She remembered:



*When we started the adoption process in Ontario, we soon found out that most of the children in adoptions were children with special needs. Unless you're going to have a surrogate mother and you're going to feed her and you're going to watch her 24 hours, 24-7, really, what guarantees are there?*

The reality of adopting a child is that most children will require extra support in addition to a safe and caring home. Claire was keenly aware that any child they adopted would require extra time, love, and special support. That is the reality for many adoptive parents. Claire's philosophy regarding adoption was, not only to provide her and her husband with children they desperately wanted, but also to be able to provide a safe and caring environment for a child in desperate need for a home. They made the decision to improve the life of a child and had a realistic view of adoption and what to expect. They were not able to predict the future nor know exactly how becoming a parent would change their lives, but they were aware that some struggles and adjustments were going to be part of the process.

#### Making the Connection – Love at First Sight for Parent and Child

Claire talked about a feeling of destiny when she first saw a picture of the twin boys:

*I heard it many times from many people who have adopted. We saw them and it was like 'oh my God, look at those boys!' And that was it. We were sunk. We saw lots of children but these were the ones for us. It clicked. It just fit. There was a bigger force happening here. There was someone much much stronger in this picture that was guiding us this way.*

Claire felt an instant connection to these children. She fell in love with them at first sight. To her, it was a somewhat strange experience. Claire and her husband only wanted one child and thought they would prefer to have a little girl. It was a surprise to her that she felt such a connection to two young boys.

Part of the connection Claire felt surrounded several coincidences between the lives of the twins and her own family. She explained:

*Doug's father's is a twin so there is a twin connection. Doug's father was 42 when Doug was born and Doug was 42 when the twins came. There were lots of connections there.*

The decision to adopt provided a feeling that things were meant to be.

Early on, Claire's mind was set that she wanted these boys in her family. It was equally important to Claire that the boys shared in that feeling of connection. She wanted the connection to be mutual. She stated:

*We did not adopt our children. Our children adopted us. They have to know that they had a choice. It's very important. When they are older, we want to make that very clear to them. We were in love with them and we knew that. But they had to make the final decision that they wanted to come here to live with us.*

#### Bridging Two Worlds – A Period of Difficult Transitions

The boys had previously lived in a long-term foster placement. According to Claire, the boys felt they already had a family. Claire acknowledged that she needed to work hard to bridge the gap between her world and the only world the boys ever knew. It was a difficult transition for both the children and Claire. Given that the twins were 5 years old at the time of the adoption, it was important to Claire that the boys were aware of what was going to happen. In the minds of the boys, they had a family already. Claire described the day that the boys found out that they would be living with her and Doug. She recalled:

*They came for a sleep over and the social worker told them that Doug and I were going to become their new mommy and daddy. She was very compassionate. She told them that their old mom and dad couldn't keep them safe anymore and that Doug and I would keep them safe. It was very hard. It was very, very hard. Justin was ready to move right in. Samuel took it very hard. In the foster home, Samuel could do no wrong and Justin could do no right. Justin was punished more because he's more impulsive. He's the one who always gets caught, like with the*

*hand in the cookie jar. So, of course, Justin would want to come here because it's better than where he was. And of course Samuel wouldn't want to leave because he was the favorite child.*

Claire talked about the first few months that the boys were living in the home. She described that first period as a...

*honeymoon phase. You go through a period where you know that there is going to be a lot of adjustments and a lot of anger. They're children. They don't have the vocabulary or the emotional knowledge to understand what they're dealing with. So it comes out in language that they know, which is usually aggression. Verbally sometimes and it can certainly be physical too. You go through that phase. You're kind of like on high energy all the time. You're trying to out think them. And it can be exhausting.*

Part of the adjustment to the new home was grieving the loss of the only other family the boys knew. Claire recalled that...

*it's painful and we've gone through a lot of pain. They talk about their other parents. I advocated very strongly for them to have a play therapist. I was very strong in saying that they needed good counselling. They were taken from their home. They were at school so they didn't even get to say good-bye. Imagine the layers of loss that they would have. And that's all part of the grieving.*

Time appears to be a key element in the process of adjustment. Claire talked about how the boys were withdrawn and unsure of themselves during the first month in the home. They were hesitant to join in family events or initiate activities. She remembered that...

*they never asked for anything. They never did anything basically. If I said 'go play with your toys,' they'd play with their toys. If I said 'let's go out to the park,' we'd go to the park. But it all had to be initiated from me. Nothing came from them. Unless it was impulsive behaviour or aggression. It's only been in the last year that they now ask for things.*

After hard work and commitment to her children, Claire feels pride when her children state that they feel belonging and connection to her family. She feels immense

joy that her children can overcome negative experiences and feel safe and secure in their new identities as Claire and Doug's children.

Adjustment seems to be an on-going process for Claire and her family. According to Claire, there will likely be other future transitions and adaptations to overcome later in life. Claire talked about being prepared for future transitions that could occur, including when the boys eventually want to find their birth family or parents. She stated:

*We will support them when they want to find their birth mother and help them in every way that we can. We have an opportunity to help. That's who they were but that's not who they will be. We have an opportunity to help them develop themselves. We know it's hard. It's very hard. We don't make light of it. You have to be very committed to taking this on. If your relationship isn't strong it will weaken it. It will find the cracks and certainly sever them. I'm very clear on saying that this is a rough road and you have to be the strongest advocate for your kids.*

#### Dealing with Abusive Pasts – The Need to Save

Claire talked about her motivation to adopt. She felt that she was meant to do more with her life and there was a reason God placed her on this earth. She feels she was meant to be a strong parent for these boys. She explained:

*I had a miscarriage through fertility. And it just wasn't meant to be. You know, God had a bigger plan. And here they are with us now. We have a lot of strong ethical and moral beliefs and we did the right thing. And we're very very happy with our choice and we can't even imagine what our lives would be like now without them.*

The twins' history involved abuse and abandonment. Claire, deep in her soul, desired to save these boys. She acknowledges that despite her intentions, she cannot understand the trauma these children have experienced. She explained:

*Some people who come into the adoption process just want to love these children and give them a safe environment. That's because we don't understand. We haven't lived that horrific life. We have a hard time. We can be empathetic, but we certainly cannot really truly understand it.*

Claire talked extensively about how she needed to learn to cope with the boys' anger, fear, and aggressive behaviour when they first came into the home. Part of Claire's frustration was the understanding that she was not able to provide the boys with early bonding and nurturing. She commented:

*When you have a biological child, you've done the nurturing. You've done the bonding. The child knows that when you say 'no'; that that usually means 'no.' When you adopt older children who come from abusive situations, they've never had boundaries, so they don't know boundaries. So they don't know if you really mean it [no] or, quite frankly, they don't care if you mean it. They're in a survival mode and they'll do whatever it takes to survive.*

### Two Families Beginning A New Life Together

Claire spoke about her excitement when she sees the boys becoming interested in activities she treasures. It shows how their two families have connected and merged into one. The joining process began on their first meeting when they took pictures to commemorate the occasion. Claire described the use of pictures as a prominent aspect of their lives. For Claire and Doug, having the boys take pictures of them as a group was the beginning of sharing their lives and interests.

Claire describes herself as a voracious reader and wants to instill a love of reading in her children. Claire also described her life as full of humour. She beamed proudly when she talked about how the boys have begun to use humour in their own lives. For her, "it's like a bonus." This shows how two worlds can connect given time, love, and commitment.

### Making a Difference – The Joy of New Learning and First Experiences

The twins' previous home lacked much of the essential stimulation and interaction that most children need. She recalled:

*They didn't have the interaction. Like at McDonalds, which you and I might not care for McDonalds, but it really is social development for young children. They learn to play. They learn to interact with other kids. There's just a whole component there. And they missed that. They didn't have the right stimulation. They knew every Arnold Schwarzenegger movie, knew all the wrestlers but never saw Sesame Street, never saw a Disney movie, and they were nearly six. So, not the right stimulation at all.*

Claire commented that it was often overwhelming to watch the boys make connections to their new world. She stated:

*They never had juice and they drank watered down canned milk. So, our thing was to have as much fresh fruit for them as possible. And they would open the fridge 30 times in an hour. I learned quickly not to say, "would you like some juice?" because it wasn't about that. They just needed to see that the juice was there. With Fetal Alcohol children, their brain is like Swiss cheese, filled with holes. Like they're not connected. So it's their way of connecting and re-connecting. So opening the door is the connection 'juice is there. I can have it whenever I want it.' So it's that type of connection that they needed to do.*

Claire is amazed at the little things that her children learn and experience. When they arrived, having lived through trauma and abuse, the boys had limited experiences. It was overwhelming for Claire to be part of some of the boys' first experiences. Claire fondly remembers:

*They had never been to a movie before. So, when they came with us they ate one kernel of popcorn at a time. And they still do that to this day. It's just the most beautiful thing to see. They are such movie critics and they love the movies. It's just a joy to see. They'd never been to McDonalds until we took them. Never rode a bicycle. They didn't have a real birthday party. They didn't really celebrate Christmas. We've had so many firsts with them. It's overwhelming for them and us, sometimes.*

Claire takes pride in seeing the boys flourish. She is awe struck that the boys have become phenomenal eaters, learning to love fruit, vegetables, and food that they never experienced before. The boys have also grown physically. Claire believes, "It just shows you what environment can do."

### Celebrating Differences in Culture

Part of connecting two families through adoption involves understanding culture. Claire is proud of the boys' aboriginal heritage and is willing to incorporate that heritage into her family life. She has extensive experience with native culture and the support she receives from the native community has been instrumental:

*We embrace it [native culture]. We get to learn a whole new culture. It's just amazing. I worked out on a reservation when I graduated. I have incredible respect for native people, because I learned what it was like to live on a reservation. I got first hand exposure to a lot of the gifts. That was 29 years ago when I came here. The native people I was involved with years ago are incredibly supportive of us adopting their children. It's thrilling. We're proud of our heritage. It's very important that they should be proud of who they are. It is who they are.*

### Coping With the Demands of Parenthood and the Search for New Solutions

Claire commented that one of the challenges with becoming a parent of two boys with Fetal Alcohol Syndrome was dealing with challenging behaviors. Claire felt somewhat prepared when her boys came, however she acknowledges the need to be constantly searching for new information. She became keenly aware of her children's needs and abilities and talked about the need for patience. She also needed creativity to help the boys replace negative learned behaviors with positive ones. She sees her "job as very much teaching them the skills that are going to make them successful. And so far, I find that I'm right on target." To ensure this happens, Claire commented that she has had to learn to "pick her battles." She is more aware of her children's abilities and the connections they are able to make in order to make positive behavior and life choices. She has learned what her children need and is willing and able to make sacrifices to provide for them. She understands that her "kids need a very structured environment. They will need structure the rest of their lives. So we give it to them."

Claire commented that she is constantly looking for new ways to help her children learn. She described herself as a voracious reader and is always researching new techniques, methods, and ideas to implement in her home. Learning is continual and constant. Part of the learning curve is learning to be flexible. The challenge occurs when something that worked before stops working now, and she needs to try new things. Claire has learned a lot about herself and her children by experimenting with new ideas and implementing new techniques. She hopes to pass her thirst for knowledge and new learning on to her children.

#### Reaching a Point of Exhaustion – Being Afraid to Ask for Help

Claire remarked:

*There are so many layers of emotions being played in at all times that you burn out if you don't have supports. And I burned out. I really found myself going for a nosedive and it was exhausting. When I had my spiral downwards I basically just cried and slept, cried and slept and just stayed home. I think it was a turning point for me to realize that I do need support.*

Becoming a parent, whether through adoption or natural birth, can be exhausting. The transition to parenthood is difficult. This transition is even more difficult when one feels alone and lacks the support of others, either from family, friends, community, or professional agencies. Claire talked about how she and her husband so desperately wanted children. They spent time researching adoption and studying parenting techniques. They felt that they were very prepared when the boys first came into their lives, so it was very difficult to ask for help when she needed it. Claire explained:

*Doug and I wanted children for a long time. I certainly critiqued my siblings on their parenting skills. How do I now reach out and ask for help? It was almost like I was ashamed that I couldn't handle it.*



Claire commented that, as an adopted parent, she felt that she was capable of handling any issues that arose because she was supposed to be well prepared. When things became difficult, it was hard to take the time to give back to herself and ensure her own needs were met. She noted, “You need to be comfortable in your role as a parent before you can start to reach out.” It took time but Claire was able to reach to others for support and this has been a tremendous help.

#### Advocacy as a Coping Strategy

Once Claire was able to ask for help, she became aware of all the supports that did exist in her community. Claire became very involved with post-adoption supports and now chairs an adoption support group that meets once a month. She has become dedicated to helping other families through difficult times and works cooperatively with social workers and other professionals to gather resources and information. Learning to cope with parenting is an on-going process for Claire and her family, but it took her reaching a period of exhaustion and desperation before she was able to reach out to others. She is now involved in helping others and advocates for, not only parents of children with developmental disabilities, but also any parent who needs help.

#### Marital Support – Redefining Yourself as a Couple

Claire talked openly about her relationship with her husband. They were both 42 years old when the twins arrived, and they had been married for 10 years without children. Part of adopting children involved examining their relationship. Once the children arrived, they had less time to spend with each other. Claire commented:

*I missed my buddy. We had no time together anymore. That's hard. As much as you try and put it in place, you've got young children now. There are a lot of things in the equation that get lost. You have to redefine who you are as a couple and that is sometimes a struggle in itself. I really miss him.*

Claire has made efforts to spend more time with Doug, including incorporating a date night once a week. The date night “has been vital” for her marriage.

Claire described her relationship with her husband as very strong. They both seem attuned to the other’s needs. Claire beamed:

*Doug is so wonderful. If he comes home and supper is not ready, chances are that it has been a rough day, homework wise or whatever. He just pitches right in and takes over. Or says, ‘come on guys, I’m gonna take you out for dinner and give mom a break.’ He’s just phenomenal like that. And that makes it work for us. It’s the fact that I know he’s there when I need him.*

Spousal support makes difficult days easier for Claire to cope with. Working as a team seems instrumental when raising children.

Claire and Doug also had the opportunity to adopt the boys’ biological sister. Their strength as a couple helped them deal with this difficult life choice. Part of that decision was based on the boys’ best interests. As a couple, they were aware of their own limits and comfort zones. Because they were aware of the dedication and energy they required to meet the boys’ needs, Claire and Doug decided not to adopt another child. For Claire, clear communication, trust, and honesty are important factors for couples and parents.

#### Family Support as Essential

Besides marital support, external family support was also instrumental to Claire, not only in providing respite and relief, but also in providing needed moral support.

When in the process of adopting their children, Claire talked about how important it was to her that their families supported their decision. She commented that everyone involved with the adoption was very supportive and “knew that it was the right thing for us.” This support has been vital to Claire.

Claire was very open in looking back on her life. She was able to cope with the stresses in her life as a result of hard work and family support. She views herself as having worked hard to accomplish all that she has in her life. She described herself as having a “strong family upbringing” and has learned to be compassionate by watching how her extended family treats others. She talked about how her own mother always treated others with care and respect. Claire had a sense of community and respect for others as a result of feeling a close connection to her family. In times of need, Claire felt the support she needed because of this bond.

#### Adoption as a Learning Tool for Others

Claire talked about how adopting Samuel and Justin was helpful to members of her extended family. She noted, “We encouraged our extended families to use our adoption as an educational tool.” Claire was surprised how others were affected by their adoption experience. Her husband’s older sister was adopted. In previous generations, adoption was not something that was openly discussed within his family. The adoption of the twins allowed discussion about the topic and gave Doug’s sister permission to talk about her own experiences for the first time.

#### A Change in Friendships

Claire talked about how her relationships with friends changed after she adopted the twins. In her view, the adoption of children with developmental disabilities often brings about special challenges for families. Not everyone can fully comprehend these issues, specifically those who do not have children. She stated, “Normal families [families without any children] sometimes don’t understand. They don’t understand my adoption concerns or some of my Fetal Alcohol Syndrome concerns.”

Claire's relationships with others have changed as a result of becoming a mother. Claire commented that she is "not into superficial anymore." She prefers to spend her time with other parents who have children. She is more actively involved in family activities and finds it more difficult to make time for friends or acquaintances who don't have children of their own. She explained, "We find our new friends are people who have families." As life changes, one tends to gravitate toward people with common interests and experiences, not only for recreation but also as pillars of support. For Claire, this was just part of the change that happened when she had children.

#### Rewards of Parenting - Seeing Oneself as a Mother

Claire talked repeatedly about the joys of parenting. It took time and hard work to earn the boys' trust, but once established, she felt intense happiness to be a mother to them. Being able to enjoy the small things in life, like the cuddle on the couch, are the things that Claire treasures deeply. Claire proclaimed, "I love being a mother. I love being the mother of these two boys." Claire can no longer imagine her life without the boys. She exclaimed, "They're just so immersed in my life."

Claire talked about how others think she is a wonderful woman for taking the boys in and providing them with a home. She is quick to inform others that she also receives intense rewards for being a parent to these children. She remarked:

*We say they are gifts from God. They truly are. It was meant to be. We were to come into their life and they were to come into ours. So when people try to put us on a pedestal, we're quick to tell them that it's a 2-way street. Look what we've gained. These boys are giving us a life too. A life with children, which we would not have had if they didn't come into our life.*

### Knowledge of Personal Strengths and Sense of Identity

One must have a good sense of self in order to describe his or her life perspective and life priorities. Claire described herself as “very grounded” and as having a “very strong moral code on respect.” As a child, Claire was often told by others that she had a spirit of helping because she always wanted to befriend those without friends or care for those who needed her help. She entered a profession that enabled her to care for others, and she noted that people were often attracted to her enthusiasm and sense of leadership. Claire is comfortable working with people who are different. She has volunteered extensively and has experience with many different people with a variety of needs and life circumstances. She has learned to be compassionate and nurturing and took easily to her role as mother.

### Realization of Life Priorities and Personal Change as a Result of Being a Parent

Claire has a strong sense of self. She is also aware of her priorities in life and the need to change these priorities once she became a mother. She explained:

*Before my house was spotless. Now that I'm home and we have children, there's a lot that I had to let go. I think I was trying to be super person and I realized that I just couldn't do it all.*

She was able to realize her own limits and decided to focus on what was most important.

Claire now sees the world “through the eyes of two 8-year-old children. [She] certainly experiences life totally differently.”

Claire views her own self and identify as changed. Becoming a mother was a...

*big change for me. I worked and had my own career. I had a reputation. I had it all, and I gave it up. But you don't lose who you are. I'm no longer who I was. I was just your wife, and now I'm the boys' mother. I am also somebody else. You have to tell people constantly who you are. After a while I realized that I didn't care anymore. It's not that I don't care what you think about me. It's just that it's*

*not that important. It's more important that I'm the boys' mother. It's more important that I'm Doug's wife.*

Having said this, Claire seems aware that others perceive her as changed. Her life as career woman and wife are now different. She sees herself as changed because she views things differently. At the same time, she is still a strong leader and maintains the strong morals and ethics she always had.

During the adoption process, Claire knew that her work and life were going to change. She and her husband made the choice to have children and to sacrifice career and money in order to realize their goals as a family. Adoption, for Claire, was the right choice.

#### Pride in Children's Accomplishments and Acknowledgement of Hard Work

Claire remarked:

*They might not learn the normal way, but they do learn. It's just about finding a way that they learn best. We'll always find a way to teach them because they want to learn. They are little sponges right now. They soak it up.*

Claire's role as parent involves not only being a provider, caregiver, and nurturer but also a teacher and advocate. Teaching her children has involved intense work from everyone involved, including herself, her husband, and teachers at school. She takes immense pride in watching her children learn, knowing that all learning for them takes time, energy and hard work. She acknowledges that her children...

*have certainly come a long way. They couldn't print their names. They couldn't count to 10. Couldn't tie their shoes. Who we are today and where we are today has been due to a lot of hard work.*

Claire is immensely proud that the boys have made such tremendous progress both socially and academically. She talked excitedly about the progress that her son is making:

*He is not the child that he was when he came to live with us. His social development and his social skills have improved. He's charming, he's funny, and he's artistic. He has an incredible sense of humour.*

Claire remarked that she didn't always feel that she was making an impact on the boys. She told a story that illustrated how she felt when she realized that all of her hard work was really making a difference. She recounted:

*Before we went away to Disneyland, we've never been in that type of crowd, so we were a little concerned about how that was going to be. To dart off somewhere, lose yourself in a crowd, that's a big thing. So, we were telling them that when we go to Disneyland they have to hold hands like a family. If we get lost we have to go to one of the characters or one of the people who are doing the rides, because they're the safe people. At school, Justin had to write a letter. The teacher showed us the story and it was all about going to Disneyland and holding hands with mom and dad and what to do if we got lost. I said to Doug, 'wow, he is hearing us.' At the time he acts like he doesn't. I just wonder how much he does know. So it was really really good to see that.*

#### Importance of School Support and Advocating When Things go Wrong

Claire remarked that the boys' teachers at school have played a large role in helping her children. She commented that...

*the teacher this year is phenomenal. Justin is reading and writing at a moderate grade two level. They are doing time now, months of the year, days of the week. They are doing all that and they are doing very well with it.*

School has not always been a positive experience for Claire and her boys. She recalled:

*Last year we had a teacher that really had a problem with one son. And if you're a special education teacher you know that the punishment has to fit the crime and it has to be immediate. She would make him wait till the end of the day, to sit in class all day, to tell me what he did wrong at the end of the day. Plus she would have Samuel in the classroom and she would give him one of the privileged jobs such as erasing the board. So it reinforced their old behaviour. It reinforced who they were in their other home. I had to report this teacher. I had a hard time with that. And the principal at the time wasn't really supportive. I finally agreed that she would talk to me once a week and the children would go with a friend. She was not going to set my son up for failure. 'Cause I mean, where does it go? He hides that anger or he buries it and it manifests itself in aggression. Every time. Because that is a child. That's the only way he knew how to survive.*

Claire felt pride in being able to stand up for her son and advocate for his best interests.

Despite the above noted difficulties, school has also been a major support for Claire and her boys. She is happy to receive support for her sons to assist with transitions during the day and to help her children achieve at their maximum potentials. She is very grateful to have had some experienced teachers who were willing to be flexible and keenly aware of how to problem solve with her boys. She commented:

*Just to show you how fabulous our teacher is...They do what they call 'changing words.' They change the beginning of a word with an ending to make it a different word. And Justin has a really hard time. He hates it. And his teacher said 'why am I doing this to this child? I know I can make him do it but it's a power struggle. I don't want to do that anymore.' So she said to him, 'Justin instead of doing that, I'm going to have you sit with Mrs. X and do some other language arts stuff. How do you feel about that?' She asked his permission and she gave him a choice. And he looked at her and he thought about it and he said, 'that's fine. I would like that.' He did a lot of work and she said she is hoping that maybe in 2 or 3 weeks he'll want to come back into the group. But it will be his choice. And he will be much more successful. To me, that is a fabulous teacher. She's willing to change her teaching ways to reach my son. We're so grateful to have her.*

#### Realistic View of Children's Strengths and Needs – Helping Them Reach Realistic Goals

Claire and her family have worked hard to build on the boys' strengths. They are aware of the need to be creative in finding ways for them to be and feel successful at school and in other areas of daily living. Claire is also aware of the boys' limitations and tries to ensure that they can achieve success in areas in which they are capable. Claire stated that...

*in a couple of years, Doug's going to buy an old clunker and teach the boys how to fix it up. They will learn about bodywork and mechanics. That's our reality. We're not talking about rocket scientists here. We're not rocket scientists. So we want to be able to give them as many skills as we possibly can. And Samuel's eye-hand coordination is phenomenal. He also has a very mechanical mind. They both are very good at that. I think that they would benefit greatly from that. And that can open up doors for them in so many areas.*

#### Priority in Teaching her Children Strong Values and Respect



Claire voices her beliefs, values, and opinions loudly and hopes that her children will leave her home feeling respected. Part of her role as mother is to teach her boys the family values that she embraces. She reported:

*I am very much into teaching my children good, strong social skills. I really want to raise polite children. I look at my job as to teach my sons to respect women. Period. And that is me as a mother and that's other girls they are playing with and that's their youth work. And part of that is acknowledging us when we talk to them. And so we work on acknowledgement. We're successful most times. My children write thank you notes. My children say thank you. It's important. I think that's part of my mind-set, to acknowledge and to say thank you. The boys had none of that when they first came.*

#### Respect For All Children and Humanity

Claire has a very positive view of all people, regardless of disability or challenges they face. Claire's extensive background as a caregiver and advocate has made her a strong advocate for her children. She commented:

*I'm really big on volunteerism with children with special needs. They need a place to shine. They will shine in any environment that looks at them as if they are worthy people. Any seniors complex or any rehabilitation center, anything like that is going to look at any child with special needs in that light. And teach them that they are truly needed and honored and respected. I'm very strong in that belief. I don't think that there's anybody who doesn't have a future. I don't see any child as not having a future. I just see unfortunate parents that can't see that future. That's the sad thing. It doesn't matter who your child is or what your child's abilities are. I don't care if they don't do anything but are in a group home environment. They're somebody in that group home environment. They're part of the puzzle. They're part of that unit and they all have gifts. I just think you'd be narrow minded if you don't see that.*

Claire is able to use her skills and views to help her own children achieve success. She is cognizant of her children's needs and realizes their strengths and challenges. She is also able to see how their strengths fit to make the lives of themselves and others brighter. Claire views her children as having a gift to teach others. She believes that...

*everybody has a place in our future. We need the entry-level people as much as we need our researchers and scientists. I think that each child has a gift and you*

*just have to help nurture it and find it. If you have a child who has Down syndrome or if you have a child who has Cerebral Palsy or multiple disabilities or whatever. Every one of those children has a place in our society. If not for any other reason but to teach other people to be tolerant and to be accepting.*

### Margaret's Story

Margaret is a mother of three adopted children. Her first child, Nicholas, is age 7 years. He was adopted at birth and does not have any known disabilities or special needs. Their second child, Matthew, is now age six. He was adopted at the age of 9 months and has been diagnosed with Down syndrome. Matthew also has serious medical issues affecting the functioning of his heart. Margaret and her husband, Harold, most recently adopted a little girl, Sarah, who is 2 years of age. There is a possibility that Sarah may have some features of Fetal Alcohol Effects, however she has not experienced delays in development to date.

Margaret is a homemaker and is actively involved with community organizations and advocacy regarding adoption and children with disabilities. Margaret and her family are members of a community living association and frequently attend conferences and workshops to obtain current information about disability and Down syndrome. Margaret has a strong view of inclusion for all her children. She was eager to share her experiences about raising Matthew and her adoption experience with a child who has a developmental disability.

### The Decision to Adopt – The Choice and Process

Margaret and her husband, Harold, could not have children of their own as a result of infertility. They decided as a couple to pursue adoption as a means to have the family they always wanted. They decided early in the process that they would be willing and able to adopt a child with a mild to moderate developmental disability. In Margaret's mind, she would be willing to consider any child provided she was informed and could make a decision based on all available information.

The adoption of their first son, Nicholas, was a successful experience. Margaret and her husband chose to remain with the same agency for the second adoption, of their son Matthew. Matthew's adoption was open, meaning that both natural and potential adoptive parents would be able to communicate openly and share information about Matthew and his needs.

Matthew's birth family chose Margaret and her husband as a suitable family to adopt their son. Margaret was approached by the agency and told about Matthew and the fact that he was diagnosed with Down syndrome and had a very serious heart condition. Margaret was then given the choice to decide whether she would be able to care for Matthew and be able to meet all of his medical, cognitive, and social needs.

At that time, Margaret talked about how she felt the need to take time to think about the pros and cons of the adoption, and whether she felt her family could accept Matthew into the home. Part of the decision making involved Margaret taking a close look at her own family and the needs of everyone involved. Margaret described her family as very active, often involved in outdoor activities such as camping, cycling, and cross-country skiing. She wanted to adopt a child who could be involved in these kinds of activities. In her mind, Matthew would likely be able to participate, with necessary support and assistance. This was one key element that helped with the decision process.

Margaret also spent several days gathering information from doctors, public health centers, and other parents who had children with Down syndrome. She commented, "We wanted to know what we were getting into before we got into it." When they first considered adoption, Margaret never thought about adopting a child with multiple disabilities. This was a difficult decision for her and Harold to make.

Margaret's motives for adoption also played a role in her decision. Margaret commented that she and Harold did not have "any great motives for taking Matthew in. We just really wanted a playmate for Nicholas." Age was also a factor she considered:

*One of the things with us was our age. We were quite a bit older. It could be that we didn't have a choice of other kids or that other people wouldn't have chosen us. We might have had Nicholas and nobody else. You never know.*

Margaret and Harold made an informed decision to adopt Matthew. They felt that, given all the information they were able to obtain, Matthew would indeed fit into their family.

Part of the adoption process involved some difficult times. Margaret commented that it took several months for Matthew to become their legal child. As a result, they were not able to access needed medical services and support. They were not able to access relief and extra funds to care for Matthew's needs. Margaret described herself as feeling very empathetic toward Matthew's birth parents who were having a difficult time accepting the adoption. She did not feel compelled to rush through the court process, but at the same time felt very alone in dealing with Matthew and his needs. One incident described this frustration very well:

*Over Christmas Matthew had open-heart surgery. By then he was about 9 months old. At that time, Matthew legally still had his biological name. So we brought him (Matthew) to hospital for the surgery and we asked the nurse to phone us as soon as he was out of the surgery. Because we had Harold's parents there and his mom's in a wheel chair and they're really old and they couldn't really look after Nicholas who was 1 ½ years old at that time. So, we came home to wait until the surgery was over. And we're waiting and we're waiting and we're waiting. And I guess what happened when the surgery was over, they phoned his birth parents. And they thought, well that's nice that the surgery's over and everything. And they thought we were at the hospital. And meanwhile, nobody's at the hospital. So when we finally phoned, they asked us why we weren't there? So, that was a bit of a fiasco. The other thing was that we could have gotten that covered. You know, hospital visits, parking, and all the extras. We could have gotten a babysitter and been at the hospital and had that covered through Services for Children with Disabilities. Except we didn't qualify because we hadn't gone to court. It was kind of a miserable experience.*

### Empathy for the Birth Family – Understanding Their Grief and Loss

Margaret talked extensively about the circumstances surrounding the adoption of Matthew. Matthew's birth family was reluctant to give Matthew up for adoption, yet knew that they could not be the parents that Matthew needed. Margaret commented that it was very difficult for Matthew's family to finalize the adoption. Margaret had to wait several months before knowing whether Matthew would be coming to live with her family. This experience was frustrating for Margaret, yet she felt that she could not voice her frustrations, given the grieving and emotions that Matthew's natural parents were experiencing. She explained that...

*it was hard for us [to watch Matthew's family through the decision process of adoption]. A lot of empathy. They said [you can take Matthew home] next month. Maybe in a few weeks. Then we started saying we would like to have him but is he coming or isn't he? They were having a really hard time too. They had him home and there were siblings and so it was really hard. It was really hard for them. I think the biggest thing was that they had no idea that they were going to have a kid with Down syndrome. They were expecting a healthy baby. And we were sort of hanging on for a couple of months and finally we said that, on this particular day, either we have him by then or else we decide we don't want him anymore. Then they said OK. And he came home with us.*

Margaret felt much empathy toward Matthew's parents. She knew that they had a difficult decision to make and were grieving the loss of their child. In her eyes, giving birth to a child with a disability would be difficult to cope with. For Margaret, she was able to make an informed decision about whether to accept Matthew into her family. For her, this resonated as a key difference between birth and adoptive parents. She believes that...

*if you have a child with a disability, you have the option of giving them up or putting them in an institution or something. You don't really have an option to pretend that this isn't here. When people have a child born with a disability, they go through this incredible grieving process. This whole thing about you thought*

*you were going to have this kid and then all your dreams are sort of shattered. We had the option of taking him or not taking him.*

Margaret still involves Matthew's family in Matthew's life. They are included in birthday parties and family events. She noted that having an open adoption could be difficult and awkward at times:

*I ran into the dad who worked close to where I did my groceries. A couple of times I would be doing grocery shopping and he would be getting his lunch at the grocery store or something. And he'd see Matthew and he'd be crying all over Matthew. And hugging him and saying 'oh that's my son and isn't he a sweet heart?' It was really neat but you knew that it was still really, really hard for that family. Much harder than it was for us. We already knew at the beginning that this was what we were getting into.*

#### Dealing with Medical Complications

As an infant, Matthew was extremely medically fragile. He spent time in intensive care and had open-heart surgery. There were many complications associated with the surgery and he required extensive care during the first year of his life. Margaret and her husband were aware of these difficulties and used this information to inform their adoption decision:

*There were a lot of medical needs. Matthew had to be fed through a little thing in his stomach. [Prior to the adoption] we went to the pediatrician every week and then we went to his house and practiced feeding him. We talked with his parents and they had decided that it was just too much for them. They wouldn't be able to look after their other kids enough. [Medically], Matthew was in really sad shape. When he was born he was just in really really sad shape.*

Margaret commented that there was extensive learning involved in how to care for Matthew. He required time-consuming interventions to assist with feeding. She was able to learn most things by doing but sometimes found herself overwhelmed and unprepared to handle all situations that arose. She recalled one time when the family...

*decided to go to Saskatoon for a couple of days. While we were there, his stomach thing popped out. So I had to go to emergency. At that time, I didn't know a lot*

*about what I was talking about [regarding Matthew's medical needs]. So, it was a little funny. They would ask what his history was and I knew some of it. I couldn't even spell his doctor's name! That was a bit of a do.*

Margaret also has a view that children with disabilities are somewhat more medically fragile:

*Kids with disabilities, I think they're medically more fragile than other kids. If they get sick, especially Down syndrome, they have small nasal passages, and small ears, and Matthew's got the heart problems. In the winter, if he gets sick, it seems like he doesn't really get over it. It takes a long time.*

Extra precautions and planning were often needed to ensure that Matthew remains healthy and that his medical needs were met.

Margaret is aware of what the future might hold for Matthew. There is a continuing risk that Matthew will require additional surgeries or experience heart-related illnesses, but Margaret is hopeful that Matthew will remain healthy and lead a long and fulfilling life. The awareness that Matthew may not live into adulthood is a concern.

However Margaret has not given up hope. She explained that...

*his heart is really bad and he's going to need a transplant. If he lasts until he's 16, he'll get a mechanical valve. His heart may do him in before he's ever an adult. Or it may not. If he'd been born 10 years earlier, he wouldn't be alive today. He's on the cutting edge of science. They [scientists] are learning to do all these new things and he's coming along and getting them. Harold's brother was only supposed to live to be 2 and now he's hitting 50.*

One frustration for Margaret is Matthew's difficulties telling others when he is ill. Children with cognitive delays are not always able to voice their pains, needs, and wants. As a parent, Margaret finds it frustrating that Matthew is not always able to communicate effectively with others. This is most dramatic when medical issues are evident. She noted that...

*Matthew has a very high pain threshold. I don't often know there's anything wrong with him. Like all of a sudden he says 'ouch my toe.' Well, his one big toe*



*was twice the size of his other big toe. He had a big giant infection in there and he couldn't even stand on it. Any other kid would have said 'ouch my toe' probably 4 days earlier when it was starting to get sore. A lot of these things like sores or hurts or things, you don't know what's the matter. He's up in the night crying and nobody knows what's wrong with him. I don't think he knows himself if he has a stomachache, or if he has a headache, or if he needs to poop or something. He might cry but not have said why. I think you have to be more of a detective than you do with other kids.*

### Life's New Challenges

Parenting a child with multiple disabilities can be a challenging task at times.

Margaret commented that it was difficult when Matthew first came into the home. At that time, Matthew was an infant and required extensive medical intervention. His heart condition left him lethargic, and Margaret needed to spend most of her time feeding and caring for Matthew's personal needs. It helped for Margaret to have spent time with Matthew prior to the adoption to learn about his needs and practice her skills in caring for him. Despite this practice, adjustment was still necessary when Matthew arrived in the home. She recalled that...

*it was hard [when Matthew first came to live with us]. Harold took time off work. It happened to be that my mom was out visiting for a bit so that helped. It took a good hour to feed him anything. And because he had this bad heart, he didn't do anything. He'd just lie there. He didn't really cry. He didn't really kick or fuss or whatever. He slept a lot. I could leave him sleeping but then you had to spend a lot of time feeding. It took a bit of getting used to.*

Parenting a child with a disability involves many changes to life's daily routines.

She noted that, "There are obviously extra expenses and a lot of extra work. And you really don't know what to expect." Things in Margaret's household work on a slower schedule. She noted that is important to...

*have patience. Don't be in such a hurry, specifically with Matthew. Matthew tends to be very stubborn. You need a lot of patience. Everything is slow. When he doesn't want to do something, he just lays down. Boom like a lump. But because*

*with Down syndrome they have such low muscle tone, he's like a rag. And it's seems to be harder [to deal with that].*

People adjust and life goes on, just differently.

### Impact of Disability for Siblings

Matthew is a middle child whose older brother and younger sister are developing normally. All three children are close in age, making Margaret's household extremely active and busy. Part of Margaret's motivation to adopt Matthew was based on how Matthew would influence their older son Nicholas. They wanted a playmate for Nicholas, a sibling who would be close in age to share life experiences. As toddlers, Matthew and Nicholas were able to interact easily and bonded. As the boys grew older, it became more difficult for the boys to interact. Matthew's cognitive delays made it difficult for him to play the same games as Nicholas. Nicholas was becoming increasingly interested in activities that Matthew could not cognitively or physically participate in.

Margaret's motive to adopt a third child was also based on similar logic, to help Matthew progress socially and cognitively. She declared that...

*we probably wouldn't have gotten another child. Matthew was so far behind Nicholas. He's slow at learning and everything. We thought that Matthew having a younger sibling would encourage him to keep doing stuff. We weren't thinking of having more kids but we thought that would really help to move Matthew along and to challenge him. And it's been really good. He's had a chance to be an older brother to show Sarah how to do things that he knew how to do. And it's really helped for his self-esteem. She's still somewhat behind him but it won't be long and she'll be helping him. Now she's doing stuff, which he wouldn't really do but he can't be outdone by his younger sister! So, low and behold, there he goes.*

Having three children works for this family and Matthew fits nicely into the mold.

Margaret has noticed how having a child with a disability affects other siblings within the family. She described the difficulty Nicholas has experienced adjusting to having a younger brother with Down syndrome:

*There are a lot of things in this family that are slower. We can't do some things because Matthew has Down syndrome. Mom and dad run off to extra meetings because Matthew has Down syndrome. It's not always fun for Nicholas. I think he does tend to sometimes feel like he's at the short end of stick. And we try to do extra stuff with him. That's the big thing to do. To try and do that kind of stuff and to try and see if we can get a baby sitter, etc.*

Nicholas had the most difficult time when Matthew began kindergarten at the same school. Margaret described:

*Nicholas is not very outgoing. Matthew is now in his same school going to kindergarten. Everybody in the school says 'hi' to Matthew. Nobody says 'hi' to Nicholas. Matthew's always saying 'hi, hi, hi' and everybody says 'hi Matthew' back. Matthew's really little and all the kids think he's cute and they all love him. So, Nicholas has been somewhat miserable and acting out. We're trying to spend more time with Nicholas. We went to this sibling workshop and I think that helped. It's definitely an issue that we'll be dealing with as time goes on.*

Daily fighting between the brothers is also commonplace at home. The boys sometimes have difficulty playing together, and they are becoming further apart developmentally. Margaret described how...

*Nicholas and Matthew share a room. So Nicholas has this pesky brother sharing a room, which would be fine if you have a brother who is 4 years younger sharing a room. But he's supposed to only be 1 year younger.*

It saddens Margaret to hear Nicholas make statements including, "I hate Down syndrome!" and "Do we have to go to that Down syndrome meeting?" Margaret views these challenges as continuing to be issues that they will have to learn to cope with within their family.

#### Dealing with Negative Stereotypes – The Need for Advocacy

As a result of her adoption experience, Margaret described herself as becoming more actively involved in community and advocacy endeavors. Margaret has become aware of the negative view that the general public has toward children with disabilities. As a result of community prejudices and negative stereotypes, Margaret has needed to

advocate to have Matthew included in various programs. She has become involved with Matthew's school to ensure that he is included in the regular classroom program. She has needed to advocate on Matthew's behalf to ensure that he is involved with both church and community activities. She remarked that...

*a lot of it is in trying to make sure that your child is included with the regular community. A lot of the people at our church are teachers. When all the kids go to Sunday school, they didn't think that Matthew should be going to Sunday school alone. They thought that a child with special needs must have an aid to come with him.*

Margaret's response to community views is often to take it as it comes. She stated, "You just go along with it [community prejudices] as it comes up."

Margaret is never surprised at the issues that continue to arise regarding Matthew and his exclusion from community programs:

*I find it interesting sometimes. Things that you never thought about. Nicholas was in play school once a week and it was called 'Mom's Day Out', a cooperative thing. The idea was for stay-at-home moms to get a break and the kids to learn to socialize. They took kids age 19 months and up. I didn't send Matthew right away because I thought I would wait until he's a little bit older. I was involved with the parents that are involved behind the scenes to see what's happening. And then I was told by the president, 'well, you can't assume that Matthew can just come. The parents aren't gonna just allow that.' My thoughts were 'why not?' I mean they're allowing kids that are 19 months. Here Matthew is 3½ and he could do anything they could do. All of a sudden you get that attitude. It's a surprise. If we'd been those kinds of parents, we probably wouldn't have adopted Matthew in the first place. We had been exposed to kids with disabilities before, so we just thought they were part of normal life, the way everybody else is. But you find out that other people don't think like that.*

Part of Margaret's role as a parent and advocate has also been as an educator to others.

She described herself as always...

*doing a lot of educating. I feel funny using that word. I hear other parents say 'I'm always educating everybody.' And I think you don't have to go around educating people. It's just the mindset of people. Getting them used to the fact that there are all kinds of people in this world and these are some of the people. Just live your life and let everybody just get along.*

Margaret understands why the public has difficulty interacting with people who are different or have disabilities. Dealing with the unknown is often a scary experience. For most people, they have limited contact with children with developmental disabilities and just do not know how to act or what to say. She believes that “people say things sometimes because they just don’t know.” Margaret even admits that she finds herself acting the same way when faced with new challenges and experiences. Margaret tells one story about Nicholas:

*Nicholas is in grade one, and he has a boy in his class with autism. I don’t really know how to react with him. Until I ask. And people don’t really know whether to ask. Do I just ask her? Do I just act normally? Matthew wears glasses. Will he lose his glasses? Well, if you ask me I would say ‘no.’ He’s like most kids. If they need them to see, they won’t lose them. Its just people really aren’t sure how to act or what to do.*

Margaret has learned to ask and not be afraid to ask the questions that will help her deal with new situations.

#### Awareness of Positive Qualities

Margaret is keenly aware of Matthew’s positive qualities. She feels that Matthew is a valued member of society with rights, strengths, and privileges. She states strongly that he deserves to be included in all aspects of community and sees her role as advocate to ensure that he is. She remarked that...

*he is going to read, because he’s already kind of started. I think he’ll be going a long way, the same as any other kid. You want your kid to be able to be a contributing member of society. So that he feels good about himself. That he can help other people. That he can make his own way and make friends. So that he can fit in like you and me and everybody else.*

She often strives to teach others that children with disabilities have worth and value in society. She believes that...

*the biggest change is probably with [her] own mom. She was a nurse and never had a lot of personal contact with kids with disabilities. She still has that concept of 'oh poor kid. Oh poor little kid.' She doesn't live in town and she doesn't see us more than once a year. We talk about what happens and stuff but she isn't right here. I'm continuously saying, 'well you know, he's the same as the rest of the kids. He might be slower and you have to account for what he can do and can't do.' But, don't say 'poor Matthew' because [saying] 'poor Matthew' doesn't help anybody. Least of all Matthew.*

### Importance of Inclusion and Early Support and Intervention

Margaret has strong views regarding inclusion both in community and education. She constantly works to ensure that Matthew is able to be an active participant in activities that he enjoys, without fear of negative consequences or stereotypes. Margaret is a strong voice of support for inclusive education for children with developmental disabilities. To date, Margaret has been very pleased with the support provided by the school to enhance Matthew's education. In her mind...

*it's all about inclusion. I think that a kid, especially like him, but a lot of kids with special needs, belongs in the regular classroom. Rather than in a classroom with all these behavior problems which they are going to go ahead and copy and then have more problems than what they already have. Matthew plays outside with the neighborhood kids and that's where he belongs. Part of the community. And his principal in his school is that way as well. [The school] is going to help as much as possible.*

Matthew is currently involved in a regular kindergarten program. Margaret has some concerns that things will change as Matthew gets older and is worried that school may not always be able to meet his needs. She stated:

*He's in a regular kindergarten classroom with an aide right now. Right now we have access to anything we want. It's really nice. He has a speech pathologist, occupational therapist, physical therapist, and an aide in the classroom. All these people working towards these goals. Once he finishes kindergarten, that's it! It's going to just be us. There is a lot of funding up until the end of kindergarten. In grade one, all the funding is gone. And there is no funding for kids with Down syndrome.*

Early support at school, in Margaret's view, is essential to ensure Matthew learns the needed skills to be a productive member of society. Her...

*biggest hope is that he'll be able to get the amount of support that he needs. I am quite convinced that if he gets enough support when he's young, that he'll be able to read, and that he'll be able to have a good concept of numbers and how to deal with money. Matthew is starting to learn how to read. But he will never learn to read unless one person is sitting with him working on reading. He will never learn to print unless one person is sitting with him. And same with arithmetic and numbers. As far as the social part of school, I think he'll do a lot of it by himself. I'm just hoping that we can get somebody to help him with the other stuff.*

### Importance of Moral Support

Margaret described her extended family as extremely supportive. Her family is not able to provide respite or relief to assist with childcare due to the fact that they live out-of-town. Her family does, however, provide needed moral support that helps Margaret cope with difficult times. To her, this is the most important kind of support a family can give:

*Our families are supportive. Although they're not here, we know that the moral support is there. Whatever we do, our parents are behind us. They're with us in thought, and they stand behind the decisions that we make. I think that's what is important. Financial support or 'help' support is not always as important as knowing that you have that moral support behind you. That is what gives a person more energy to do things. Because you know that you're not going to have to justify it to anybody. I don't have to explain, 'I'm doing this because...' I just do it. And the family is going to say, 'good for you guys.' I think that's the really important support.*

### Strength as a Couple

Margaret talked briefly about her relationship with her husband. She commented that strength as a couple is essential to ensure that home routines run smoothly. Margaret reported that she and her husband work together to meet Matthew's needs. They utilize their individual strengths to solve problems and deal with daily routines:

*When we go to specialists, we go together [as a couple]. When you go to a specialist, they'll often talk about something that you never really thought about before. Harold's the person who usually then remembers to ask questions. I don't always think about that stuff after we get home. So, I drag him along to do the note taking and that kind of thing.*

She views Harold as a strong support and ally. She commented that, "Harold and I are often on the same wavelength. We have a lot of support from each other."

#### Professional Support as Instrumental

Margaret described professional support as instrumental throughout all stages of the adoption process. From the beginning, the adoption agency was helpful, in terms of providing information about developmental disabilities and Down syndrome, and connected Margaret with several advocacy groups in the city. Since then, her family has become involved in yearly conferences and other events in the community. These agencies have connected her to other parents who have children with developmental disabilities and she finds these supports informative and uplifting. Contact with other parents provides new ideas, social support, and the opportunity to share personal stories and challenges. Professional support has also enabled Margaret to access needed funds and services within her community. She is able to receive money for relief, extra doctor visits, and time to spend with her husband outside of her role as mother. This monetary support has been instrumental for Margaret to cope with the stresses of parenting.

Professional support has also been available from various medical personnel involved with Matthew. Margaret explained:

*We have found medical professionals to be really good. We didn't have a pediatrician before we got Matthew. We just went to the clinic because we're healthy and we only go once every 3 years. We had no doctor or pediatrician or anything. Matthew came attached with a pediatrician. I don't know exactly why he got that pediatrician; she is also a pediatrician who deals a lot with people who have foster kids. She will stand up for the foster parents against the system*



*and that kind of thing. We're really really happy with her because she is so good that way. And she has the same philosophy as us. If it's not broken don't fix it. I think that's common with many professionals. You pick the professionals that have the same philosophy as you.*

### Changing Nature of Friendships

Margaret described her family as very private, preferring to have few close friends rather than numerous acquaintances. They do have friends who are foster parents and have made new friendships with other parents who have children with disabilities. They tend to value those friends who have the same life philosophy as their own. She noted that...

*I think the people that we relate to have changed. People that don't have time for somebody who has a disability...I don't know if we have a lot of friends who are like that anymore.*

### The Importance of Faith – Dealing with Uncertainty

Margaret described herself as having a strong belief in the power of faith. She reported:

*I'm sure that strong faith helped in a lot of things. Faith probably helps any parent when their kids are throwing up all night or whatever is happening. It's helped a lot.*

Margaret reported that she tends not to worry about the future or about things that she knows she cannot control. She commented:

*I don't tend to worry about 10 years down the road. I'm trying to get through today. I'm not that kind of person. I would never have lived if I had to worry about all that. I'm one of those people, that if I can do something about it, if I worry about it and I can do something about it then we do it. If we can't do it, well then that's where the faith part comes in. You just say 'o.k. life, let's go.' As you get more and more things piling up, you just sort of figure that's the only way to go. I've got stuff to do here and now everyday. If I spent my time worrying, who would make supper?*

When she can plan for the future, she does so with flexibility. For example, Margaret has already begun to think about when Matthew becomes an adult. She has made the decision that Matthew will live outside the family home when he turns 18. She is, however, aware that many things can happen between now and then. She commented:

*I believe in crossing the bridge when you get to it. You have a perfectly healthy child. They get hit by a car, and then you have a quadriplegic child. You never know what's going to happen. I think that's a large part of how we live. Matthew has Down syndrome now. He's still going to have Down syndrome later. Our other child is healthy now. But who knows the future? You have no idea what's going to happen. And who's to say that this is going to be any harder than something else in life?*

### A New Take on Life

Margaret commented, "I don't remember my life before. It's gone. I don't know if it's a lot different than other kids. Having kids totally changes your life." Becoming a parent was a life changing experience for Margaret. Raising a child with a disability has also enabled her to see her world differently than before. She described herself as "less bigoted" and "richer with people and new relationships." She has become aware of things in her life that are positive and good and has learned to appreciate her fortunes and opportunities. She described herself as often taking her health for granted prior to having Matthew. She is more aware of things that she has, that she didn't treasure before. She said, "I am more thankful and aware of the good things."

### Harold's Story

Harold is a father of three young children. Harold and his wife, Margaret, could not have children of their own as a result of infertility. They have adopted all three of their children. Harold's eldest son, Nicholas, was adopted at birth and is now age 7 years. He does not have any special needs. Their second child Matthew is age six and he was adopted at the age of 9 months. He has been diagnosed with Down syndrome and has some medical complications affecting the health of his heart. Harold most recently adopted a little girl, Sarah, who is age 2. To date, Sarah is not exhibiting any delays in development, although there is the possibility of Fetal Alcohol Effects.

Harold is employed as a professional engineer. He is actively involved with work as well as family activities. His wife is a stay-at-home mother and does the majority of the parenting during the day. Harold works early hours each morning to ensure that he is home for dinner and is able to help Margaret with evening and bedtime routines.

Harold has personal experience with disability, since he, himself, is hearing impaired, his older brother has Spina Bifida, and further, he formerly coached for the Special Olympics. Harold is also involved with advocacy work in his community. He is a strong voice for inclusive education and frequently attends conferences and workshops related to inclusion and other issues affecting individuals with disabilities.

### Being Prepared – Making an Adoption Commitment Once Informed

Harold said, "I didn't specifically want to adopt a child with a disability but I was open to the possibility." Going into the adoption process, Harold was aware that many children in need of homes have special needs. His eldest son, Nicholas, was also adopted. The process of adopting him was smooth. Harold and his wife, Margaret, had discussed

the possibility of adopting a child with a disability. They decided to consider any child for adoption by examining that child's individual needs and personality. It was important to Harold that any child they adopted would compliment their family composition.

Having appropriate information to make a decision was equally important to Harold. He explained:

*Even before the phone call about Matthew, there was discussion about what type of child we were looking for. We certainly did not put down 'we are looking only for a special needs kid.' If the circumstances were different and the birth mother with a so-called 'perfectly healthy kid' came along, we would have looked at that. But, we were open to it. I think the process helped us prepare for the possibility. Other people were certainly supportive in terms of making sure that we had the information we were looking for and trying to understand, as much as possible, the implications of that type of decision.*

Throughout the adoption process, Harold and Margaret were able to make an informed and conscious decision to adopt Matthew. Harold was aware of the presenting concerns and issues, namely Down syndrome and a medically fragile heart. He...

*knew there were going to be issues. We probably couldn't fully understand the extent of the issues and the complications of the issues and those types of things. I don't think you can until you are in the situation. But we did make that conscious decision. We had the choice. We had the choice of saying 'well that's nice but we're not interested.'*

Part of the decision process for Harold and his family involved talking to other people with knowledge and experience about Down syndrome. Harold consulted doctors, other parents, and professionals in the field of rehabilitation. He read several books and asked a lot of questions. He felt he had the luxury of time to ensure his decision was informed and well planned.

Harold talked about other adoptions where the luxury of information is not always present. Part of adopting a child is being aware that any child can have issues and

difficulties. Once a parent, you adjust and accommodate and parent as best as you can.

He commented:

*Even before Nicholas, I think we were open to the possibility of looking at a kid with special needs. When you're a kid who is in your mother's womb it's possible that something happens during that time or there are problems. Or there could be problems that are not obvious. Or problems and issues that are not known until the kid is born. If we had made a commitment to the birth mother and that kid was born and there was an issue, we were not going to say, 'well, too bad, we're walking away.' We just couldn't foresee doing that. So once you make a commitment, you need to take the good with the bad.*

For any adoption, one must prepare for anything. For Harold, there were never any guarantees for a perfect child.

### Dealing with Medical Issues

Matthew is a child with many medical needs. When first born, Matthew required immediate surgery to correct an intestinal problem. Matthew's heart was very weak and he had open-heart surgery at the age of 9 months. Harold needed to learn to care for Matthew's medical needs. Through this process, he learned how medically fragile Matthew was. Harold described early life with Matthew as very busy with many appointments with doctors and much time spent caring for Matthew's hygiene needs and feeding. There was little time for other activities including caring for Nicholas, who was also an infant at the time of Matthew's adoption. He recalled:

*We did know about the heart condition when we brought him home. It was probably somewhat more significant than what we had understood. That's nobody's fault per se. It's just one of those things that happens. Very shortly after he was born he did have some surgery on his intestines and stuff. That was a life or death thing. At the time when Matthew came home he had a leaky heart valve. He was fed by a g-tube. That's basically a hole in the stomach and a valve with a syringe. I suppose in a way that was easy because we'd fill up the syringe and push it in and he's fed. We didn't use that for very long because we wanted him to start sucking the bottle and stuff like that. It took him a long time, maybe 45 minutes to an hour to get 4 ounces of food once on a bottle. It took a long time to*

*feed him. You're basically feeding him and changing him and putting him to bed and that's about all we could get done.*

Harold remembered Matthew being extremely lethargic and sick the first few months in the home. He was concerned that Matthew was gravely ill and was relieved when Matthew was able to have his heart surgery. Harold noticed that things at home became easier following the surgery, and Matthew began to progress both physically and mentally. He recalled:

*In December, he had the heart operation. Certainly, that made a big difference. Within a week of coming home after the operation, he had a lot more energy than previously. He started drinking his formula much quicker. Before the operation, he was just basically a blob. He would just lie there and not try to move around or anything. He basically had no energy. Of course any time you have medical issues, particularly when you have no energy, you're not thinking about developing about anything. When I'm sick with the flu, I don't want to be reading this book about plants or related to work or some other interest I may have. I just want this thing to go away. I think he went through the same thing, except for a longer period. But once he did have the operation, we did notice a lot of improvements very quickly.*

### The Joys and Challenges of Parenthood

Harold is a proud and dedicated father. Due to infertility, Harold and his wife could not have children of their own. He feels very fortunate to be able to be a father and revels in the joys and happiness that parenthood brings to his life. He enjoys spending time with all his children. He feels pride when his children are able to learn. The most rewarding aspect of parenting, for Harold, is “the joy of seeing the kids develop.” When asked about his middle child with Down syndrome, Harold was quick to respond, “He’s a lot of fun to have with me. He’s generally a happy guy and quite friendly and open. There are a lot of positives.”

In addition to the joys of parenthood, Harold talked about the times when life is frustrating and challenging. As with any parent, there are difficult times and stressors

associated with raising any child. For Harold, he talked about some challenges unique to parenting a child with a developmental disability. During the first few months, there was period of adjustment to new routines. He remembered that, “The first few months were quite tiring for Margaret and myself. On weekends and stuff, I would be doing night duty to care for Matthew and his medical needs.”

As Matthew became older, Harold talked mainly about the developmental challenges that Matthew must face and it’s impact on the family:

*Matthew certainly has a lot of developmental challenges and issues ahead of him. It can be a little frustrating at times that things come to him so slowly. Nicholas, our older child, learned a lot of things where he just did it and it wasn’t a big issue. With Matthew, through a lot of encouragement, pushing, prodding, pleading, he finally gets something. When he finally gets it, it’s quite positive. But it’s a long time. And then with Sarah, the youngest kid, you see her doing some things where you know a couple years ago, you had such a big struggle to get Matthew to do or understand. She picks it up fairly easily. And it’s a little hard for Matthew.*

Harold talked about some of the behavioural challenges that he learned to cope with. One example involved Matthew’s eating habits:

*He has a pretty limited selection of foods that he enjoys. At first, he wouldn’t eat potatoes or rice or whatever. So to make sure that he totally doesn’t starve and get up in the middle of the night, we’d give him a sandwich. At one point, we got to the point where before he’d have his sandwich, he would have to have two scoops of potatoes or whatever we had as the main meal of the family. At one point he was doing that but not readily. A little while later he just couldn’t. He would forgo the reward of the sandwich because he didn’t want to have those two scoops.*

Harold reported that having a child with a developmental disability requires patience and a slower pace of life. Matthew needs extra help to complete most tasks and is slow to learn new skills and information. Harold commented that...

*there’s been a couple of times where we seem to have been making progress in an area and you think you’re ready to move onto the next stage. Then, a couple of weeks later or a couple months later you’re back two or three steps.*

There is, however, always joy in seeing Matthew progress and learn.

### Never Enough Time - Balancing Everyone's Needs

Matthew will always be medically more fragile than others. He continues to have a weak heart and may require a heart transplant in the future. In addition to Matthew's medical needs, there are other cognitive and developmental delays that require extra support by caregivers. At times, this support can be time consuming and affects other routines in the household.

Harold commented that Matthew's developmental delays play a role in how the family works together as a whole. Things in the family occur at a slower pace. Harold commented that the family has had to adjust routines to accommodate for Matthew's unique needs. Harold explained:

*Matthew does need more attention. Simply because sometimes if you want him to do something, whereas the other kids will do it in 30 seconds, Matthew (he's stubborn) and it takes him 10 minutes. So you're spending those 10 minutes with Matthew getting him to do it and have 10 minutes of lost time with all of them. This takes time away from stuff that maybe you want with the other kids. And I think to a degree, Nicholas notices it and sometimes he tries to get his share of attention. Not necessarily positive behaviour and then you have another situation to deal with.*

Part of Harold's experience is the frequent dilemma of choosing when to provide Matthew with the extra time and attention he needs. He noted that it is often difficult to remain consistent when there are other children involved and when other life priorities interfere. He stated:

*With other kids, once they pick something up, like pulling their pants on or getting their pants off or whatever, once they pick it up they're fine. With Matthew, he does that for a while but when he's tired or when he's lazy (I think all of us are lazy once and a while), or if he gets to the point of 'I don't want to do that', it doesn't matter what the issue, he says 'help.' Sometimes we have a tendency to hurry to get something done, rather than spending the extra 5 minutes coaching*



*him to pull his pants up. We pull it up for him because you want to get out the door and get on with doing things. It's challenging to figure out when it's really best to spend that extra time saying 'well I know you can do it', and talking with him or encouraging him to do it or telling him 'well you stay here until you do it and I'm going to go do something else with the other kids.' Which might mean that you don't get out of the house for 15 or 20 minutes. But when you see other priorities in life, it doesn't matter how it gets done but it has to get done now. And then we have to move on to something else. That, I think, is a weekly challenge.*

As with most families who have more than one child, there are daily concerns and issues that arise, regardless of whether a child has a disability. Children are not always well behaved and demand a lot of parental attention. It is often difficult to find time for one's spouse, other children, and oneself. Parenting for any and all parents is a difficult task. He believes that...

*all families, even with kids that don't have challenges or disabilities, it's difficult for parents to balance how much time you spend individually with a particular kid and how much time you spend with the kids as a group. I guess the hardest thing is balancing time and attention with the different kids and, to a certain extent, also to balancing time with Margaret and other personal activities. That can be difficult at times.*

### Raising Three Unique Children

Harold is the father of three young children, all of whom are unique in their skills, interests, and needs. Harold has found it difficult to coordinate everyone's interests and needs in everyday family life. It is apparent to Harold that Matthew learns more slowly. At times, Harold described feelings of frustration when he looks at Matthew's learning progress compared to his siblings. Harold is concerned that Matthew may feel stress when he knows that he cannot accomplish the same tasks as well as his siblings, especially his younger sister. He stated that...

*on birthdays in particular, we kind of look at Matthew and say, 'Well, yeah we were kind of hoping he'd be a little bit more advanced than he is now.' I think certainly as Matthew gets older, that's going to be an issue for him. When he knows full well that his sister is 4 years younger than him and his sister is doing*

*A, B, C, and D and he can't do A, B, C, and D. He's doing it much slower and in a lot of cases, not at all. He might be doing A and C but he can't do B. I think that will be an issue for him.*

Harold finds it difficult to watch his youngest child grow and excel, knowing that Matthew is also watching and not making the same gains. He exclaimed:

*Some things just take so darn long for him to grasp! It's quite possible that Sarah, the 2-year-old, is going to be driving a tricycle before Matthew, who is now 6. When Sarah drives a tricycle, I'll be quite happy. In a way I'll be somewhat sad because I know Matthew hasn't got it yet.*

The family is actively involved in outdoor activities, including cycling, hiking, and cross-country skiing. Harold is concerned that Matthew may not fit in with vacations and recreational activities that they choose as a family. For example:

*With Nicholas, he's into driving his bike. He likes to ride his bike up and down the street. When we go camping he likes to ride his bike. With Matthew, he's nowhere near driving his bike yet and we can't even get him to drive a tricycle yet. So at this point, if we go biking, he's still small enough to fit in one of the chairs on my bike. But, within a couple years, that's not going to be practical. So, what do you do when you go camping and you have Nicholas, who, like a lot of boys, likes to run around and do things? And Matthew's much more into going to the playground and playing in the sandbox. How do you handle that type of situation?"*

Harold commented that their household functions based on consistent structure and routine. The routines within the family are the same for the all the children. The children are still young and require this structure to learn and develop. Helping Matthew learn to adjust to change and changes in family routines will be a task that Harold envisions for the future. Harold is already starting to see how "normal parenting tactics" do not work for Matthew. He explained further:

*With Nicholas, the older one, he has an understanding of consequences and actions. So I can say, 'Well if you don't do this then X will happen.' And if he doesn't want X to happen, then he does what you ask him to do. And if he doesn't care too much about X, then it's the wrong thing to get that issue moving. With*

*Matthew, a lot of times you say 'if you do this then X will happen.' Even if he likes to do X, it may not encourage him to get moving and do what you like him to do.*

Harold envisions changes in the home as his children get older. While he is cognizant of the family's need for flexibility, he knows that Matthew will always need more rigid structure. The difficulty for Harold will be balancing the needs of all the children. He commented:

*I am anticipating that as the kids get older, especially Nicholas, they will be able to function better with less routine. Matthew will probably function better if it's a regular routine, whatever that routine is. So it's quite possible that our house may be more routine than it otherwise would be. We could end up with issues because Nicholas may want more flexibility and be able to handle it, whereas Matthew can't.*

#### Family, Professional, and Community Support as Instrumental

Support is essential when raising children. Harold values the support he has received from medical professionals, adoption service personnel, and extended family. This support has assisted him in advocacy, gathering information, and coping with difficult and stressful life challenges.

Harold described his adoption experiences as very positive. Matthew's was an open adoption and Harold relied heavily on the local adoption agency for information during the initial stages of the decision-making. He described:

*We did go through an adoption agency, the same agency for all three kids. The people at the agency were pretty supportive and certainly did their best to make sure that we had information to ensure we could make an informed decision.*

Medical professionals involved with Matthew, including heart specialists and pediatricians, have also played a major role toward supporting the family and providing information, quality care, and advocacy. Harold commented that most specialists were

very knowledgeable about Down syndrome and able to provide accurate information to assist in most decisions regarding Matthew's health care and well-being.

Harold's extended family has been another source of support, despite the fact that most live out-of-town. Knowing that the family has accepted Matthew is very important to Harold. He stated:

*Our extended family is out of town. Because of the distance, there's not a whole lot of physical support and involvement. But certainly, after Matthew came to us and we were visiting and stuff, there was good acceptance with the rest of the family.*

As Matthew grows older, school will become an important focus in his life. For Harold, it is crucial that Matthew receive any needed educational support and specialized programming to ensure he is able to progress to his maximum potential. Matthew is currently in a kindergarten program. So far, Harold reported that school has been a major source of support for Matthew and the family. Harold has a strong view of inclusion for his son and values Matthew's school for sharing his views. He declared:

*There is this whole issue of inclusion in education. It could also be inclusion in a regular swimming program or how the people at church treat the kid. I am of the opinion that inclusion in the regular classroom is very positive for Matthew. I also think it is positive for the other kids. Not everybody reads as quickly as I do. Not everybody reads the way I do. I think inclusion is pretty important.*

Given Harold's strong views regarding inclusive education, it was important for Matthew to attend the right school and finding this school began long before Matthew was old enough to attend school. He explained:

*We were looking for a school to put Nicholas into kindergarten. We went around and specifically talked to numerous principals and said that, 'We've got two kids; one is a regular 5-year-old going into kindergarten and the other has these issues.' We wanted to find a school where both of them were going to be able to go. We wanted to find a school for Nicholas but I guess, in a sense, we were looking more for a school for Matthew. To make sure that he would fit in.*

Harold's careful search for an appropriate school was successful. There is a lingering question for Harold about whether the situation will remain as positive, as Matthew progresses through school. For Harold, dealing with uncertainty is another facet of parenting, specifically when a child has a disability. He elaborated:

*The school that we are going to is very supportive. So far the experience has been positive. I know in talking with some other parents, that they have had some pretty negative experiences with the school system, in particular the issue of inclusion. In my opinion, I think a good portion of the principals, teachers, and other parents have the idea that all these special needs kids should be shuffled off to a class and put in a corner somewhere or dealt with however you need to but not in the regular classroom. The basic issue for special needs kids in some jurisdictions, I understand, is quite a big issue. So far we have had a positive experience. Now whether that will continue or not, who knows?*

#### Strength as a Couple

Harold talked openly about the support he receives from his wife. The decision to adopt Matthew was a mutual decision. He commented:

*We both knew each other enough and felt enough to know that we were simply willing to look at the possibility of special needs and special needs children.*

Given the strength of their marriage, they were able to deal with the stresses of the adoption with little outside support. In his mind...

*we didn't really feel a need for any other additional support. Once we had made the decision to take Matthew, we were pretty strong. We made the decision. We probably didn't know all the issues, but we were determined to make it work.*

Harold and his wife have remained a unified team throughout their roles as parents. They have a routine in place within the home that allows for each of them to fulfill their own roles. They cooperate on a daily basis. He remarked:

*I try to be out of the house by 7 o'clock in the morning. Simply because Margaret has to get the kids breakfast and ready for school and off to school. She needs a certain amount of time to do that. So I either have to be involved in that process or get out of the way! It doesn't work to be half involved. It doesn't work.*

They still continue to make time for themselves as individuals and as a couple. They utilize relief services to access respite and make time to spend with each other outside of their parenting roles.

#### Previous Exposure to Disability – A Helpful Experience

Having experience with disability has been a positive force in Harold's life. Harold grew up with the philosophy that all people are different and have unique strengths and needs. His experiences made him open to accepting a child with a developmental disability into his home. Harold talked openly about some fond memories of his brother as a child:

*My older brother is in a wheelchair. He is a paraplegic. He was born with Spina Bifida so he's had that all his life and has been in a wheelchair all his life. As a kid and teenager, we'd go walking in the park. I remember a few times going through a pretty bumpy forest trail and we'd be walking the wheelchair over the logs and bumps and stuff like that, everybody having great fun.*

Another one of Harold's brothers worked as a rehabilitation professional for adults with disabilities. Harold would often visit his brother at work and gained exposure to adults with physical disabilities. As a young man, Harold actively volunteered with adults with special needs through coaching the Special Olympics. Harold reported that his life experiences left him more open to the possibility of adopting a child with similar disabilities. He was also aware, however, that parenting would be different because it would involve full-time care and responsibilities.

Harold made a comparison between physical disability and developmental delays. He noted that "there is a bit of a difference there." Most of his background experience was in working with persons with physical limitations. He commented that he believed

children with developmental delays experience more prejudice and stereotype, thus requiring more advocacy on the part of parents and caregivers. He believes that...

*parents of kids with developmental issues get drawn into those issues more than kids with the physical issues. 'Cause if a kid is in a wheelchair, they change the desk [at school] and push them around and that's much more accepted. But if the kid obviously doesn't think as quickly as the kid next to them, like with Matthew or with Down syndrome, you don't fix that.*

According to Harold, support is more specialized, intensive, and life-long when a child has cognitive delays.

#### Goals for the Future - Realistic Notion of Ability and Planning for Adulthood

No one knows what the future will hold. He commented:

*Any time we make that kind of decision, you never totally know what you are getting into. There are some types of issues that you really don't understand until you are in the situation.*

Planning for the future is also difficult, especially when the future seems uncertain. Part of the future is certain for Harold; Matthew will always have Down syndrome. Harold stated:

*Down syndrome...you don't fix that. He's going to have it his whole life. He's going to learn slower. He thinks a little bit different. And that's not going to change.*

Given this knowledge, Harold is determined to do what he can to ensure that Matthew can lead a productive life as an adult. Harold explained:

*Certainly, the future is something we are thinking about. I don't know that we have a whole lot of solutions for the next 25 or 30 years or whatever. If Margaret and I kick the bucket and get planted, there are lots that could happen. We certainly don't have the solutions for that. We know it is an issue. I guess the best way to deal with that issue is to do what we can to challenge Matthew. Give him the confidence to be as independent and self-supportive as possible. Now, will that take until he's 18 or 20? We don't know. Hopefully he'll have a job. I have no expectations that he's going to be an engineer. That's obviously not going to happen. But hopefully he can be a janitor or a stock boy in a store or something a little bit more routine.*

Harold has a realistic view of Matthew's abilities. Early support and intervention is a key goal for Harold to ensure Matthew can achieve all the success he is capable of. He has hope that Matthew will lead a long and productive life.

### Value for all People

Having a child with disability has allowed Harold to appreciate the value and talents of all people in his community. In his mind:

*Everybody has his or her strong points. Everybody has his or her weak points. I think all of us could get through life much better by being helpful to others and accepting help from others.*

Harold clearly values all people but he also recognizes their differences. Harold points out that just because someone has a disability, does not mean that we must enjoy his or her company. We still need to respect people as individuals, but that does not necessarily mean we can get along with everyone all the time. He explained:

*People with special needs, whether it's physical need or developmental need, they are people. There are country people, southern people, people that use their brain, and people that have a brain but refuse to use it. You look at the normal population and there is a range of people. Some people are nice to be around and some people are, well, those you prefer not to be with. If you took hold of both physically challenged people or handicapped people, whatever term you want to use that is politically correct at the time or people with developmental issues, you'll find that some of them are pleasant to be with and some of them are not as pleasant to be with. Some of them you say 'nice meeting you' and you go live your life. Others you go live your life and hopefully you don't meet them again. So in any population there are people out there...*

Harold challenges the idea that we must force ourselves to like people simply because it is "politically correct." Despite our views and preferences, all people deserve respect and dignity and a chance to live their lives to the fullest.

### Philosophy of Life – Life as Normal and Unchanged

Harold stated:



*I think my basic outlook on life has not changed. Maybe some of my beliefs about how a person should approach life are somewhat stronger and more solidified. And the whole idea of trying to be helpful to others and accepting help from others, that's stayed the same. Those basic beliefs, I don't think have changed. Maybe it has strengthened somewhat. But, you can't very well say 'I'm a better person because I have a kid with special needs.' Not necessarily.*

For Harold, raising a child with a disability has not changed his views of life and respect for humanity. It seems that his original views were likely what made him open to accepting Matthew in his family at the onset. Harold does, however, see his life changed as a result of becoming a father:

*I certainly have changed personally from the fact of having kids. I guess the basic decision to have kids has changed a lot of the focus in our lives. Before kids we did a lot more recreational stuff. Just the two of us together. And now, instead of a family of two we are a family of five. I think it's certainly an enriching experience to have kids, and there's been joy and fun times. And frustrating times too.*

Becoming a parent has allowed Harold to learn to be more patient in life. He commented:

*I do certainly have to be quite patient. I am probably a fair bit more patient now than I was say, 7 or 10 years ago. Now, whether that's specifically because of Matthew and his additional needs or whether, I don't know. It's just a fact of having kids in general. You have to have a fair bit of patience with them when they decide that they really don't want to do what their parent's priorities are.*

Matthew requires extra patience, but Harold views this within the context of being a child and not his disability. Every child requires attention, love, and caring. Every child has issues that require extra time and effort. It is just part of being a parent. To Harold, life is normal.

*I do realize that, to a certain extent, every family has issues because every kid is different. Some kids are more actively orientated and some kids are more contemplative or less active. I'm not saying that it's only an issue within a family with special needs. I think most of the issues that we have, any family with several kids would have. Some of those issues are maybe a bit more pronounced but I*

*don't really think we're doing something that no other family is doing. It may be the case that some issues are more noticeable. You may think about them more and maybe something comes up more frequently.*

To Harold, life with children, regardless of disability, is unique and normal for all families.

### Summary

The stories that emerged from these five individuals are unique, yet commonalities between their experiences are evident. The interview with each parent was focused on that person's individual experiences. Prior to discussing common themes that emerged, it is important to highlight the differences evident in these parents lives that make their stories unique. These parents have very distinct life stories and have adopted children with different needs.

The first story is Tammy's, the biological mother of four children. She opened her home to a foster child, Diane, who had significant cognitive, medical, and physical needs. Diane also experienced past abuse and neglect. The foster placement eventually became an adoption. For Tammy, her story is about dealing with Diane's severe needs, overcoming negative stereotypes, and learning to view all children as capable despite disability. She talked about how her life was different and how she became a better person, advocate, and teacher. Tammy has a strong marriage and family support. Her family has been enriched as a result of the adoption experience and works cooperatively to care for her daughter's special needs. Tammy's most frustrating experience has been the lack of support she receives from government, community, and educational systems.

The second story is about Pauline, a woman who has given her life to the needs of other children. She has adopted five children with severe disabilities and has fostered 22 other children in her home. She prides herself on her advocacy work and on providing family to children who have been neglected, abused, and forgotten by others. She is a single mother. Her story focused on the rights of children and less on the impact the adoption had on her personally. She talked about the need for more government and

professional services, for more adoption supports, and she also discussed the political issues surrounding adoption. For her, adoption was not a life-changing event. It was a means to give back to society and make a difference. Her experience is very different from the other parents who shared their stories. Her personal and career life has revolved around caring for numerous children. Her story focused on the process of adoption and the challenges that all adoptive parents face regardless of whether a child has a disability.

The third story is about Claire, a woman who adopted twin boys. These boys came to live with her family at the age of 5 years. They experienced intense childhood trauma, were diagnosed with Fetal Alcohol Syndrome, and lived in long-term foster placement and a residential placement for children in crisis, prior to the adoption. Claire was older at the time of the adoption. She has a strong marriage and no biological children. She is surrounded by her siblings who have their own children and grandchildren. Her story revolved not only on her own experiences, but also on the experiences of her boys. She discussed how her children coped with losing their previous family, moving to a new home, and dealing with past trauma. The main themes of the interview included issues of how adoptive parents and their children are able to blend as one family, and how two worlds can merge into one. The main themes are about flexibility, learning to become a family, dealing with grief and loss, motherhood, faith, and the joys of parenting.

The final two stories were about Margaret and Harold, a married couple who each told their own personal stories. They are the adoptive parents of three children, one of whom has been diagnosed with Down syndrome, coupled with a serious heart condition. They participated in an open adoption and were well informed of their child's needs

throughout the process. Their child came from a loving family with no history of abuse or neglect. The main themes of their stories focused on the joys of parenthood, the impact of disability on family and sibling functioning, and the importance of community inclusion for children with disabilities.

#### Family Up-Dates

As stated earlier, Claire, Pauline, and Margaret provided some up-dated family information to me during the collaborative interview. Pauline informed me that she had adopted another child with a disability. She continues to be a strong advocate in her community and is still involved in helping other parents with post-adoption information and support. Claire reported that she continues to be amazed and proud of her children's accomplishments. She noted that her children have made tremendous growth academically, socially, and emotionally. As a family, they continue to work together, enjoy time spent in shared activities, and have discovered the joys of travel and camping. Claire also continues to be a prominent advocate in her community.

Margaret was also contacted and shared some of her family up-dates. She viewed her story as a fair representation of her views at the time. Things for her son, specifically educationally, had changed. Her son was now in the third grade and the transition from kindergarten to grade one was difficult, given that there was less available support at school. Margaret also noted that other issues related to daily routines, childcare, and education were changing as her children grew older. She anticipates additional changes and challenges as her children reach adolescence.

The feedback from these three parents exemplifies three important points. First, experiences are constantly changing and adaptation is needed throughout life. Second, the

views and philosophies of these parents, specifically regarding the joys of parenting and their dedication to advocacy has not changed. The third point is that their adoption experiences have remained positive.

Part of the reason that these parents experienced little change in their opinions may have been related to the fact that, at the time of the initial interview, these parents were coping effectively with their roles as adopted parents. They were able to view their experiences in a positive light and that their initial interviews focused mainly on their views, philosophies, and strengths as parents. Had these parents been experiencing overwhelming stress, their views at the collaborative interview may have changed more dramatically, either in a positive direction indicated by a positive transformation, or in a negative direction which may have involved adoption disruption. Given that these parents were initially happy and secure in their parenting roles, it makes sense that few dramatic changes were evident in their stories 2 years later.

### Thematic Analysis

Given the differences in life experience of the parents interviewed and the means by which their children became part of their families, the commonalities evident among their lives appear even more relevant and meaningful. The commonalities among the participants will now be explored and discussed. Based on the data collected, 10 common themes were identified. The major themes and respective sub-themes are presented in Table 1 and provide an organizational framework for the following discussion (p. 156).

#### Adoption – A Lengthy and Overwhelming Process

Each of these individuals came to be parents through unique circumstances. Despite these differences, each person viewed the process of adoption as often stressful and uncertain. Collectively, the parents experienced a degree of difficulty adopting their children. All experienced delays in the process and encountered legal complications that affected the ease of placement of these children into their homes. All of the parents discussed the initial adoption screening as difficult to endure and time consuming. All of these adoptions were successful, but required these parents to be patient and advocate for the children they wanted to adopt.

Harold and Margaret participated in an open adoption and had extensive contact with their son, Matthew, and his birth parents throughout the entire process. Harold and Margaret talked about the experience of having to wait for their son's birth family to make a final decision about placement. Although they were presented with the option of adopting their son, the birth parents experienced second thoughts once the process started. As a couple, Harold and Margaret spent several months waiting for Matthew to enter their home and additional months for the adoption to be legalized. During the legal

Table 1

Breakdown of Major Themes and Respective Sub-themes

<b>Major Theme</b>	<b>Sub-theme (as applicable)</b>
Adoption: A Lengthy and Overwhelming Process	
Connecting People Through Adoption	Making Emotional Connections Family Connections: Adjustment and Transition Connecting with Birth Parents Making Cross-Cultural Connections and Celebrations
The Need to Save: Dealing with Abusive Histories	
Knowledge, Choice, and Realism: Keys to Adoption Commitment	Knowledge and Choice Realism: Accepting the Permanency of Disability Planning for the Future
Challenges, Demands, and Sacrifices	Time, Money, and Physical Demands of Parenting The Stress of Dealing with Medical Fragility
Value of Support and Services	Importance of External Support Marital Strength
Advocacy in the Face of Adversity	Dealing with Negative Stereotypes Learning to be an Advocate Need for Self-Reliance – Thinking Outside the Box
Happiness and Personal Growth	Joys of Parenthood Transformations
Respect, Faith, and Self-Awareness	Respect for All Humanity – Value of All Children Importance of Faith Patience, Flexibility, and Self-Awareness
The Value of Family: Normalization of Adoption	



waiting period, Matthew was placed in their home. Margaret reported feeling tremendous frustration due to the fact that they could not access needed services for their son. He was not legally their child and therefore they did not qualify for respite, relief, or financial support.

Claire and Tammy also experienced several months of waiting and uncertainty. For Claire, there were long delays in the process due to legal issues involving the previous foster placement. Tammy's daughter, Diane, lived in her home as a foster child for 5 years prior to the adoption. There was continual contact with Diane's biological mother. Tammy became very attached to Diane and advocated strongly that she be eligible for adoption. They were successful in their efforts, yet it too was a lengthy process.

Pauline's story is somewhat different. Most of the children she has adopted were placed in her home as a result of crisis situations. When Pauline adopted her first child, she was married, working, and deemed a suitable parent by adoption personnel. The adoption of Pauline's second child was more difficult. According to Pauline, adoption personnel did not believe that Pauline, who already had a child with high needs and had since become a single parent, could manage a second child. The child Pauline wanted to adopt was initially sent to live with biological relatives. It turned out that these relatives could not cope with raising a child with a disability. They were physically abusive with the child, leading to a severe brain injury. For Pauline, dealing with the politics surrounding the adoption process has been difficult. She works avidly to change the system for other prospective parents. For all of these parents, adoption was a lengthy

process, often involving uncertainty regarding whether a placement would be approved or finalized.

### Connecting People Through Adoption

Adoption inherently involves the connection of people. Parents and children must learn to become part of a family. This involves learning to love each other and becoming emotionally unified. These parents noted that adoption inherently involves connecting families and family members. This includes birth parents with adoptive parents, children with parents, and between siblings.

Connection not only involves the feelings that prospective parents have toward the child but also the child's emerging feelings toward the adoptive parents. The notion of connection, in this sense, appears to overlap with the notion of attachment. Children who have difficulty forming a bond with adoptive caregivers often display behaviours that can be interpreted by new caregivers as distant and confusing. It can seem that children with attachment difficulties have not connected emotionally to their new parents. As noted by Howe and Fearnley (2003), children with attachment difficulties often have a "poor understanding of emotions...that in turn reduces their capacity for empathy. Their experience of being in caregiving relationships is that they are frightening and dangerous, hurtful and unpredictable, careless and confusing." (p. 377). Howe and Fearnley also state that children with attachment difficulties often do not feel safe in close and loving caregiving environments and seek to avoid affection and love provided to them. This can result in behaviour that is aggressive, hostile, and/or controlling.

For the purpose of the current discussion, connection is focused more on parental feelings of love for their children and the parents' perceptions of how their child has

bonded within the family. Connection is also viewed as how parents envision their link to their child's birth family and to their child's culture of origin. For this reason, connection, as presented in this study, appears to be a concept distinct from attachment.

Several parents reported feeling strong connections to their children at an early stage in the adoption process. All of the parents experienced strong emotional connections to their children and described feelings of intense love for their children. These connections appeared to occur almost instantaneously for some and sometimes even occurred prior to having met the child to be adopted. Adoptive parents often reported feeling some connection to birth parents and empathy for their experiences. They also discussed the process through which they were able to connect their children's previous family to their own. Part of this connection involved connecting new siblings and adjusting to new cultures and life views. The following will discuss the theme of connection in more detail, specifically in relation to emotional connection, culture, siblings, and birth parents.

#### Making Emotional Connections

Two of the parents interviewed shared the experience of making emotional connections. Emotional connection in this context can be thought of as the bond that forms between the child and the new parent. Claire and Tammy described becoming emotionally connected with their children. Claire felt this connection with her boys before they were even placed in her home. Claire and Tammy shared a common feeling that their children adopted them. Both of these mothers felt intense love for their children and were unwilling to accept that they could not have them as part of their families. They were drawn to these children and felt that they were destined to be caregivers and

providers to them. Claire described feeling that there was a higher power guiding her toward fulfilling her life destiny. Apparently, motherhood for both of these women was inevitable. Not only did they choose their children, but their children chose to be part of their families as well. Neither of them could fully describe nor understand the connection. It was, however, a life altering experience.

#### Family Connections: Adjustment and Transition

A theme of connection between two existing families was very dominant for Claire. This is salient for Claire given that her children were older at the time of the adoption and that her children had previously lived in a long-term foster placement. The transition was difficult when the children first came to live with Claire and her husband. The boys experienced tremendous grief, sadness, and loss because essentially, they were removed from the only home they had ever known.

Over time, Claire described feeling pride in watching her children feel more comfortable in their new roles as “Claire’s children.” She felt joy when they labeled themselves as part of her family and when they joined in shared family activities and traditions. This experience may not be as salient for families who adopt younger children or children who had no previous family experience. The idea of family connection was significant for Claire and her children.

Related to the concept of overall family connection is the experience of adoption for siblings within the family. For many of these parents, other children were present within the family prior to the adoption. The issue surrounding sibling coping arose as a common experience for Harold and Margaret. Harold and Margaret have three young children, all of whom are adopted. Sibling issues were prominent in both their

experiences. They both commented that their eldest son, Nicholas, had difficulty coping with Matthew's disability. Harold and Margaret both struggled to provide Nicholas with attention and time. They felt that they were not always able to give him the support and attention he needed and deserved. They commented that Nicholas often felt left out both at home and school. At home, Harold and Margaret reported that their household routines were structured to meet Matthew's needs. However, these routines were not always appropriate to deal with their other children who often required less routine and more flexibility. Harold and Margaret also noted that they kept very busy with advocacy efforts, leaving less time for group family activities. At school, Matthew often received extra attention from teachers and other children, making Nicholas feel less important and less well liked.

Relatedly, Harold talked about the difficulties raising three unique minded children. All of his children have diverse needs, interests, and abilities. It is often difficult to incorporate everyone's needs on a daily basis. For this family, sibling adjustment and transition have been difficult. It may be related to the fact that all children in this family are young, close in age, and that all young children, regardless of disability, require attention. For Margaret and Harold, balancing family needs has been difficult. Family connection has involved time and adjustment.

Tammy's experience was very different. Tammy's other children were adults at the time of the adoption of Diane. They were included in the decision to adopt Diane and were actively involved in her early care. For Tammy, the adoption was a positive experience for her other children and the family as a whole. The family connection

occurred prior to the adoption of Diane and was a process beginning when Diane was a foster child.

Pauline's experience is also very unique given her family situation. With 27 children as part of her family, a large network of support surrounds all of her children. Her adopted children thrive, knowing they have extensive family to provide support, friendship, and care. Her children feel comfortable when other siblings can care for their needs, rather than having to rely on outside respite and support. For Pauline, siblings provide valuable support to the family and have been a tremendous support to her and her adopted children.

The process of adoption involves family transition and adjustment. Multiple families must blend into one. Siblings must cope with welcoming another child into their family. Family adjustment seems to have been easier when siblings were older and adopted children were younger or unattached to a previous home or family life. Active involvement of all family members, including siblings, also appears to make the process of adjustment easier.

#### Connecting with Birth Parents

A common topic that emerged from the parents interviewed involved their views of the biological parents of their adopted children. None of these participants were natural parents to a child with a disability. Through their adoption experiences, many felt that they gained some understanding of the experiences that biological parents feel and endure, both when their child is born with a disability and when faced with giving their children up for adoption. They felt connected to these birth parents.

Margaret and Harold both described biological parents as experiencing grief and sorrow when faced with the birth of a child with a disability. Margaret, in particular, described feeling empathy for her son's birth parents as she witnessed them struggle through the decision making process of adoption and the shattered dreams of the child they were expecting.

Pauline's perception was also to view birth parents as grieving the loss of their healthy children. She viewed birth parents in an extremely courageous light. She voiced a great deal of respect for those parents who were able to self-reflect on their abilities and be aware of their inabilities to parent children with severe disabilities. She respects birth parents willing and able to give their children away in the hope that both they and their children can have a better chance at happiness in life. Margaret, Harold, and Pauline all felt that they understood the grief and loss that biological parents felt when faced with dealing with disability and the adoption of their child.

All of the parents interviewed talked about the issue of guilt. Tammy commented that birth and adoptive parents are separated by the guilt that they experience. As adoptive parents, Claire, Margaret, Harold, Tammy and Pauline all commented that they felt no responsibility for the disabilities that their children have and their perceptions of birth parents is that many must cope with the thoughts that they caused their children's disabilities. They felt empathic understanding for the birth parents whom they believed faced the guilt, not only for the children's disabilities, but also for placing their children for adoption.

### Making Cross-Cultural Connections and Celebrations

Pauline and Claire both adopted children of native aboriginal heritage. A common theme connecting their experiences has been how they have embraced their children's native backgrounds and incorporated their culture into their own lives. The notion of cross-cultural connection was very evident. They both are dedicated to ensuring that their children are aware of and proud of their native heritages. Pauline has chosen to live in a neighborhood with a high aboriginal population so her children can feel more connected to community. Claire incorporates native traditions in their lives and is supportive of her children's desires and wishes to enhance their own family history and heritage. This openness to culture has helped connect these children to their new families, while still respecting their previous senses of identity.

### The Need to Save – Dealing with Abusive Histories

Three of the parents interviewed for this study adopted children who had experienced past abuse, neglect, and/or trauma. These parents expressed difficulties dealing with their children's behavioural outbursts and aggression. In some cases, these children suffered additional disabilities, most notably brain injury leading to physical and/or cognitive delays, as a direct result of the abuse they experienced. Part of these parents' motivations to adopt was to provide safe and caring family environments to these children.

Pauline talked extensively about the issues of abuse, abandonment, and feelings toward past trauma her children have experienced. Pauline has had to work hard to help her children cope with the loss of their birth families and the lasting effects of physical and/or emotional abuse. Helping break the cycle of abuse occurring within families is



part of her motivation to adopt her children. She works diligently to help those children who cannot help themselves. In her mind, dealing with the, often complicated, emotional issues are more difficult than dealing solely with a child's developmental disability. She commented, "I think that one of the biggest things to deal with is kids' past baggage and not with a disability." It's dealing with the challenges of children who have been "messed up" that Pauline finds most overwhelming.

Children who have experienced abuse or life trauma may exhibit behavioural difficulties. Claire's children were victims of abuse and she reported that their behaviour was often difficult to manage. They were continually dealing with anger and resentment and needed to work through many layers of emotions in order to heal from the trauma they witnessed and experienced. When angered or overwhelmed, her children often resorted to verbal and/or physical aggression. Parenting on a daily basis was a challenge. Claire also talked about the issues of dealing with her children's birth family and emotional past. It was a difficult transition for her boys to leave their previous family and to join Claire and her husband. Her children experienced much loss and grief and continue to adjust and adapt to their new lives. Claire talked about time being a healing mechanism. The passage of time has enabled her children to adapt and transform into members of her family. They have grown to love Claire as a mother and have begun to heal powerful emotional wounds.

Tammy was also able to talk about the difficulties dealing with children who have experienced loss and abuse. She had been a foster parent for several years to a young boy who exhibited difficult and often aggressive behaviour. For her, dealing with a child

whose behavior is out of control is more difficult than parenting a child with severe and multiple disabilities.

A common thread surrounding Claire, Tammy, and Pauline's experiences involved the need to save their children from previous home lives or situations that were damaging or inappropriate. Claire described her motivation to adopt quite clearly. She felt she was meant to be a strong and caring mother to her boys. She acknowledged that, despite her intentions, she could neither truly understand the trauma her boys experienced nor erase the past completely. Pauline's motivations to adopt were similar. She described herself as committed to providing family to those children who would otherwise be alone. She was making a life choice to be committed to any and all children who needed family, love, support, and security. Like Claire, her motives were to help children in need. Tammy's motives for adoption were similar. She wanted to provide a stable home for her daughter who, in infancy, had experienced trauma, abuse, and abandonment. Tammy was committed to providing a family to this child. She also described herself as a strong parent who could provide the care and nurturing that her daughter desperately needed.

#### Knowledge, Choice, and Realism: Keys to Adoption Commitment

A key theme that emerged for these parents involved the commitment to be parents. Commitment involved accepting a child with a disability into their homes and families for the long-term. These parents discussed commitment as a driving force behind the success of their adoption experiences. Commitment, however, involved several key components that these parents felt helped them prepare for the adoption of their children. These parents talked about the importance of being informed and being able to prepare for the arrival of their child into their homes, prior to being able to make a commitment to

raising a child. Knowledge allowed these parents to make informed choices, to be realistic about their children's needs and abilities, and to accept the permanency of their children's disabilities. Knowledge also allowed them to plan for the future.

All of these parents described themselves as strongly committed to caring for their children. Pauline remarked that commitment is the main force that determines the success of any adoption. These parents were all aware of their children's needs and were committed to being parents, regardless of the outcomes, challenges, and difficulties. Harold remarked, "Once you make a commitment, you need to take the good with the bad." For these parents, commitment was the force that stemmed from knowledge, choices, and acceptance of their children's disabilities. These concepts will now be explored in more detail.

### Knowledge and Choice

Knowledge and choice emerged as two key elements to adoption commitment for all parents interviewed. A requirement of participation in this study was that parents made the choice to adopt a child or children with disabilities. All of these parents adopted their children with full knowledge of their children's strengths, abilities, and special needs. They chose to be parents to their children despite the existence of disabilities. Choice, inherently involves being aware and having full knowledge of one's child prior to adoption. Claire, Harold, Margaret, and Pauline all understood that many children placed for adoption have extra needs and will most likely require extra love, support, and care. They all made the commitment early in the adoption process to be open to adopting children with known disabilities. Even if they had adopted healthy children, all of these parents were aware that there were no guarantees. There was no absolute way of ensuring

that any child placed in their homes would not require extra support, either immediately or in the future.

For Pauline, her life calling was to provide family for the unwanted and /or children who were considered difficult children to place in a family. She chose to be an advocate and parent of 27 children with varying degrees of disability. In doing so, she is fulfilling her life goal. She commented that parenting is not difficult because “I’m making a life choice. I’m always doing what I wanted to do.”

Tammy also made the choice to adopt. Her choice, however, was not to adopt any child with a disability. Her choice was to adopt a foster child who had already been a part of her family for the past 5 years. She entered the adoption fully aware of her foster child’s needs and disabilities.

Making a choice involves knowledge, and knowledge often involves time and education. Harold and Margaret made the choice to adopt their son after extended research and thought. They educated themselves by consulting other parents, nurses, doctors, and professionals who had experience caring for children with special needs. They armed themselves with knowledge in order to make an informed decision. Once they made their decision to adopt, they were committed to having their son as part of their family.

#### Realism: Accepting the Permanency of Disability

Realism was a notion raised by two of the parents interviewed. Realism, in this context, refers to the idea that parents have a realistic view of disability, including the needed supports and permanency of the disability itself. For some parents, it was this realism that aided in their decision to adopt a child with a disability. Pauline and Harold

raised the notion that adoption cannot fix a child's disability. Harold talked repeatedly about accepting his son's disability early in the adoption process. He was aware that he could help his son read, write, and learn new skills. He was, however, cognizant of the fact that some circumstances were not going to change, including the diagnosis of Down syndrome. That would always be an issue.

Accepting the permanency of disability was a concept that emerged for Pauline over years of being an adoptive parent. Pauline initially approached adoption as a means to help children overcome their limitations. Pauline described her early experiences as expecting too much from her children, leading to disappointment and frustration when her children failed to develop according to her expectations. She needed to learn to be more realistic about their abilities and needs, and to accept that some things cannot change.

Once parents are able to accept the permanency of disability, they begin to have realistic expectations for their children's learning potential and future capabilities. For both Pauline and Harold, coming to this realization aided in their ability to feel pride in their child's accomplishments.

### Planning for the Future

A topic that emerged for all the parents interviewed was planning for their child's future. All of these parents have thought about the future and what it will look like for their children. All have begun to make plans for their children's physical and emotional care in the event that they can no longer parent. The future, however, looked different for most of these parents. Differing views were related to ideas about the extent of the child's

disability, level of acceptance of the child's disability, and the age of the child at the time of the interview.

Claire and Tammy were both older at the time of their respective adoptions. For them, there was some concern about who would care for their children in future years. Claire has been proactive and focuses much of her time and energy teaching her boys the skills she believes they will need to be successful later in life. She has a realistic notion of their abilities and works to provide them with the skills and the motivation to be productive learners. In her mind, her children will lead rewarding and independent lives as adults, provided they continue to receive early support for their learning. Tammy is aware that her child will need life-long commitment and support. Tammy has begun to prepare herself for when her daughter will move out of her home and into a group care facility. She is concerned about the quality of care available and is making plans to ensure that her daughter's needs are met. She feels some solace in knowing her other children will be able to provide some support. She feels strongly that her daughter will live a productive life.

Harold and Margaret began planning for their son's future prior to the finalization of the adoption. They made the decision early that Matthew would live outside the home as an adult. Harold and Margaret are also realistic about Matthew's abilities and are working diligently to teach him the skills he will need to live independently in the community. They worry about the present more than the future and prefer to deal with issues as they arise.

Pauline also views her role as parent in the present. She sees herself as making a difference in her children's lives now and today. For her, she knows there will be a time

when she can no longer care for her children. She is of the opinion that the government and other support agencies will need to be available to care for her children once she is no longer able. She commented, “The government has an obligation to pay. I didn’t make them so the government can pay later on when they need to. I’ve saved them big bucks in between.” For her, the future is not something she can control, and therefore she chooses not to worry.

All of these parents have thought about the future of their children and how they will live and cope once they, as parents, are no longer able to provide the support the children need. Concern for the future is a common theme that connects these parents. Part of this concern surrounds the concept of disability and realistic expectations for their children. These parents have framed their concerns for the future around their perceptions of what they believe their children are capable of achieving. Having a realistic expectation of their children’s strengths and needs, has also helped these parents focus on teaching their children the skills to live more independent lives in the future. These parents cope with their concerns about the future by proactively teaching their children needed skills and planning for their future living arrangements, care, and support. Concern for the future has not lead to overwhelming stress, given that these parents have learned to worry only about issues and concerns within their immediate control. For the parents in this current study, realistic expectations appear to have strengthened their ability to cope with the uncertainty of the future. Planning for the future is another indication of commitment to their children.

### Challenges, Demands, and Sacrifices

Parenting, regardless of whether a child has a disability, involves transition, challenge, and sacrifice. The participants in this study all pointed out that parenting children with developmental disabilities entails a certain level of stress and strain. Key areas of stress were identified in regards to lack of time for self, spouse, and family, financial concerns, fatigue, and the physical demands of parenting. These parents also noted the additional stress of coping with a child who is medically fragile.

#### Time, Money, and Physical Demands of Parenting

These parents all commented that caring for a child with developmental disabilities is time consuming. Extra time is needed to care for personal and medical needs, doctor's appointments, school meetings, advocacy efforts, and completing daily routines.

Harold and Margaret commented that their son requires extra time and assistance to eat, dress, and complete most tasks. Time is an issue that they struggle with daily. They do not always have time to give their son the help and attention he needs and they have difficulty balancing time with their son and their other children, each other, and themselves.

Pauline's time is also very precious to her. Given the number of children in her home, balancing time for all their needs, appointments, and her own work commitments is very difficult. Pauline commented that she often forgoes sleep to ensure she has enough time to meet all her responsibilities during the day.

Tammy also finds it difficult to have enough time to manage daily commitments. Tammy's daughter requires assistance with all aspects of daily living and Tammy is



needed full time at home. This leaves less time for other leisure or recreational activities as well as activities that involve other family or time with her spouse.

Claire also acknowledged that she has less time to spend with her spouse or complete activities to enhance her own well-being. The time demands of parenting are often overwhelming for her.

Caring for a child with developmental disabilities not only involves time, but also money. Financial limitations were topics mentioned by all participants. All reported that there were extra expenses involved with raising a child with developmental disabilities. Extra expenses often including specialized equipment, clothing, food, medications, respite, and even home renovations to accommodate wheelchairs and physical needs. Claire, Tammy, and Pauline made sacrifices regarding their career choices. These women gave up working outside the home in order to provide extra care for their children during the day. For Claire and Tammy, their husbands also chose less prestigious employment in order to be more involved with the family and closer to home. All of these factors served to limit money needed for extra expenses involved with handling their children's needs.

Despite financial limitations, these parents were in agreement that social and financial supports were necessary services that have assisted them through difficult times. It was also noted that financial support available through government and community agencies were often not enough to eliminate most of their financial burdens. Many voiced some hope that additional government money would be made available for families in need.

Caring for a child with physical limitations also requires extra demands on the body. There is extra lifting involved on a daily basis that becomes more difficult as

children grow into adolescents and adults. Pauline and Tammy both have children that use a wheelchair. For them, the physical demands of care giving are difficult and overwhelming. To a certain extent, the body adjusts and becomes accustomed to the extra work and strain. As time passes, daily routines can become more difficult. Tammy commented that she is often saddened by the fact that she no longer has the energy to enjoy recreational activities with her daughter. She does not have the strength to take her swimming or tobogganing. Even bathing her daughter is becoming more and more difficult. Tammy, Pauline, and Claire talked about physical and emotional exhaustion. As a result of parenting, Pauline reported that she sometimes sleeps only 2 or 3 hours per night, or at sporadic times during the day. Her body has become accustomed to the routine, and she is able to cope. However she feels the physical effect of fatigue on a daily basis.

Claire and Tammy commented that their ages play a significant role in their ability to cope with the physical demands and lack of sleep they both experience. Both women were in their mid-forties at the time of their adoptions. Both reported feeling concerned about their ages and speculated that dealing with many issues would have been easier had they been 10 years younger. Both also reached a point of physical exhaustion and relied on family support to manage.

Claire acknowledged her personal wish to be “super mom.” She felt that she could handle the multiple roles of mother, wife, advocate, professional, and teacher. Over time, she has learned that she is not physically or emotionally able to handle the responsibilities of all these different roles without help. She has learned to ask for help

and prioritize her responsibilities. She has needed to learn how to manage her physical, emotional, and psychological well being to avoid burnout.

### The Stress of Dealing with Medical Fragility

Harold, Margaret, Pauline, and Tammy talked extensively about the medical concerns they had for their children. All four individuals were faced with life and death situations involving their children. Most described these events as overwhelming, frightening, and life changing. When a child is medically fragile, parents must cope with unforeseen emergencies and be immediately ready to deal with high levels of stress. Weekly visits to local emergency rooms were not uncommon for these parents. Through their experiences, they came to recognize their children's strengths, spirits, and will to survive. They have also learned to be tremendous advocates to ensure their child's medical needs are being met. These parents have found comfort from caring and competent medical professionals. They also retain the views that, as parents, they know what is best for their children and know what needs to change or stay the same. They have learned to work cooperatively with professionals and have become team players for the medical care of their children.

Margaret had an additional concern regarding medical issues and her son. A large concern for her was Matthew's inability to communicate when he is ill or hurt. This often led to more serious infection or illness as a result of a lack of early detection and early intervention. She viewed herself as being a detective and always searching for problems that may exist. To a certain extent, both Pauline and Tammy also reported the need to adopt a detective role. Both mentioned having to advocate to professionals to ensure

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needed services based on their observations and intuitions about their children's behaviour and medical needs.

### Value of Support and Services

The value of support and services was a common thread connecting all the parents interviewed. Adopting a child with a disability entails extra demands over and above those needed when raising a child without a disability. The need for social, professional, community, family, and marital support was noted by these parents as instrumental in their ability to cope with the extra demands of parenting.

### Importance of External Support

All of these parents voiced concerns regarding limited resources and community supports to assist with the care of their children. Those supports that are available have been extremely valuable to these parents. They all value the support and camaraderie they have received from other parents and from caring and competent professionals. Increased financial support, respite, and educational programming were deemed as highly needed by these parents.

Looking at their individual experiences, Margaret and Harold voiced some concerns that government financial support was not always available when needed. They did feel that social, community, and educational supports have been available and were a positive experience. They have been able to access respite, relief, and educational assistance. They do, however, have serious concerns that supports will not always be adequate enough to meet their son's changing and unique needs.

Pauline was another parent satisfied with available community and social resources. She is well informed about supports that are available and is thankful to birth

parents who have been pioneers in creating the supports, that as an adoptive parent, she utilizes today. Pauline also recognizes the need for additional services in the area of education. In her experience many existing educational programs have not met the needs of her children, requiring her to advocate for change and additional resources.

Claire's experience has been somewhat different. For her, utilizing supports was something she did not immediately consider. In her mind, she felt she could handle whatever situation arose. She felt prepared to be a parent and was committed to meeting all of her responsibilities on her own. Claire reached a point of exhaustion and needed to summon tremendous courage to ask for help. Once help was ascertained, she felt very supported by her community. Educational support was something Claire talked about extensively. She has felt supported by the teachers at her children's school but has also experienced frustration and anger. She has needed to advocate for her children to ensure their educational and emotional needs were consistently being met.

Tammy's story exemplifies a different perspective. She experienced tremendous frustration and anger regarding the current supports available to parents of children with developmental disabilities. Tammy's experience has been one of constant challenges regarding adequate school programming, financial and governmental support, and dealing with political bureaucracy. Tammy commented that she had difficulty accessing respite, relief, and money to buy needed adaptive equipment. In her mind, "Social services were no bloody help at all. Post-adoption supports are a joke." She viewed the process to obtain support as demeaning to her child and family. She commented that she resented having to "sell her child out in the community" and often found that her child did not qualify for subsidies and/or supports. Tammy needed to be a strong advocate for

her child, resulting in increased stress, fatigue, and mental exertion. In her mind, support and services should be more readily available to all parents in need.

Despite some lingering feelings that there is not enough social, professional, educational, and community support for families who are raising children with disabilities, these parents view their existing supports as instrumental to their ability to cope with the challenges and demands of daily living. Key areas of support parents identified included family, social agencies, educational personnel, and medical professionals.

Tammy remarked “In order to stay fresh and be able to cope, you have to have some breaks from the child.” Family and community support has been a tremendous help to all these families to provide needed moral support, help with daily chores, and financial aid. Family support has also been instrumental. Knowing that important people in their lives supported their adoption decisions and life choices was viewed as equally important as financial assistance. Competent and caring professional support was also deemed as important, specifically when faced with a child who is medically fragile or exhibiting difficult behaviours. Professionals who share in the same life philosophies and views about children with disabilities were often viewed as most helpful. Support has helped these parents gain information, remain informed, and has assisted them in decision making.

Community support was another aspect of support discussed by all these parents. They have all relied on talking to and/or learning from other parents in similar life circumstances. These parents have all become more involved with support groups, conferences, or informal meetings with other birth or adoptive parents of children with

developmental disabilities. These supportive parents have provided needed camaraderie, friendships, and a shared understanding for their experiences.

### Marital Strength

Harold, Margaret, Tammy, and Claire talked extensively about the support they received from their spouses. For these couples, the decision to adopt was a joint endeavor. For most, it was initially difficult to balance time between the needs of their children and the needs of their whole family, partner, and themselves. Claire described the process as redefining who they were as a couple. It was difficult to spend less time with each other, having been married for 10 years without children previous to the adoption. For Claire, Harold and Margaret, it was the strength of their marriages that allowed them to rely on each other for support and handle the stresses of parenting with ease. Tammy noted that her spouse has been highly involved with parenting. The sharing of care giving duties was viewed as extremely helpful by most parents. These parents presented themselves as unified teams working cooperatively to meet the needs of their children.

### Advocacy in the Face of Adversity

Another common theme for these parents was the fact that all these parents experienced some form of adversity, discrimination, and/or lack of adequate support and services regarding their children. These parents became painfully aware of the negative stereotypes associated with disability and needed to work diligently to ensure that their children were respected and able to participate in needed programs and services. These parents learned to be self-reliant and to advocate on behalf of all children with disabilities.

### Dealing with Negative Stereotypes

All of the parents interviewed in the current study commented that negative views of disability continue to permeate their lives and cause significant stress. They encountered people with negative views, not only in the community but also among professionals. Tammy reported that she has experienced times of frustration when faced with lack of hope by professionals and external support systems. Pauline, Tammy, Margaret, and Harold also encountered these pessimistic views and lack of hope by professionals. Their children were medically fragile and most professionals did not expect their children to survive. Medical professionals told them to keep an emotional distance in the event that their children died. For Pauline, the death of one of her children became a harsh reality. She did not, however, heed medical advice to keep an emotional distance. Her son, although he lived only a short time, remains a prominent part of her family.

Community prejudices have also been a common experience for these parents. Tammy reported that she often felt unsupported by educators and members of her community. She has needed to be a strong advocate to ensure her daughter's basic needs were being met and that she was included in her community. Similarly, Pauline has been a strong advocate to ensure that persons with disabilities are viewed as valuable and capable. She too has endured living with negative stereotypes and is frustrated when others assume that a person with a disability cannot learn, achieve, and feel loved by family. Pauline commented, "I think people forget that just because one area of the brain is damaged, it's not the whole person."



Harold and Margaret talked extensively about their views of inclusion. They both have strong views about the importance of their son being included in social, community, and educational programs. They also have experienced community prejudice and isolation. Margaret voiced some understanding of how people in her community obtained their negative views of disability. She saw these views as originating from lack of experience in dealing with people who are different. Margaret said she continues to be surprised when others view her child as incapable of being involved in church groups, community activities, and leisure and/or recreational programs. She has also needed to be a strong advocate for her son to ensure his rights and privileges are protected.

All of these parents had previous experience and exposure working with or caring for persons with developmental disabilities. They had a positive view of disability prior to the adoption of their children. They all strive, on a daily basis, to educate those around them about issues of disability and the strengths their children do possess.

#### Learning to be an Advocate

All of the parents interviewed remarked on the lack of available services and support as well as the negative views of disability by society. Advocacy was a task that they used to ensure their children's rights were protected and that their children received needed funding and support. Advocacy was noted as a major part of their daily living. They also felt the need to change or create educational programs, relief, respite, financial assistance, and community inclusion. For many, advocacy served as a valuable coping strategy when faced with unforeseen stressors and challenges. As parents, many have also extended their advocacy efforts to helping other families, both birth and adoptive, who are raising children with disabilities. Pauline, through her advocacy work, has been

involved in changing legislation surrounding issues of adoption and has made gains in breaking the cycle of abuse that permeates many families. She has worked hard to change the public perceptions of adoption, trying to make adoption be seen as a normal way to have children. Within the school system, these parents have worked toward improving the educational programs in which their children participate.

#### Need for Self-Reliance – Thinking Outside the Box

Given the lack of supports and services these parents felt existed, three of these parents sought to create their own solutions to problems they encountered. The ability to think “outside the box” was often necessary. Tammy commented that raising a child with a disability not only involves changing the perceptions of society but also changing personal perspectives. It requires parents to think differently and change their normal perspectives. Claire described herself as a voracious reader, always searching for new information, techniques, and solutions. Harold talked about the need for flexibility and the importance of striving for new and different ideas to handle difficult behaviours or situations. These parents learned to educate themselves and became more independent in their abilities to provide support to their children.

#### Happiness and Personal Growth

All of the parents interviewed felt immense happiness, pride, and gratification as a result of their parenting experiences. For all parents, personal growth and transformation was evident. Most commented that they had a change in their life perspective and became better people as a result of their parenting experiences. It remains to be seen if these positive changes are a result of parenting alone or directly linked to parenting children

with disabilities. Adoption was ultimately viewed as a joyous event worthy of celebration.

### Joys of Parenthood

Despite the daily challenges of parenting, the individuals interviewed expressed deep love, admiration, and pride in their children's abilities and spoke candidly about the positive aspects of being a mother or father. These parents have strong views that their children are valued members of society. These parents view their children as capable, intelligent, and gifted. Claire was one mother who talked repeatedly about the joy she felt in being a mother. She expressed joy in the moments when she cuddled with her children and spent quality time enjoying their company. She values every moment of motherhood and sees her children as "gifts from God." Harold described himself as a dedicated father. He stated that he feels pride in watching his son learn, grow, and develop. He enjoys spending time with his son and revels in the progress he has made since living in the family home.

Watching these children learn and accomplish unexpected tasks has been one area of joy that each parent talked about. Having been given bleak outcomes for their children by professionals, watching their children learn to do things they previously thought impossible has been a tremendous experience. Tammy talked about how her daughter, deemed to be "a vegetable," has learned to walk and speak. To her, her child is a medical miracle.

Claire's experience was similar, despite the differing needs of her children. Claire's children had a history of abuse. They lacked appropriate environmental stimulation for most of their early lives. Claire felt great awe in watching her children

experience things for the first time, including their first movie, trip to McDonalds, and family vacation. It has been a positive experience to watch her children learn and grow psychologically, physically, and emotionally. She also feels great joy in watching them make connections to her and her family. Claire's children have learned to love and feel attached to new parents, when most professionals felt that attachment for her children would be difficult. Watching their children make tremendous gains in their learning was an experience all of the parents interviewed described. These parents viewed these gains as one of the most rewarding aspects of parenting.

### Transformations

Transformation is a term used to designate an outcome in which a person feels significantly and permanently changed. According to Palus (1993), transformations entail a change in people's values, beliefs, attitudes, and views of themselves, others, and society. Becoming parents has been life changing for all these individuals. Altogether, these parents described themselves as more patient, more aware of priorities in life, having a stronger sense of self and one's personal limitations, becoming less bigoted, happier, and more thankful for life's blessings. Not all of these parents reported that these changes were a result of parenting a child with a disability. Some concluded they were simply a result of becoming parents. Harold noted that his life changed dramatically after having children. His life has become more enriched and he has learned to focus on family factors ahead of other life issues.

In addition to personal change, most of these parents talked about changes in their work roles and friendships with others. Pauline, Margaret, Tammy, and Claire chose to become stay-at-home mothers for their children. Tammy and Claire's husbands also

changed employment positions to spend more time at home. Claire, in part, saw her role as changing from wife and career woman to mother. In her eyes, she was no longer the person she was prior to having children. She is now a mother and that is most important.

All of these individuals also commented that their relationships with others have changed. They have become closer to family and friends who support them. They have less interest in socializing with others who cannot relate to their personal experiences. They value camaraderie with other parents in similar life situations and have made new relationships with other parents they have met through conferences, community and/or support groups. Their lives have changed and they are content with these changes.

#### Respect, Faith, and Self-Awareness

The parents interviewed discussed the importance of several personality characteristics they felt were instrumental to their positive adoption experiences. A strong connecting thread between all participants was their belief and respect for all people, regardless of inherent differences in race, gender, and/or disability. All parents were open to accept others despite differences. Another quality of importance was a reliance on faith to deal with life's challenges. Self-awareness also emerged as a common personality characteristic. All of these parents were able to identify personal qualities they felt enabled them to be successful parents. Most notable were patience, flexibility, and adaptability.

#### Respect for All Humanity – Value of All Children

All of these parents have strong beliefs in the value of all children, regardless of gender, race, or disability. They have a belief in ability and do not focus on their children's disabilities or the characteristics that set them apart from others. Most of these

parents had previous experience working with others who had disabilities. They entered their adoption tolerant of the differences inherent in all people. Their views allowed them to be strong advocates for their children and see how their children's gifts and talents can benefit others in their communities and society as a whole. Claire stated it most clearly when she said that "Every one of those children has a place in our society, if not for any other reason but to teach other people to be tolerant and to be accepting." The main message these parents talked about entailed respecting all and ensuring all people in society are treated with respect, dignity, and have a chance to live their lives to the fullest. Part of their roles as parents was to ensure these rights for their own children.

#### Importance of Faith

Faith appears to be a strong common link for Pauline, Margaret, and Claire. Their faith has helped these parents cope with the uncertainty inherent in life. It was a life lesson for Pauline to finally understand that some things in life cannot be controlled or predicted. She learned to "accept that things are in place and things happen for whatever reason." Margaret described herself as having strong faith to deal with the uncertainty of daily living. She learned not to worry about the future or things that cannot be controlled. She has come to accept life's challenges and deal with issues as they arise.

Faith has also played a role in Claire's decision to adopt her children. Claire talked about a higher power working with her when she first saw a photograph of her children. She described being drawn to their photograph and felt an immediate connection to these boys. The faith that these parents possessed aided in their ability to cope as parents.

### Patience, Flexibility, and Self-Awareness

Several of these parents reflected on personal qualities they felt made them better parents. All felt that patience and a realistic view of their children's abilities were key to successful parenting. All parents relied on consistent structure and routine within their homes to aid in their children's learning and development. Tammy described herself as an "above average parent, a perfectionist, and good nurturer." Pauline described herself as organized and committed. All parents described themselves as needing to be flexible and adaptable to change. Claire felt that having a strong sense of self and a spirit of wanting to help others was most important when parenting. Taken as a whole, these parents saw themselves as committed parents, striving to meet the needs of their children. To do so, they all have become more aware of themselves and their personal limits and abilities. They have become more self-aware and tolerant of unexpected events and life's surprises.

### The Value of Family: Normalization of Adoption

These parents all have a life philosophy that values the role of family in society. They became committed to providing families to children in need. The needs of their family and children were often placed above other life priorities, including housework, occupations, friends, and community commitments. Tammy declared, "I don't think that there are really any throw-aways out there or that people should be institutionalized without an attempt at family. I think that family comes first and foremost whether it's a family chosen by the child or a child that's chosen by a family."

For these parents, having adopted their children has made their lives and families complete. They have difficulty envisioning their lives prior to having their children. They

have made many sacrifices to improve the quality of life for their children and families as a whole. Their commitment to family is bidirectional; providing a family to children in need and also fulfilling their life goals of being parents. In essence, the positive aspects of family benefit them and their children.

Given the importance of family, Pauline and Claire clearly communicated that adoption should be viewed as a normal way to have children and to make families complete. Claire discussed her views regarding the stigma of adoption. Her husband's sister was adopted and the topic of adoption was never raised within the family until Claire and her husband adopted their boys. Her adoption allowed the family to explore issues of adoption and emotions surrounding adoption with more freedom. Adoption became a learning tool for the whole family.

Relatedly, Claire and Pauline talked about the views that society has about adoptive parents. They commented that others often viewed them as exceptional parents of exceptional children. They often felt that others idealized their experiences, placing them, as mothers, on a pedestal. Both of these women clearly communicated that they did not feel that their life choices were extraordinary. Their decisions were just to adopt children and have families. They want others to view their lives as normal.



## Discussion

The above thematic analysis provides the reader with the common themes identified by the five participants. One is able to see the similarities and differences that each parent encountered. It is now important to examine these themes in respect to previous literature within the realm of adoption and disability.

### The Adoption Experience

Parents in this study experienced the process of adoption as a stressful, lengthy, and overwhelming process. Barriers to adoption included legal complications, time, age of parents, marital status, and presence of other children with disabilities in the home. One parent reported that adoption personnel were hesitant to place a high needs child with an older or single parent, given the extra needs that parenting would likely entail. Historically, children with disabilities have difficulty securing permanent placements due to the fact that there are few appropriate and willing families to care for them (Phillips, 1998). It was surprising to find that these parents, who were able and willing to care for a child with a known disability, experienced difficulty throughout the adoption process. Part of this difficulty may be linked to legal issues and connections to birth parents.

Legal barriers to adoption were reported as significant for several of the parents interviewed. Most of the children in the current study were still legally connected to birth or foster parents prior to the adoption being finalized. It seems logical that children still connected to their birth or foster families or children removed from previous placements as a result of abuse or neglect have more complicated legal issues to resolve prior to adoption. Waiting lists for services and delays in the adoption process are often inevitable, given these unique circumstances. A study by McCarty and Waterman (1999)

found that several parents reported feeling additional stress when dealing with the dissolution of birth parents' rights and the need to attend legal hearings to ensure the adoption of their child. Most adoptive parents expect that adoption takes time, however more services may be required to parents who are waiting for adoptions to be legalized and finalized. For the parents involved in the current study, lack of services during these uncertain times was most difficult.

When examining previous research studies that focus on the process of adoption, most report that parents are generally dissatisfied with adoption personnel's knowledge of disability issues (Coyne & Brown, 1986; Kramer, 1999; Reilly & Platz, 2003; Wimmer & Richardson, 1990). This finding was not supported by the current study. Parents in this study were generally satisfied with adoption personnel and staff involved with the adoption process and felt fully prepared for the arrival of their child into the home. All were able to meet their children prior to placement and were given full and complete histories of their children's past and development. Four parents noted that adoption services prior to placement helped prepare them for the arrival of their children. Sources of stress were largely a result of uncertainty in the adoption process, specifically for children legally attached to other caregivers. The issues of uncertainty and legal processes affecting adoption, specifically when a child has a disability, is an area of research that deserves further exploration.

### Connection

The notion of connection was the most prominent theme in the lives of the parents interviewed. Emotional connection to the children they adopted was described by several of the parents as intense love and a feeling of being drawn to their children. One parent

even felt drawn to children that she did not already know. This is a new finding in relation to previous research. Earlier research by Todis and Singer (1989) examined families who adopted children with special needs. One finding revealed that a main reason for adopting was having previous attachment or connection to the children through a foster parent relationship. This finding resonates for Tammy, who came to adopt her daughter through a similar connection and experience. Some research has been conducted that examines the initial feelings of love for children and the attraction that adoptive parents can feel toward children (Goetting & Goetting, 1993; Marx, 1990). This study highlights emotional connection as an important finding. Additional research regarding how this connection occurs and factors that enhance and/or diminish this connection would be worthwhile. It would also be interesting to examine if this connection is the same or different for parents who adopt infants versus older children, if it differs between mother and fathers, and how child characteristics (i.e., disability or behaviour difficulties) affect initial connections and emotions. It may also be interesting to examine initial connections and the relation to adoption disruptions.

The notions of family and sibling connection are concepts often noted in the adoption literature (Marx, 1990; McGlone et al., 2002; Mullin, 1999). The participants in the current study commented that the process of connecting family members required time and patience. For older children, connections to new parents and new homes were difficult and required time and patience. The adoption can also affect other members of the family, particularly siblings. For younger siblings, the acceptance of a child with a disability in the home can lead to negative consequences. Harold and Margaret commented that their eldest son had difficulty coping with the adopted son's disability,

leading to feelings of neglect and acting out behaviour. Age of siblings appears to have been an important factor in sibling adjustment. Families with adult children at the time of the adoption experienced less sibling adjustment as a result of the adoption. Additionally, siblings who were actively involved in the family decision to adopt experienced better transition to the adoption compared to siblings who had less involvement in the decision making.

Research is available that explores the impact of disability on siblings. Early literature does note that when a child with a disability enters the home, family patterns of interaction change (Cahill & Glidden, 1996; Gallimore, Weisner, Bernheimer, Guthrie, & Nihira, 1993). Understandably, there is less time for family recreation and parents must learn to balance time to meet the needs of the family as a whole. A recent study by McGlone et al. (2002) found that siblings experience difficulty adjusting to the presence of a new family member with a disability and often feel they receive less attention following the adoption. Mullin (1999) found that siblings experience positive and negative effects following the adoption of a child with special needs. Positive effects were noted to include camaraderie with a sibling, learning to share, and the development of new coping skills. Results of the current study support these previous findings. For the parents of younger children, difficulties with finding time for family recreation and other family needs were evident. Siblings were reported by parents to be expressing feelings of isolation and less attention following the adoption. Positive rewards such as increased family cohesion and interactions, however, were also noted to occur.

It would be interesting to examine how members of the family cope and adjust to the addition of a new child in the family when that child does not have a disability. Is the

adjustment merely a factor of the adoption process or is it directly linked to the presence of a disability in that child? The current study found that younger siblings experience greater difficulty with transition and are directly impacted by the presence of a disability in their adopted brother or sister. Qualitative inquiry, with a focus on sibling experiences, may help future adoptive parents understand the issues that other children within the family may experience and assist in preparing siblings for the arrival of another child, with or without disability, into the family. Interviews with siblings themselves may provide a deeper understanding in this area.

The theme of connection is also important to consider when trying to understand the link between birth and adoptive parents. Logically, birth and adoptive parents are connected to one another by the children in their lives. Most parents in the current study commented about the feelings toward the birth parents of their children and have spent some time trying to understand and empathize with their experiences. These parents shared the view that birth parents experience grief, loss, and guilt as a result of having a child with a disability. These parents were also in agreement that adoptive parents do not have to cope with these same feelings, making their parenting experiences less stressful.

The idea that biological parents feel guilt and sorrow when a child is born with a disability is not new. Research in the areas of family and disability focused on the negative impact that disability has on parents and family. Grief and shattered dreams were common themes highlighted (Barnett et al., 2003; DeMyer, 1979; Gray, 1993; Gupta & Singhal, 2004; Harris & Powers, 1984; Howard, 1978; Konstantareas, 1991; Shea, 1984; Whelan & Hudson, 1987). The current study found that parents felt great empathy for birth parents and respected their decisions to place their children for

adoption. Some commended birth parents for having the strength and personal insight to place their children for adoption in the hopes of the child having a better life. The current study reinforces the notion that, at least these adoptive parents, lacked the guilt and shame associated with their child's disability (Glidden & Bush, 1990).

### Special Needs Beyond Developmental Disability

Special needs adoption refers to a broad range of issues that will likely entail extra support to children and families. Issues include age of children at placement, transracial adoption, emotional difficulties resulting from previous trauma, and other factors such as medical issues or disabilities that require extra support and services.

The current study aimed to examine the experiences of parents who adopted children with disabilities. It became clear once the study progressed that the presence of a developmental disability was not the sole special need that the adopted children in the study possessed. All of the children had additional special needs that impacted on the family functioning. These included histories of abuse, multiple caregiver placements prior to adoption, significant medical concerns, behavioural difficulties, transracial adoptive placements, and older age at the time of placement. Findings can likely resonate for other parents of children with multiple and complex issues including, but not limited to, developmental disabilities. Three prominent issues arose from the current results that deserve further attention. They are: (a) adoption following abuse, (b) a celebration of culture, and (c) dealing with medical concerns.

### Adoption Following Abuse

A strong theme that emerged from the current study surrounded the notion of adoption following abuse. The unfortunate reality for many adoptive parents is the

realization that many children in foster care, regardless of age, gender, race, or disability, have experienced abuse, trauma, and/or neglect. Adoptive parents, therefore, need to be cognizant of how these abusive pasts can affect their adoption experiences.

The parents in the current study reported that it was often difficult to cope with their children's abusive pasts, acting out and/or aggressive behaviour, as well as the grief and loss their children experienced as a result of being removed from previous homes. These parents were unified in their endeavors to provide a safe, caring, and loving environment to these children in need of family and protection. Initial adjustment in the home was often difficult. Time was also recognized as a healing factor when bridging two worlds.

Previous research in the area of adoption following abuse has found that children typically exhibit a higher degree of behavioural difficulties (Smith & Howe, 1994) and have some difficulties attaching emotionally to new caregivers (Dance et al., 2003; Hughes, 1999). The results of the current study also found that Claire's children, who had a previous history of abuse, exhibited aggressive, violent, and unpredictable behaviour at times and it took time to grieve the loss of their previous relationships to family and life history. Claire's children struggled with coming to terms with their own anger and behaviour resulting from trauma. A unique aspect of the current study was the fact that developmental disability also played a role in the lives of these children. For some children, the abuse and trauma led to cognitive delays as a result of brain trauma. For one mother, the effects of the abuse were less noticeable, given that her child was unable to remember the abuse and was no longer cognitively capable of processing those events. For several of the children in this study, the existences of cognitive delays may have

made the psychological and emotional effects of the trauma less noticeable for adoptive parents.

The current study serves to provide additional information from the perspective of parents, regarding abuse and adoption. Current results are especially important considering that the factor of disability adds an additional element of information. Further research regarding the link between abuse, disability, and adoption is recommended.

### A Celebration of Culture

Cross-cultural connection was another important sub-theme identified in the current study. Openness to cultural differences was key in aiding the connections between parents and children, children and their past, and families between cultural communities. Both Claire and Pauline discussed their experiences adopting children of Native Aboriginal heritage. Both of these parents celebrated transracial adoption and were dedicated to incorporating their children's heritages into their own lives. They reported experiencing positive feelings from their community and generally felt supported by both their community and the Aboriginal communities that their children came from. Most research in transracial adoption has been conducted in the United States and has focused on Black or Latino children adopted by Caucasian families.

Results of the current study generally support previous findings in that parents frequently report having loving, warm, and caring relationships with their children adopted transracially (Feigelman, 2000). Recommendations by previous researchers for parents of children adopted transracially include being open and aware of cultural issues, living in integrated communities, and helping children identify with their cultural histories (Smit, 2002). The parents of the current study were active in incorporating their



children's culture into their lives and were deeply involved in multicultural communities and activities. Their involvement and dedication to their children's cultural awareness have likely enabled these parents to view cultural differences as a means for celebration.

### Dealing with Medical Concerns

Four of the parents interviewed discussed the additional stress of coping with their child's medical and health concerns. These parents talked about the numerous unforeseen medical emergencies, weekly trips to emergency rooms, and life threatening surgeries. The results of the current study support previous findings that note that parents of children with disabilities experience elevated levels of stress in relation to child health problems (Roach et al., 1999). A study by Szymanski and Seppala (1995) found that many adoptive parents worry excessively regarding the medical needs of their adoptive children. Recent research by McGlone et al. (2002) also found that adoptive parents of children with chronic medical problems reported increased stress levels post-adoption.

Early research by Holroyd and Guthrie (1986) supports the notion that stress patterns in parents are consistent with the nature of the child's illness or disability. It seems logical that issues that require extra care and attention (i.e., medical concerns) would lead to increased levels of stress and strain. Other studies, however, show that parents of children with psychological or cognitive disabilities experienced more stress within the family than families of children with physical problems, due to societal attitudes regarding disability, child characteristics, behavioural issues, and parental feelings of shame and guilty (Bouma & Schweitzer, 1990). One parent, Tammy, voiced that dealing with her child's behavioural difficulties were more stressful than coping with medical emergencies. This finding is also common in new research. A study by Baker et

al. (2003) found that parenting stress was linked more to behavioural difficulties rather than disability issues.

In summary, the results of the current study found that parents of children with disabilities experience stress in relation to the difficulties their children encounter. Stress was associated both with medical concerns as well as behaviour problems, with both issues leaving parents with little control over situations. It seems that unpredictable events and events that pose risk to their child or others invoke the most stress for parents.

### Commitment

Keys to adoption commitment were found to include a combination of knowledge, choice, and realism. Knowledge involves parents understanding the nature of their children's disability and having information about what to expect following the adoption of their child. Knowledge enabled parents to make informed decisions about whether or not a child would blend with their families and to make judgments about their own ability to be effective parents. Realism involved accepting the permanency of disability and was important in allowing parents to successfully plan for their children's futures. These key components enabled these parents to commit to becoming parents.

Little research has specifically examined adoption commitment and its link to knowledge, choice, and realistic expectations. Previous research does support the notion that clear knowledge about a child prior to the adoption leads to more positive outcomes following the adoption (Rosenthal & Groze, 1992). Adoption outcomes are at risk of termination if parents do not receive adequate information about the children they adopt (Festinger, 2002; Rosenthal, 1993). Making the choice to be willing and able to care for a child with a disability is also a key component to many adoption successes (Coyne &

Brown, 1985; 1986). As reported by Glidden and Bush (1990), adoptive parents can choose the kind of child that will fit into their lifestyles and family characteristics.

Commitment and preparation for the entry of the child in the home were noted as key elements mediating the effectiveness of post-adoptive placements (Glidden & Bush, 1990).

In the current study, realism was another important theme related to how parents made the decision to adopt as well as their ability to cope in the future. Historically, research tended to view adoptive parents of children with a disability as adopting to “cure” children. Many adoptive parents believe they have an ability to alleviate or rectify a child’s handicap following the adoption (Unger et al., 1988). Newer research has found that parents, who believed that love and affection would rescue children from their disabilities, felt intense sadness and frustration when their child were not cured following the adoption (Szymanski & Seppala, 1995). Unrealistic expectations for the children’s accomplishments can lead to increased family stress (Westhues & Cohen, 1990). Adoptive families who are informed of their children’s needs prior to the adoption are better able to prepare for their child’s entry into the home and have realistic notions of their children’s abilities. Realistic expectations regarding child development have also been shown to be a factor that results in more positive adoption outcomes (Rosenthal & Groze, 1992). “The more appropriate a parent’s expectations for the child, the more positive the impact on the adoption” (Reilly & Platz, 2003, p. 799). Parents in this study believed that realistic expectations of ability and acceptance of a child’s needs lead to more positive parental coping, planning for the future, and willingness to accept life’s challenges.

### Challenges

Parents in this study also shared the view that raising a child with a developmental disability involves life challenges. The adoptive parents of the current study noted that they sometimes felt overwhelmed with the demands of childcare, specifically in relation to lack of time, financial stress, fatigue, and the physical demands of caring for children with physical limitations. These parents noted that it was often difficult to meet the needs of their children as well as their own personal and family needs. They all felt they needed to forgo sleep in order to accomplish daily tasks. The toll of childcare demands on their physical well-being was also noted as tiresome and exhausting. All of the parents were older at the time of the adoption and felt that they often lacked the energy for recreational activities. The toll of dealing with lifting and the physical care of their children was also seen as difficult to manage. All parents, however, were able to cope with these demands in various ways, including organizing their time, arranging for respite support, and by adjusting to new and different routines.

This was an expected finding given the plethora of historical research that has examined family stress when a child has a disability. Most research conducted with biological parents supports the notion that parenting a child with a disability often leads to lack of time for self care, financial limitations, and physical exhaustion (Bailey et al., 1999; Boyd, 2002; Byrne et al., 1988; Dyson, 1997; Failla & Jones, 1991; Hancock et al., 1990; Henggeler, 1990; Lessenberry & Rehfeldt, 2004; McAndrew, 1976; Perry et al., 1992; Philip & Duckworth, 1982; Rodrigue et al., 1990; Sanders, 1993; Turnbull & Turnbull, 1990). Studies also find that as children with disabilities reach adolescence, their increased size and strength make the physical demands of care giving more

pronounced (Bristol & Schopler, 1983; Konstantareas & Homatidis, 1989; Perry et al., 1992; Trute, 1988). New research studying adoptive families tends to also produce similar and consistent results. Lack of time and childcare demands were often reported as stressful for adoptive parents of children with special needs (McGlone et al., 2002).

The focus of recent research is moving toward an examination of long-term adjustment for families raising children with disabilities and less on stress reactions. Recent research by Glidden et al. (2000), Glidden (2000), and Glidden and Schoolcraft (2003), has noted that adoptive parents show positive post-adoption adjustment despite increased parenting demands. These studies, along with the current results, support the idea that parents can and do experience life challenges, however adapt accordingly and are able to cope and problem solve effectively in the long-term.

#### Support

The parents interviewed in the current study were unanimous in their opinions regarding the importance of social, professional, community, and family support. External support systems such as educational programs, respite services, financial aid, post-adoption supports, and health/medical care were regarded as highly valued yet not consistently available when needed. The most valued support for many parents was moral support from caring family members and camaraderie from other parents and caring professionals.

Historically, research has found that there is a lack of community, societal, and professional supports to parents raising children with special needs (Hancock et al., 1990; Sobsey, 1996; Weiss, 1991). Social support has long been viewed as a positive means to decrease stress (Gill & Harris, 1991; Gray & Holden, 1992) and most parents rely heavily

on supports in their communities as coping methods (Adams et al., 1990; Antosh, 1990; Law et al., 2001). Early support has also been shown to have positive effects and benefits for parents (Hendriks et al., 2000). A preliminary report by Kuloslu-Aksaz (1994) found that early counselling helped parents become more realistic about their children's abilities and helped link them to parent and community support groups.

Despite the obvious need for support and community resources, research has noted that parents are often not supported and unable to access needed services. A study by Bailey, Blasco, and Simeonsson (1992) found that parents expressed a need for more information from professionals regarding their children's conditions, strategies to help their children learn, and information on how to access services. Other studies have reported that parents request more services linking them to other parents in similar life situations, more time away from their children, and additional financial subsidies to assist with providing the best services for their children (Stainton & Besser, 1998). Families also often report the need for respite services and residential placements that meet the needs of their aging children, more contact with other families, more community acceptance, and improved educational programs (McLinden, 1990; Scorgie et al., 1996).

Similar issues have been found regarding the need for services for adoptive parents. Many parents report a need for more background information regarding their children (du Porto & Phillips, 1996; Dumbleton, 1996; Kramer, 1999; Marcovitch, Cesaroni, Roberts, & Swanson, 1995; McDonald et al., 2001; Phillips, 1998; Ward, 1996), additional post-adoption support, home support, respite, and additional contact with other parents in similar life circumstances (Dumbleton, 1996; Marcenko & Smith, 1991; McDonald et al., 2001). The parents in the current study concur that additional

supports are needed regarding respite, financial assistance, support groups, and post-adoption support.

In addition to external support, the parents of the current study noted that spousal support was instrumental for positive coping. Marital strength and unification enabled couples to work together to solve problems, cope with challenges, and share in childcare demands. Early research has found that marital strength and cohesiveness can serve to promote positive family adaptation (Abbott & Meredith, 1986; Trute, 1988) and decrease overall family stress (Fisman, Wolf, & Noh, 1989; Saddler et al., 1993). Families that cope effectively with raising children with disabilities generally have higher levels of family cohesion, higher family hardiness, and healthier marital relationships (Scorgie et al., 1998). Studies by McAndrew (1976), Glidden (1996), and Scorgie et al. (1996), also found that many marriages became stronger as a result of children with disabilities in the family. Coping is further enhanced when fathers play active roles in care giving (Westhues & Cohen, 1990). A recent study by Kramer (1999) supports this finding. Kramer found that most families in their study relied most heavily on spousal support over and above the professional services available.

An important finding in the current study was that parents viewed emotional support from families as more important than financial or instrumental support. Several parents remarked that it was important to know that extended family was supportive of decisions they made and respected their choices in terms of the adoption. This finding supports research by Trute (2003), who also found that parents valued emotional support provided by extended family over and above other support provided. Further exploration in this area appears warranted.

### Advocacy

The parents in the current study all faced some form of discrimination, adversity, and/or lack of support or services for their children. Many parents became keenly aware of the negative stereotypes evident in the community regarding persons with developmental disabilities. Many felt that their children were excluded from educational and community programs. As a result of these negative experiences, all of these parents adopted the role of advocate. They became more involved in their communities, worked hard to ensure their children were respected and included, and have creatively solved otherwise difficult situations. Thinking unconventionally was often noted as a requirement to ensure their children's needs were being met.

For several decades, parenting children with disabilities has often been viewed in a negative light. Early research focused on disability as a source of family stress (Fotheringham et al., 1972), parental devastation, and sorrow (Coyne-Cutler, 1984; Turnbull & Turnbull, 1990). Despite new research that highlights the positive aspects of parenting and disability (Hastings & Taunt, 2002), it appears that societal views toward disability are slower to change. Research does support the notion that many parents feel that society is discriminatory toward their children and families (Phillips, 1998; Scorgie et al., 1996). Many parents are disturbed by societal reactions to disability, whether these reactions are pity, pointing, or discriminatory comments. Negative social attitudes can be stressful to parents raising a child with disabilities and can limit community integration.

Research supports the concept that advocacy can serve as a coping mechanism for many families, especially when they are faced with lack of support and community prejudice (Law et al., 2001). Parents, who engage in advocacy and community education



that challenges society's view of disability, experience less stress related to stigmas compared to parents who feel angry yet avoid or move away from situations that involve negative evaluation of their children (Baxter & Cummins, 1992).

### Joy, Personal Growth, and Transformations

Joy and personal growth was a strong theme connecting the experiences of all parents in the current study. Despite difficulties encountered, all of these parents felt intense love for their children and happiness in their parenting roles. All of these parents felt pride in watching their children learn and grow. These parents were grateful to be parents and have the family that they could not have otherwise had. These parents experienced personal growth. Many felt that they had become more patient, happier, and gained increased awareness of life as a result of being adoptive parents.

New research focuses on positive aspects of parenting children with developmental disabilities. Rewards of parenting associated with the adoption of a child with a disability include joys of parenthood, development of strong family ties, bonding with a special child and between siblings, being loved by a child, seeing a child progress and learn, and the satisfaction of knowing that your actions are helping a child (Kausar et al., 2003; Kearney & Griffin, 2001; McDonald et al., 2001; Mullin, 1999; National Adoption Information Clearinghouse, 1999). Other findings report that parents become better problem solvers, feel gratified when children learn, and feel pride in their roles as care takers (McLinden, 1990; Scorgie et al., 1996). Many parents also gained a better appreciation for life and experience closer family unity and strength (Glidden, 1996; Stainton & Besser, 1998).

The findings of the current study are consistent with previous research noting that adoptive parents are able to express joy in their roles as parents and have become better people as a result of their experiences. It should be noted that one parent, Harold, felt that parenting in itself was the reason for joy in his life. Harold was clear in noting that his joys in parenting are not necessarily linking to raising a child with a disability. His joy was related to being able to have a family that would otherwise not be possible. This leads to an important question that has yet to be explored, specifically for adoptive parents. Is the connection between joy and parenting related to whether or not a child has a disability or merely linked to parenthood alone? Parents in the current study reported that the joy and positive aspects of parenting were related more to the fact that they had become parents, which was something they all desperately wanted. Caring for any child is likely going to lead to life changes and feelings of pride, joy, and enrichment. It appears that the parents' experience of joy and happiness has little to do with the children's disabilities. This result leads us to conclude that all families experience challenges and happiness regardless of whether the child has a disability. These results may point future research in the direction of the normalization of life when a child has a developmental disability.

#### Profile of an Adoptive Parent

The parents in the current study commented on several personality characteristics that they felt enabled them to be successful parents. All of these parents had strong beliefs in the value of family, ability, and children. Their respect for all people, regardless of differences, likely made them more willing and able to care for children with developmental disabilities. All parents stated that the need for patience, organizational

skills, flexibility, and ability to cope with change were important. Faith was also noted as instrumental to dealing with life's uncertainties.

Previous research has found that many adoptive parents are warm, caring, accepting of individual difference, and have experience with parenting. Key qualities also include patience, understanding, flexibility, organization, strong parenting skills, and strong values and beliefs (Coyne & Brown, 1986; National Adoption Information Clearinghouse, 1999; Perry et al., 1992; Rosenthal & Groze, 1992; Todis & Singer, 1989; Unger et al., 1988). The families in the current study voiced that the aforementioned qualities have helped them become better parents and cope with difficult life transitions.

In addition to personality characteristics, faith is a concept that has been discussed more often in the literature. Faith, spirituality, or religious convictions have often been noted as mechanisms to enhance personal and familial coping (Glidden et al., 1999; Krauss & Seltzer, 1993; Skinner et al., 2001). Raising a child with special needs has also been found to lead to increased spirituality, family unity, growth, and strength (Scorgie et al., 1996; Stainton & Besser, 1998). Results of the current study also support the notion that faith can be a positive coping tool.

### Normalization

Normalization was a novel concept that emerged for the families interviewed. These families clearly viewed adoption as a normal method of becoming a family, both for children in need as well as couples who cannot have their own children. These parents emphasized the value of family and felt that all children, regardless of disability, should have the opportunity to love and be loved. These parents did not view their decisions to adopt as extraordinary, and some resented being placed on a pedestal for doing so.

Several voiced the need for society to view adoption as a normal way to enhance family life.

The concept of normalization of adoption was a unique finding to the current study and, to the researcher's knowledge after a thorough review, has not been addressed in previous research. The increased acceptance and visibility of adoption may partially explain this finding. Similarly, Claire commented that the adoption of her sons became a learning experience for her extended family. Her husband's sister was adopted and the topic of adoption was not previously discussed within the family. The adoption of the twins has allowed this family to talk openly about issues of adoption and Claire's sister-in-law now has the opportunity to share her feelings and experiences. More work is needed to explore the social views that may be attached to adoptive parents of children with disabilities.

## Conclusion

The results of the current study reinforce and expand upon what we know about the experiences of parents who chose to adopt children with developmental disabilities. The current study provides a refreshing look at the experiences of four adoptive families. As a researcher, I have gained valuable insight into the lives of the parents I interviewed. Their stories have allowed me to fully explore the process of adoption and family life when a child has a disability. There are several key pieces of information that have emerged from the current investigation that deserve a final comment.

The parents interviewed in the current study had some difficulties finalizing the adoption of their children. Despite these difficulties, most felt supported by adoption personnel both during and after the adoption took place. These parents felt that they were given adequate and complete background information about the children they adopted and were well prepared for the entry of the child into their home. Support and access to services during the adoption process was noted as an area that deserves further attention. Prospective adoptive parents should also be aware of the difficulties in the adoption process and be cognizant that adoption takes time and patience.

Connection was a prominent theme that emerged from the current study. It appears that connection has been a neglected area of previous research. Further research should examine the role of connection for adoptive parents to their children and how initial bonds are reinforced. It would be worthwhile to examine how initial connections affect post-adoptive outcomes and how to foster this connection for prospective adoptive parents.

Another important element that surfaced was the effect of adoption on siblings already present in the home. Age and decision-making power in the adoption appeared to play important roles in sibling adjustment. Older children and those with a more active role in the decision to adopt appeared to adjust positively to the adoption experience.

One key element of importance involves the complexity of life circumstances of children placed for adoption. The current study initially sought to understand the experiences of parents who adopted a child with a developmental disability. It became clear that the children placed for adoption had very complex needs that included older age, different cultures, histories of abuse and/or neglect, and different levels of openness with birth relatives. Results should be interpreted in light of the complexities of needs of each child. Results do indicate that adoptive parents, regardless of the needs of the child, experience challenges and rewards. Stress in adoptive parents appears to be linked more to unpredictable life events (i.e., medical emergencies, behaviour difficulties) and discriminatory practices in the community, rather than unique needs of the child. Transition for both parents and children placed for adoption does occur and parents learn to adapt successfully over time. Adaptation appears enhanced when parents have access to needed support and services, when extended families are emotionally supportive, when they are surrounded by caring and knowledgeable professionals, and when spouses are able to provide support within the home. Adoptive parents choose to have a family and choose a child who will fit their lifestyle. They are committed to these children and it seems that choice and commitment also make the adoption transition more manageable.

On a final note, it should also be noted that the joys in parenting were not unanimously noted to be a direct result of raising a child with a disability. Joy in

parenting was also noted to be a result of having the opportunity to be a parent and to experience the family life that these parents so desperately wanted. It was also important to many families that adoption be viewed as a normal way to achieve family. The parents of the current study placed a strong value on family and the value of all children. They did not feel that their actions to adopt a child with a developmental disability placed them on a pedestal compared to other parents. They viewed their role as similar to all other parents, trying to provide the best life for their child. Adoption, for them, was a means to have the family life they wanted. The children they adopted, despite their complex needs, were able to make their dreams come true.

#### Potential Benefits

Findings from this study will likely result in a greater understanding of adoptive parents' experiences in relation to children with disabilities. The results of this study support the notion that adopting a child with a disability, despite the challenges, can be a positive experience for parents, siblings, and family. The benefit is that this research has the potential to expand knowledge, for birth and adoptive parents, as well as professionals involved in adoption. Other professionals including teachers, social workers, psychologists, and medical professionals can benefit through a better understanding of what parents experience when raising children with disabilities. Hopefully this knowledge can serve to change social policy, educational programming, and societal views regarding disability, family, and adoption. Possible areas of social/policy change could include:

1. Increased information and access to post-adoption supports for parents who adopt children with developmental disabilities or other special needs;

2. Increased support and services for parents in the waiting period of adoption;
3. Increased monetary funding for respite services and/or specialized equipment (i.e., medical supplies, wheelchairs) to families raising children with developmental disabilities or other special needs;
4. A wider variety of educational programs to meet the diverse needs of students with developmental disabilities, specifically children with multiple physical, emotional, and/or cognitive needs;
5. Educational and community programs that value inclusion of children with differing physical, medical, emotional, and developmental needs;
6. An increased focus on preventative intervention for children at risk of abuse and neglect by caregivers; and
7. Policies and procedures within the current healthcare system that assists families in coordinating specialized services (i.e., physicians, psychologists, occupational/physical therapists, social workers, teachers, etc.) for their children.

This research provides a descriptive view of family life and adoption and the findings might enable professionals to provide more comprehensive and family-focused services to adoptive families in similar situations. Information could also be used to assist prospective adoptive parents in understanding issues and challenges that may arise, and provide information regarding services and supports they may need. This research also has the potential to change existing services to parents and families raising children with developmental disabilities. It became evident that many parents felt a greater need for financial, educational, and government support following the adoption of their children. Many parents faced challenges in obtaining these needed services, supplies, and supports.



It is apparent that social policies currently in place should be revisited to ensure family needs are being met in a more efficient and consistent manner.

#### Areas for Future Research

There are still gaps in the research that deserve further attention. It may be worthwhile to examine the effects of adoption on siblings in more detail. Consideration should also be given to understanding experiences in relation to the age of siblings at the time of the adoption and their ability to be involved in the adoption choice. Also important would be to examine the adoption experiences for adopted children themselves, as well as the experiences of parents who give up their parental rights. What do birth parents of children with disabilities experience when they decide to place their children in adoptive homes? This kind of research has yet to be conducted in relation to special needs adoption. Qualitative examination of these experiences can expand what we know about families and provide additional information to families considering adoption.

Another area that deserves further attention is to look more closely at the role of culture in the adoption experience. Canadian data and the effects of transracial adoption for native Aboriginal children are important, yet often ignored areas of research.

An additional area that deserves further attention surrounds the notion of connection. Questions that have emerged from the current study include:

1. How does the process of connection occur for adoptive parents?
2. How does connection occur for children placed for adoption?
3. Is connection different for mothers and fathers?
4. Is connection different for younger versus older children?
5. How do child characteristics affect a parent's connection to his/her child? and

## 6. How does connection relate to post-adoption outcomes?

Learning how connection can be enhanced can be valuable information for parents and professionals in the field of adoption.

The current study noted the importance of support both during the adoption process and following placement. Additional research would benefit from analyzing the supports needed by families during uncertain and lengthy adoption procedures. The importance of moral versus instrumental support following adoption can also provide valuable information to parents and professionals.

The current study highlighted the importance of understanding family experiences by looking at the complexities inherent within each family. The children involved in the current study had many special needs, over and above the presence of a disability. Most notable was the existence of abusive past histories. We would benefit from future research that examines, in more depth, the links between abuse, disability, and adoption.

Lastly, the participants in the current study voiced their opinion that adoption should be viewed as normal. Additionally, personal transformations appeared linked more to becoming a parent and less to becoming a parent to a child with a disability. This is a new and important finding. Additional research may be able to provide a more in-depth understanding in this area.

### Considerations of the Study

The current study is a starting point for future research in the area of adoptive families raising children with disabilities. Qualitative research is well suited to examining family experiences related to raising children with disabilities, and there are some considerations. Qualitative research relies heavily on language as a vehicle for

understanding and analysis. As a result, the participants used were chosen based on their ability to effectively communicate their feelings, thoughts, and experiences. Thus, these results have depended heavily on the participants' but also on the researcher's ability to elicit interview information. As well, the trustworthiness of the research depended heavily on the researcher's skill and ability in effectively communicating and capturing the key aspects of the participants' experiences through language.

It is also important to note that these participants were very willing to share their experiences in this research. Other parents' experiences may differ greatly from those in this study. As such, the reader cannot make any generalizations. One difficulty the researcher experienced was identifying parents who adopted children with disabilities. Parents were identified through adoption agency personnel and most participants were known directly to agency staff based on their advocacy and volunteer efforts. Contact with other parents was difficult, often due to closed adoption records and parents' rights to confidentiality throughout their adoption processes. Readers should bear in mind that a small and convenient sample was utilized. Participants were all strong advocates in their communities and volunteered to participate in the current study. They were all parents coping well with the demands of parenting. Another study may provide new and additional information worthy of attention.

One must remember that all of these parents experienced successful adoption outcomes. Similar findings may not be evident for adoptive parents who were unable to continue caring for their children. Their life experiences may be different. These results should be interpreted in light of the fact that these parents were active leaders in the adoption community and have coped well with their experiences. Further research may

benefit from a better understanding of the experiences of parents who terminate their adoptions. This may be as instrumental to prospective adoptive parents as information from parents of successful adoptions.

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## Appendix A

## Letter to Adoption and Fostering Agencies

Linda Foti-Gervais  
Edmonton, Alberta

To Whom It May Concern:

I am doctoral student in the special education program at the University of Alberta, Department of Educational Psychology. For my doctoral dissertation, I am doing a project examining the experiences of adopting and raising a child with a developmental disability. This area of research is new and will hopefully provide useful information for parents, adoption professionals, and communities.

I am hoping to meet and talk to parents who knowingly adopted a child with a developmental disability. For the purpose of this project, the definition of developmental disability will be taken from the Developmental Disability Act of 1984 and will be “severe and chronic disabilities that (a) are attributable to a mental or physical impairment; (b) manifest before the age of 22; (c) are likely to continue indefinitely; (d) result in substantial functional limitations in three or more areas: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living or economic self-sufficiency; and (e) reflect the need for a combination and sequence of special, interdisciplinary or generic care, treatment, or other services that are life long or of extended duration.”

By having the opportunity to talk to parents, I hope to gain insight into the thoughts, feelings, and experiences that adoptive parents of children with developmental disabilities experience. By exploring this topic, I hope to increase my understanding of and interaction with families whose children have special needs.

The nature of this research involves that adoptive parents tell me their stories regarding their adoption experiences, their family life, and any other topics they feel is related to their life and adopted child. If you are an adoptive parent of a child with a disability and you would like to volunteer your time for this study, please contact me for further information. If you are not an adoptive parent but know of someone who may be interested in participating, please forward this information to him or her.

Thank you in advance for your cooperation.

Sincerely,

Linda Foti-Gervais, M. Ed.

## Appendix B

### Proposed Interview Guide

#### Initial Question

Tell me about your thoughts, feelings, and experiences related to your experience of adopting a child with a developmental disability

#### Topics and Questions of Interest

##### Reactions to Disability

1. Tell me about your thoughts and feelings regarding your child's disability.

##### Reasons for Adoption

1. How did you decide that you wanted to adopt a child with a disability?
2. What was it like when your child first came into your home?
3. How did you prepare for the adoption?
4. Did you have previous knowledge or have experience with disability prior to the adoption?

##### Stressful Experiences

1. What are the most difficult aspects of parenting for you?
2. Tell me about how you deal with daily parenting responsibilities.

##### Positive Experiences

1. How has raising your adopted child influenced your life?
2. Have you changed personally as a result of your experience? If yes, explain.
3. Have your relationships with other people changed? If yes, explain.
4. Has your outlook on life changed as a result of raising a child with special needs? If yes, explain.
5. Tell me how your adoption experience has improved your life / made your life better?

##### Outlook for the Future

1. What are your concerns, if any, that you have for your child's future?

##### Social Support Network

1. Tell me about any sources of support outside of your immediate family (extended family, friends, and other parents) that you can turn to in times of need.

Interactions with Professionals

1. Tell me about your experiences interacting with doctors and/or other professionals regarding your child
2. What kind of support and information did the adoption agency provide to you and your family both before and after the adoption?

Final Question

Are there any other areas that I have not covered that you feel are important to add to the interview?

## Appendix C

## Study Description

Dear Participant,

I am a doctorate student in the special education program at the University of Alberta, Department of Educational Psychology. For my doctoral dissertation, I am doing a project examining the experiences of adopting and raising a child with a developmental disability. By having the opportunity to interview you, I hope to gain insight into the thoughts, feelings, and experiences that adoptive parents of children with developmental disabilities experience. By exploring this topic, I hope to increase my understanding of and interaction with families whose children have special needs.

Your participation in this study will be in the form of three interviews with myself. The first interview gives us the opportunity to become better acquainted and to learn something about each other's backgrounds. During this interview I will explain to you the nature of the project, why you have been selected, and to answer any questions that you may have.

Before our second interview takes place, I would like you to take some time to think about your experiences as they related to the topic we are exploring. Specifically, think about your thoughts and feelings related to your experience as an adoptive parent of a child with a disability. As you think about your experiences, you may want to write down any important thoughts or details so that you can refer to them during the interview.

During the second interview, I will ask you to describe your experiences of adopting a child with a disability in as much detail as possible. It is an open-ended interview, meaning that it does not follow a structured format but instead, unfolds based on what is discussed. It is important that you describe your actual experience on the topic we are exploring. Please tell me about your experiences just as they happened. Remember there are no "right" or "wrong" answers. What I am looking for from you is complete honesty. (Do not tell me what you think I want to hear. I want to learn about your experiences, whatever they may be for you). The interview will be about one hour long.

During our final interview, we will examine my understanding of your experience. That is, after analyzing the interview data I will end up with a brief description of the essential aspects of your experience. We will discuss this final description in order to determine how accurately it describes your experience.

I want to mention again that your participation in this interview is completely voluntary. Also, all information will be kept strictly confidential and you can withdraw from the interview at any time without penalty. If you decide that you no longer want to participate in the project, all information about you will be destroyed.

If you have any other questions or if you would like to discuss anything with me, please feel free to contact me directly.

Sincerely,

Linda Foti-Gervais, M. Ed



## Appendix D

## Consent to Participate

I, \_\_\_\_\_, am aware that the purpose of this assignment is to understand the experience of adoptive parents of children with developmental disabilities. Through the use of an interview format, I will be asked to describe my experiences in as much detail as possible. I understand that the present project is being conducted as a doctoral dissertation by Linda Foti-Gervais (lfoti@ualberta.ca), under the supervision of Dr. Dick Sobsey (492-3755) of the Department of Educational Psychology at the University of Alberta.

I agree to participate in the project and I am willing to share my experiences with the researcher. Your participation in this study will be in the form of three interviews with myself. During the first interview I will explain to you the nature of the project and answer any questions that you may have. During the second interview, I will ask you to describe your experiences of adopting a child with a disability. During our final interview, we will examine my understanding of your experience. That is, after analyzing the interview data I will end up with a brief description of the essential aspects of your experience. We will discuss this final description in order to determine how accurately it describes your experience.

I am aware that that data-gathering interview of approximately one hour in length will be tape-recorded in order that it can be transcribed for later analysis. I realize that my participation in the study is completely voluntary and that I can withdraw from the study at any time without penalty. If I choose to withdraw from the study, any information about me or any data that I provide will be destroyed. I am also aware that if discussion of my experiences raises any concern for me that I wish to discuss further with a counsellor, Linda Foti-Gervais will suggest individuals that I might contact.

I am aware that all information associated with this study is strictly confidential and that my identity, or that of any persons that I mention, will be known only to the researcher and will not be revealed at any time. When transcribing the interview recordings, the researcher will use pseudonyms (i.e. false names) for my name and for those of any persons that I mention. These pseudonyms will also be used in writing the final report. Any details in the interview recordings that might identify me or any persons that I mention will also be changed during the transcribing. Furthermore, the researcher will be the only person with access to the tape recordings and they will be stored in a secure place (locked drawer in the home of the researcher/author). Interview recordings will be destroyed when the project has been completed. I may request that the taped recordings be returned to me at the end of the study.

I am also aware that the information obtained from the interview will be used by the researcher for the purposes of this doctoral dissertation and that the transcript of the interview, or parts thereof, conducted with me may be included in the final written report. Additionally, I am aware and give my permission to have the results of the dissertation published at a later date in either an article or presentation format. Data gathered and used for secondary research (articles, presentations) will be handled with the same degree of security to protect your anonymity.

Signature \_\_\_\_\_

Date \_\_\_\_\_

Witness \_\_\_\_\_