

**Parent and Child Perceptions of the Positive Effects that a  
Child with a Disability has on the Family**

by

Michelle Rhea Lodewyks

A thesis submitted to the Faculty of Graduate Studies of  
The University of Manitoba  
in partial fulfillment of the requirement of the degree of:

MASTER OF ARTS

Interdisciplinary Masters Program in Disability Studies  
University of Manitoba  
Winnipeg

Thesis defended on March 30, 2009

Presented to:

Dr. Christine Blais  
(Thesis Supervisor)  
Associate Professor  
Disability Studies

Dr. Nancy Hansen  
(Internal Committee Member)  
Director  
Disability Studies

Dr. Emily Etcheverry  
(External Committee Member)  
Director  
School of Medical Rehabilitation

Dr. Roberta Woodgate  
(External Committee Member)  
Associate Professor  
Faculty of Nursing

## TABLE OF CONTENTS

List of Figures and Tables .....	iii
List of Appendices .....	iii
Acknowledgements .....	iv
Dedication .....	v
Abstract .....	vi
Introduction.....	1
Review of Literature.....	3
Negative Perceptions and the Assumption of Negative Impact .....	3
The Dynamic Ecological Systems Model.....	7
The Theory of Cognitive Adaptation .....	13
The Affirmative Model of Disability .....	15
The Integrated Conceptual Framework .....	18
Positive Studies .....	20
Gaps in the Literature .....	26
Research Questions .....	28
Methodology .....	29
Participant Selection.....	29
Appreciative Inquiry .....	32
Data Collection: Appreciative Interviews with Parents and Children.....	35
Data Analysis.....	37
Trustworthiness .....	40
Results .....	43
Theme 1: What the Children Taught the Family or Enabled Family Members to Learn (Parents' Perceptions) .....	44
Sub-theme 1: New Knowledge .....	46
Sub-theme 2: New Attitudes .....	52
Sub-theme 3: New or Enhanced Positive Character Attributes .....	55
Theme 1: What the Children Taught the Family or Enabled Family Members to Learn (Children's Perceptions) .....	58
Sub-theme 1: New Knowledge .....	59
Sub-theme 2: New Attitudes .....	61

Theme 2: How the Children Enriched Family Members' Lives and Made Other Contributions (Parents' Perceptions) .....	63
Sub-theme 1: Helpfulness .....	63
Sub-theme 2: The Children's Positive Character Traits .....	66
Sub-theme 3: Positive Emotions the Children Evoked in Family Members.....	68
Sub-theme 4: Other Contributions .....	70
Theme 2: How the Children Enriched Family Members' Lives and Made Other Contributions (Children's Perceptions) .....	73
Sub-theme 1: Helpfulness .....	73
Sub-theme 2: The Children's Positive Character Traits .....	75
Sub-theme 3: Positive Emotions the Children Evoked in Family Members.....	76
Sub-theme 4: Other Contributions .....	77
Theme 3: Messages to Pass Along (Parents' Perceptions).....	79
Message 1: "It's not all rosy either" .....	79
Message 2: Reflections of the Bigger Picture, Reframing the Experience, and Understanding my Child and Family .....	84
Message 3: Would I Change my Family's Circumstances? .....	87
Message 4: The Importance of Choosing a Positive Attitude and Research Approach .....	88
Theme 3: Messages to Pass Along (Children's Perceptions) .....	89
Message 1: What to Understand About Me .....	91
Message 2: What is Cool, Fun, or Neat About Using a Wheelchair..	91
Message 3: What to Understand About my Family.....	92
Summary of Parent and Child Results.....	92
Discussion .....	98
Common Contributions and Areas of Teaching .....	99
More Unique Contributions and Areas of Teaching .....	102
The Children's Recognition of their Positive Effects .....	103
Linking Findings Back to the Affirmative Model of Disability .....	105
Linking Findings Back to the Dynamic Ecological Systems Model .....	107
Summary .....	109
Conclusion.....	111
Study Limitations .....	113
Future Research.....	115
References .....	118

## List of Figures

Figure 1: Integrated Conceptual Framework .....	19
---	----

## List of Tables

Table 1: Characteristics of Study Participants by Pseudonyms.....	31
Table 2: List of Themes and Sub-themes Presented in Results.....	45
Table 3: Summary of Parents' Perceptions of What the Children Taught the Family or Enabled Family Members to Learn .....	47
Table 4: Summary of Children's Perceptions of What the Children Taught the Family or Enabled Family Members to Learn .....	60
Table 5: Summary of Parents' Perceptions of How the Children Enriched Family Members' Lives and Made Other Contributions .....	64
Table 6: Summary of Children's Perceptions of How the Children Enriched Family Members' Lives and Made Other Contributions .....	74
Table 7: Summary of Parents' Messages to Pass Along.....	80
Table 8: Summary of Children's Messages to Pass Along .....	90
Table 9: Summary of Positive Contributions and Areas of Teaching Considered Common for Any Child/Family.....	94
Table 10: Summary of Positive Contributions and Areas of Teaching Considered More Unique to the Families' Circumstances .....	96

## List of Appendices

Appendix A: Glossary of Terms / Operational Definitions.....	128
Appendix B: Recruitment Advertisement .....	131
Appendix C: Recruitment Letter.....	132
Appendix D: Overview of Appreciative Interview Questions for Parents.....	135
Appendix E: Overview of Appreciative Interview Questions for Children.....	136
Appendix F: Parent Interview Guide .....	137
Appendix G: Child Interview Guide .....	139
Appendix H: Informed Consent Form for Parents.....	141
Appendix I: Informed Consent / Assent Form for Children .....	144
Appendix J: Ethics Approval Certificate.....	147
Appendix K: Guidelines / Instructions for Third Party Reviewers.....	148

## **ACKNOWLEDGEMENTS**

A special thanks to each of the families who participated in my study. I thoroughly enjoyed hearing your stories, and without you this project would not have been possible. Thank you to my thesis supervisor, Dr. Christine Blais, for challenging and supporting me over these past 4 years. Thank you for your persistence in teaching me the K.I.S.S. principle, how to write more concisely, and that “it’s all about the journey”. I would also like to acknowledge the contributions of my committee members, Dr. Nancy Hansen, Dr. Roberta Woodgate, and Dr. Emily Etcheverry. Thank you to my third party reviewers who took the time to offer feedback on the project findings. Lastly, thank you to the provincial government for funding this project.

## **DEDICATION**

This thesis is dedicated to my parents, Hans Lodewyks and Doris Kenny-Lodewyks, for their encouragement and ongoing support throughout my journey. I thank them for their patience with my postponed plans to move out of the house and for their faith that I could “get the job done”. The two of you are my sources of inspiration.

## ABSTRACT

Historically, children with disabilities have been perceived as sources of stress, and disability has been portrayed in Western society as a tragedy to be avoided. This is based on assumptions that the impact of disability is negative. Deficit-based vocabularies of disability are embedded in society along with this tragedy mentality, especially when there is news that parents will give birth to a child with a disability. Yet some parents are offended by the assumption that living with a child with a disability must be distressing and difficult (Scorgie & Sobsey, 2000). Accordingly, a small body of literature has emerged suggesting that positive perceptions among families with children with disabilities are common and the impact of disability can be positive (Hastings & Taunt, 2002; Hastings et al, 2005; Stainton & Besser, 1998).

This study used the Appreciative Inquiry methodology and an integrated conceptual framework combining the Dynamic Ecological Systems Model, Cognitive Adaptation Theory, and components of the Affirmative Model of Disability. Qualitative interviews were conducted with ten children and sixteen parents in order to gain insight into their perceptions of the positive effects that a child with a disability can have on the family. The purpose of this study was to add “narrative depth” to the research area (Stainton & Besser, 1998, p.67), to inquire about the positive experiences of families, to provide additional

understanding of the impacts of disability, and to allow children with disabilities a voice in research.

Findings from this study suggest that children with disabilities can have some of the same positive effects on, and make some of the same contributions to, their families as any other child. They can also have unique positive effects and make unique contributions potentially unparalleled by their non-disabled peers. These findings may have implications for how disability is perceived by medical professionals, other parents raising children with disabilities, and the public in general.



## INTRODUCTION

“People deal too much with the negative, with what is wrong. Why not try and see positive things, to just touch these things and make them bloom?” (Nhat Hanh, n.d.). Unfortunately, when it comes to exploring the experiences of families raising children with disabilities, researchers have traditionally focused on the perceived negative effects of the children on their families. In Western society, children with disabilities are often portrayed as sources of stress, and disability is often perceived as a tragedy to be avoided. This perception may be based on the assumption that the impact of disability is negative and on the failure of the general public to recognize the positive impacts and meaningful contributions that children with disabilities make.

As Stainton and Besser (1998) mention “the disabling effects of negative attitudes and assumptions on the lives of people with disabilities and their families are well documented. Indeed many authors have suggested that these attitudes contribute to the very construction of disability (Oliver, 1990; Bogdan & Biklen, 1993)” (cited in Stainton & Besser, 1998, p.68). Thus, in the hopes of reframing the experience of raising a child with a disability as one that can be rewarding and enriching, this research explored the positive perceptions of families raising children with disabilities. Appreciative interviews were conducted with ten families in order to address the following two research questions: (1) “What are the perceptions of parents regarding the positive effects that their child

with a disability has on the family?”, and (2) “What are the perceptions of children with disabilities regarding the positive effects they have on the family?” By focusing on these positive effects, this study builds on the few studies that attempt to shift common perceptions of the impact of children with disabilities (Behr, 1989; Grant, Ramcharan, McGrath, Nolan, Keady, 1998; Hastings, Allen, McDermott & Still, 2002; Hastings, Beck & Hill, 2005; Hastings & Taunt, 2002; Kearney & Griffin, 2001; Scorgie & Sobsey, 2000; Stainton & Besser, 1998; Summers, Behr & Turnbull, 1988; Turnbull, Brotherson & Summers, 1985; Turnbull, Behr & Tollefson, 1986; Turnbull, Guess & Turnbull, 1988).

## REVIEW OF LITERATURE

This review of literature discusses past and current research that sets the stage for the study. Attention is paid to defining key concepts and explaining the integrated conceptual framework used for the study. This framework is comprised of Bronfenbrenner's (1979) Dynamic Ecological Systems Model, Taylor's (1983) Theory of Cognitive Adaptation, and components of Swain and French's (2000) Affirmative Model of Disability. Each model or theory is described in the review, followed by an explanation of how the framework provides a basis for understanding the importance of positive perceptions of disability. The review concludes by identifying gaps in the literature and addressing how components of the framework are used to fill these gaps and inform the research.

For decades, families with children with disabilities, especially children with intellectual disabilities, have been at the center of a "problem-centered line of family research" (Behr, 1990, p.12) which emphasizes the stress, grieving, and other negative experiences associated with raising a child with a disability (Abbott & Meredith, 1986; Datta, Russell & Gopalakrishna, 2002; Drew, Logan & Hardman, 1984; Glidden, 1993; Helff & Glidden, 1998; McAndrew, 1976; Sobsey, 1990). While there are exceptions negativity – described as "any indication that the family or any of its individual members [have] suffered as a result of the child with disabilities" – has been predominant in research (Helff & Glidden, 1998, p.459). Studies tend to focus on the excessive care-giving demands, emotional

distress, physical and financial burdens, interpersonal difficulties, frustrations with professionals and the system, unpleasant social consequences, and the social stigma associated with a child with disabilities (Gupta & Singhal, 2004; McAndrew, 1976; Nagler & Nagler, 1997). Strained family relations (Blacher & Hanneman, 1993; Tausig, 1985) including higher levels of parental marital stress (Eyman, O'Connor, Tarjan & Justice, 1972) and marital dissolution (Jordan, 1962) have also been attributed to the presence of a child with disabilities. Nevertheless, research reporting higher rates of divorce or separation is limited and inconclusive (Havens, 2005), and additional studies have debated and discounted these findings (Scorgie & Sobsey, 2000). The traditional literature also suggests that an accumulation of pressures and care-giving demands, combined with a perceived or actual burden of care and considerable amounts of family stress and maladjustment, have been strongly correlated with some families' decisions to seek out-of-home placement for a disabled child (Cole, 1986; Fotheringham, Skelton & Hoddinolt, 1971; Tausig, 1985). Historical responses from professionals to institutionalize a child with a disability for the sake of the family have also been correlated with placement decisions (Rousey, Blacher & Hanneman, 1990).

Overall, much public sentiment has reflected the tragedy mentality of having a child with a disability. This mentality supports an assumption that families experience "chronic sorrow" and they are negatively affected by the child (Crnic, Friedrich & Greenberg, 1983; Olshansky, 1962; Summers et al., 1988). Families with children with disabilities have also traditionally been viewed as "objects of

pity,” as “victims,” or as the “unfortunate recipients of untold misery and anguish” (Summers, 1988, p.81). Naseef (2001) suggests that when parents have a child with a disability “all of the positive feelings are deflated” and parents may experience an overwhelming sense of failure (p.17). The literature also reports that it is common for families to experience shock, denial, fear, anxiety, grief, mourning, loss, guilt, shame, hostility, pessimism, anger, blame, withdrawal, inadequacy, malaise, sadness, depression, and failure to adjust (Drew, Logan & Hardman, 1984; Frude, 1992; Helff & Glidden, 2002; Naseef, 2001; Rangaswami, 1995).

Such beliefs have had the effect of generally overlooking the systematic exploration of positive outcomes and possible benefits experienced by the family (Helff & Glidden, 1998; Kazak & Marvin, 1984; Kearney & Griffin, 2001; Reynolds, 1979; Summers, 1988). Research that portrays families as victims and assumes that the effects of disability are pervasive and negative has also had a major influence on today’s assumptions about, and reactions to, disability (Summers, 1988). According to Booth (1978), perceptions of the general public have been medicalized to such an extent that the way the general public thinks about children with disabilities has become somewhat skewed (cited in O’Connor, 1995). The general understanding of disability has been shaped by the medical, or tragic, model of disability as a problem within an individual that has been caused by medical abnormality (Rioux, 1997) and that should be avoided at all costs. This has had major implications for people with disabilities. The focus on negative effects and dysfunctional families has implications not only

for the way professionals respond to children with disabilities (Wolraich & Siperstein, 1983 cited in Behr, 1989) but also for the way society views and responds to children who are disabled at birth (Turnbull, 1984 cited in Behr, 1989). As a result of the stigma attached to disability, experiencing the birth of a disabled child has at times been equated with the cycle of grief associated with death (Naseef, 2001; Bristor, 1984). Reactions to a disabled child have also, at times, supported a “better off dead” or “better dead than disabled” mentality (Gupta & Singhal, 2004; Naseef, 2001).

Among those who espouse the above views is bioethicist Peter Singer. Singer (2000) upholds the view that there is variance in the worth of human life, that certain individuals with disabilities (especially those with severe intellectual disabilities) have no moral status, are limited in their potential for happiness, and cannot lead lives that are worthwhile and rewarding. Singer also insists that people with disabilities suffer too much and that parents of children with disabilities “suffer more [than other families] and derive less pleasure from their children” (cited in McPherson & Sobsey, 2003, p.1247). Singer uses these arguments to advocate for the elimination of certain people with disabilities through the termination of impaired fetuses or by other means. His views are not unique and have implications for people with disabilities (McPherson & Sobsey, 2003), for instance life or death implications.

Much of the older literature that rationalizes practices such as prenatal screening and termination focuses on the disabled child’s characteristics as the source of the family’s stress. Consequently, the child is viewed as the source of a

problem that should be fixed or eliminated. What the literature has neglected to consider, however, is the notion that other people may contribute to the stress experienced by a family (Singer & Powers, 1993). For instance, in a study of chronic sorrow and joy experienced by parents of children with disabilities, Kearney and Griffin (2001) found that many parents reported a “shared consciousness of sorrow” but made an important revelation in doing so. Parents suggested that the sorrow they experienced originated largely from having to deal with recurring messages of negativity and hopelessness from other people such as professionals, the health system, other family members, and friends. This suggests a source of stress and negativity outside the child and that a family’s perceptions about their disabled child may be determined, at least in part, by the surrounding cultural beliefs about disability (Gupta & Singhal, 2004). Therefore, if society holds negative attitudes toward disability and surrounding cultural perceptions are largely negative, negativity can be transmitted to the family – to parents’ views of, and beliefs about, their disabled children, and to their parenting (Woolfson, 2003; Gupta & Singhal, 2004). It could also potentially affect the family’s ability to adapt to their child and circumstances. This notion of societal perceptions affecting the well-being of the child and family is the basis of the Dynamic Ecological Systems Model and serves as the basis for the integrated conceptual framework.

The Dynamic Ecological Systems Model (Bronfenbrenner, 1979) explains how each developing child is embedded in a series of environmental structures that influence development. Structures within and among layers of the system

interact with one another and with the child to influence the child's well-being and course of development. The microsystem – the innermost layer of the child's environment – consists of relations between the child and his/her immediate environment (e.g. family). Within the microsystem, bi-directional relationships and interactions have the most direct impact (Paquette & Ryan, n.d.; Vasta, Miller, Ellis, Younger & Gosselin, 2006). This model acknowledges the impact the child also has on the microsystem, but emphasizes the environment's role and the notion that family dynamics are largely influenced by the wide-ranging social contexts in which families find themselves (Shaffer, 1999).

The child and family at the center of the system interact with the macrosystem – the outermost layer of the system. The macrosystem is the cultural and sub-cultural context “in which the child lives” (Vasta et al., 2006) where beliefs about and attitudes toward the child, or disability for instance, are held. It is the “broad, overarching ideology that dictates (among other things) how children should be treated” (Shaffer, 1999, p.65). According to Berk (2000), attitudes, beliefs, and values held at this level can “have a cascading influence throughout the interactions of all other layers” (cited in Paquette & Ryan, n.d., p.2). Societal attitudes and perceptions can also significantly influence the types of experiences children have in the environments that affect them directly or indirectly (e.g. homes, schools, neighborhoods) (Shaffer, 1999). For instance, negative societal attitudes toward people with disabilities or exaggerated perceptions of the stressful impact of disability can have potentially unhelpful consequences for a child and/or family (e.g. trouble cognitively adapting to one's



experience, an exaggerated sense of fear or anxiety about giving birth to a child with disabilities).

This leads to the temporal dimension of Bronfenbrenner's model, the chronosystem, where "changes in the child or any of the ecological contexts of development can affect the direction that development is likely to take" (Shaffer, 1999, p.65). If or when there are changes or disruptions at one layer of the system, other layers may also be affected (the ripple effect). Changes could potentially alter the family's well-being and the child's course of development. This is important given the potential for positive intervention, a point this review will return to upon synthesizing the three models/theories used for the integrated conceptual framework (see page 19).

It is worthwhile to note that, like the Dynamic Ecological Systems Model, the Social Model of Disability (Oliver, 1983) acknowledges that negative attitudes, discrimination and prejudice are harmful toward, and are sometimes a major source of struggle for, people with impairments. This model provides important background because it distances itself from the individual deficits approach to disability by redefining disability as largely a social (rather than personal or medical) problem and as something that can be ameliorated by removing barriers and addressing prejudicial attitudes (Oliver, 1983). However, the Social Model has not been directly included as part of the conceptual framework because the components of the model most relevant to this research (e.g. the role of the environment and societal perceptions) can also be explained by the Dynamic Ecological Systems Model.

Amidst the focus on the child's negative impact on the family and the suggestion that the outside world may affect the child and family, researchers have increasingly begun to recognize that many families caring for children with disabilities seem to cope or adapt well to the presence of disability (Kearney & Griffin, 2001; Summers et al., 1988). The realization that many families adapt well has sparked curiosity around the characteristics, circumstances, and resources that enable families to adapt. This is where the literature around coping, adapting, and resilience comes in.

According to Pearlin and Schooler (1978), coping refers to "any response to external life-strains that serves to prevent, avoid, or control emotional distress" (p.3). Coping is also understood as "a process of achieving a balance in the family system which facilitates organization and unity and promotes individual growth and development" (McCubbin et al., 1980, p.865). Effective coping with disability can be an extremely enriching process for all family members (Nagler & Nagler, 1997). Adaptation, according to Behr, Murphy and Summers (1992) "represents a new level of functioning that is achieved over time through the adjustment process and that serves to maintain family unity, to facilitate the well-being of individual family members, and to enhance the family system" (p.8).

The terms *coping* and *adapting* are sometimes used interchangeably in the literature, yet some indicate a preference for *adapting* because *coping* seems to have the unfortunate connotation of having to put up with or endure an undesirable situation (Vohs, 1993). While the term *coping* is still used in this review, whenever possible preference is given to *adapting*. Other language used

in this section also needs to be understood in the context of how disability has traditionally been understood. Although the experience of caring for a child with disabilities is not inevitably an adverse, disruptive, threatening, tragic, stressful, or traumatic experience, some of the following literature is still useful.

The literature refers to certain families who display a sense of resilience, which the National Network for Family Resiliency (1995) describes as “the ability of an individual, or in this case a family, to use its strengths in order to positively meet life's challenges” (cited in Cole, Clark & Gable, 2001, p.2). Higgins (1994) specifies that “resilience does not mean bouncing back unscathed, but rather struggling well, effectively working through and learning from adversity, and attempting to integrate the experience into the fabric of [one’s life]” (cited in Walsh, 2003, p.14). The family resilience perspective upholds a belief in the potential for family recovery and growth from hardship and concentrates on the strengths of a family under stress (Walsh, 2003). According to Williams, Lingren, Rowe, Van Zandt, and Stinnett (1985), family strengths are:

...those relationship patterns, interpersonal skills and competencies, and social and psychosocial characteristics which create a sense of positive family identity, promote satisfying and fulfilling interaction among family members, encourage the development of the potential of the family group and individual family members, and contribute to the family’s ability to deal effectively with stress (cited in Dunst, Trivette & Mott, 1994, p.115-116).

Summers et al. (1988) suggest that all children, regardless of whether or not they have a disability, present specific challenges to their families, but families “who successfully meet the challenges of a child with a disability may be equipped with particular coping skills and resources” (p.31). These resources “refer not to what people do, but to what is available to them in developing their

coping repertoires” (Pearlin & Schooler, 1978, p.5). According to Pearlin and Schooler (1978), a coping strategy or response embodies some of the actions people take or the rethinking they do that leads to reduced feelings of stress. Successful coping strategies employed by the family play a central role in a family’s ability to adjust to disability (Summers, 1988), and adjustment and adaptation are central to resilience (McCubbin & McCubbin, 1996).

Common coping skills and resources include social and family resources (e.g. problem-solving and behavior management skills, negotiation and communication skills working with professionals, informal social and community supports, interpersonal networks), and other formal service programs (e.g. respite care, family subsidies) (Summers et al., 1988). Behr and Murphy (1993) suggest that families who also possess good cognitive adaptation skills are more likely to adapt and foster a sense of resilience in raising a child with a disability. McCubbin et al. (1980) refer to these skills as cognitive coping strategies, or “the ways in which individual family members alter their subjective perceptions of stressful situations” (p.865) – or situations that are typically seen as such – in order to better adjust to their circumstances. Not as much attention has been paid to the role of these psychological resources in adapting to disability (Woolfson, 2001). However, the remainder of the review focuses on these resources, with particular attention to the adaptive significance of positive perceptions and meaning-based coping strategies.

Researchers have discovered that positive affect – or feelings and emotions – can serve important adaptive functions (Folkman & Mascowitz, 2000).

In studying the characteristics of well-adjusted families with children with disabilities, it was observed that positive perceptions might be “powerful predictors of successful family coping” (Summers et al., 1988, p.31; also see Dunst et al., 1994; McCubbin, McCubbin, Thompson, Han & Allen, 1997; Trute & Hauch, 1988; Walsh, 2003). Today, there is widespread support for this belief. Current theoretical and empirical research insists that positive perceptions are primary sources of family strength and play a central role in successful adaptation to stressful or traumatic events (Abbott & Meredith, 1986; Behr et al., 1992; Duncan, 2001; Dunst, Trivette & Deal, 1988; Folkman & Mascowitz, 2000; Greer, Grey & McLean, 2006; Hasting et al., 2002; Hastings & Taunt, 2002; McCubbin & McCubbin, 1987; Summers et al., 1988; Taylor, 1983; Turnbull et al., 1986). This belief in the power of positive perceptions is grounded in Taylor’s (1983) Theory of Cognitive Adaptation, originally designed to explain the coping efforts of cancer patients. However, it has since been applied by some researchers to families caring for children with disabilities (Behr, 1989; Behr, 1990; Behr & Murphy, 1993; Behr, Murphy & Summers, 1992).

Taylor’s (1983) Theory of Cognitive Adaptation suggests that people are adaptable, self-protective, and often functional when confronted with obstacles or threatening circumstances. The theory suggests that adaptation to personally threatening events or experiences (which has traditionally been seen to include the birth of a child with a disability) is arbitrated by the resolution of certain cognitive coping strategies that serve to maintain positive perceptions.

According to Taylor (1983), the ability to construct positive meaning from an event or experience that is typically or traditionally considered tragic is critical, as is one's ability to enhance self-esteem and find ways to feel good about one's situation. Examples of adaptive appraisal for families with children with disabilities may include focusing on the positive characteristics of the child (e.g. strengths, accomplishments), construing personal benefits or gains, and cognitively reappraising the experience as advantageous (Summers et al., 1988; Taylor, 1983). A specific strategy for cognitive reframing entails actively concentrating on the "silver lining" or positive contributions of the child (Turnbull, Summers & Brotherson, 1984 cited in Summers, 1988). This is considered "one of the most powerful cognitive coping strategies of all" (Summers et al., 1988, p.37) and may serve to control the meaning and level of stress associated with the experience (Pearlin & Schooler, 1978). It may also serve to strengthen a sense of appreciation for the child (O'Connor, 1993; Pearlin & Schooler, 1978; Poyadue, 1993; Turnbull et al., 1988) which is one of the core characteristics of strong families (Cole et al., 2001; Duncan, 2001). According to Summers et al (1988), more of an appreciation for the ways in which children with disabilities positively contribute to their families has important consequences for societal change as well as attitudes towards disability.

Failure to reframe an experience typically perceived as stressful can manifest itself in negative attitudes and a sense of pessimism, while reframing it can result in positive attitudes and a sense of optimism (Summers, 1988). For this reason, Woolfson (2003) argues the need for cognitive change – for parents

to cognitively reframe their experiences and perceptions about their children and disability in general, in order to better adapt and more effectively parent their children. A starting point for reframing people's perceptions might be to consider an alternative to the medical or tragic model of disability, such as the Affirmative Model of Disability.

Swain and French (2000), among others, take specific issue with tragedy discourse that "is so dominant, so prevalent and so infused throughout media representation, language, cultural beliefs research, policy and professional practice" (p.572). They critique the discourse for being disabling, for characterizing the experience of disability as one of suffering, and for assuming that people with disabilities cannot be happy or enjoy an adequate quality of life. As previously mentioned the tragedy model portrays impairment as the cause of a disabled person's problems and as such perceives disability/impairment as something to be avoided, normalized, or eradicated.

The Affirmative Model of Disability has emerged in recent years within disability culture in response to tragedy discourse (Swain & French, 2000). This model is connected most strongly to the Disability Arts Movement, encompasses positive social identities of disability, and is explicit in the validation of people with disabilities and their experiences by "directly challeng[ing] presumptions of personal tragedy" (Swain & French, 2000, p.578).

Proponents of the Affirmative Model argue that the tragedy model presents major concerns for many disabled people who identify negative perceptions, assumptions, and expectations of the non-disabled, rather than their

impairments, as a major cause of unhappiness (French, 1994; Swain & French, 2000). Moreover, as Wolbring (2002) explains, “the perception of disabled people as suffering entities with a poor quality of life, in need of cure and fixing for the most part does not fit with the perceptions [many] disabled people have of themselves” (p.208). The Affirmative Model asserts a positive identity of a disabled or impaired person by suggesting that “being disabled need not be a tragedy . . . but may, on the contrary, enhance life or provide a life-style of equal satisfaction and worth” (French & Swain, 2004, p.6). The model also suggests that there may be certain benefits associated with disability/impairment. As such, this model provides an “opportunity to convert shame into pride” (Darling, 2003, p.893) and to celebrate disability as “part of a positive social identity” (Darling, 2003, p.884). By creating images of strength and pride, Swain and French (2000) argue, “the value and validity of life as a person with an impairment” might better be asserted (p.578).

French and Swain (2004) acknowledge that in some instances the onset of disability/impairment may be experienced as a tragedy which is “perhaps amplified if it is associated with the trauma of illness or accident” (p.5). They also quote others who admit that “it would be inappropriate to deny that impairment can be experienced in this way [as a tragedy]” (Oliver & Sapey, 1999, p.26). However, Swain and French (2000) and Morris (1991) argue that as more people with disabilities are adopting a non-tragic view of themselves and their lives, disability/impairment should not automatically be construed as negative but should be reinterpreted in more positive terms.



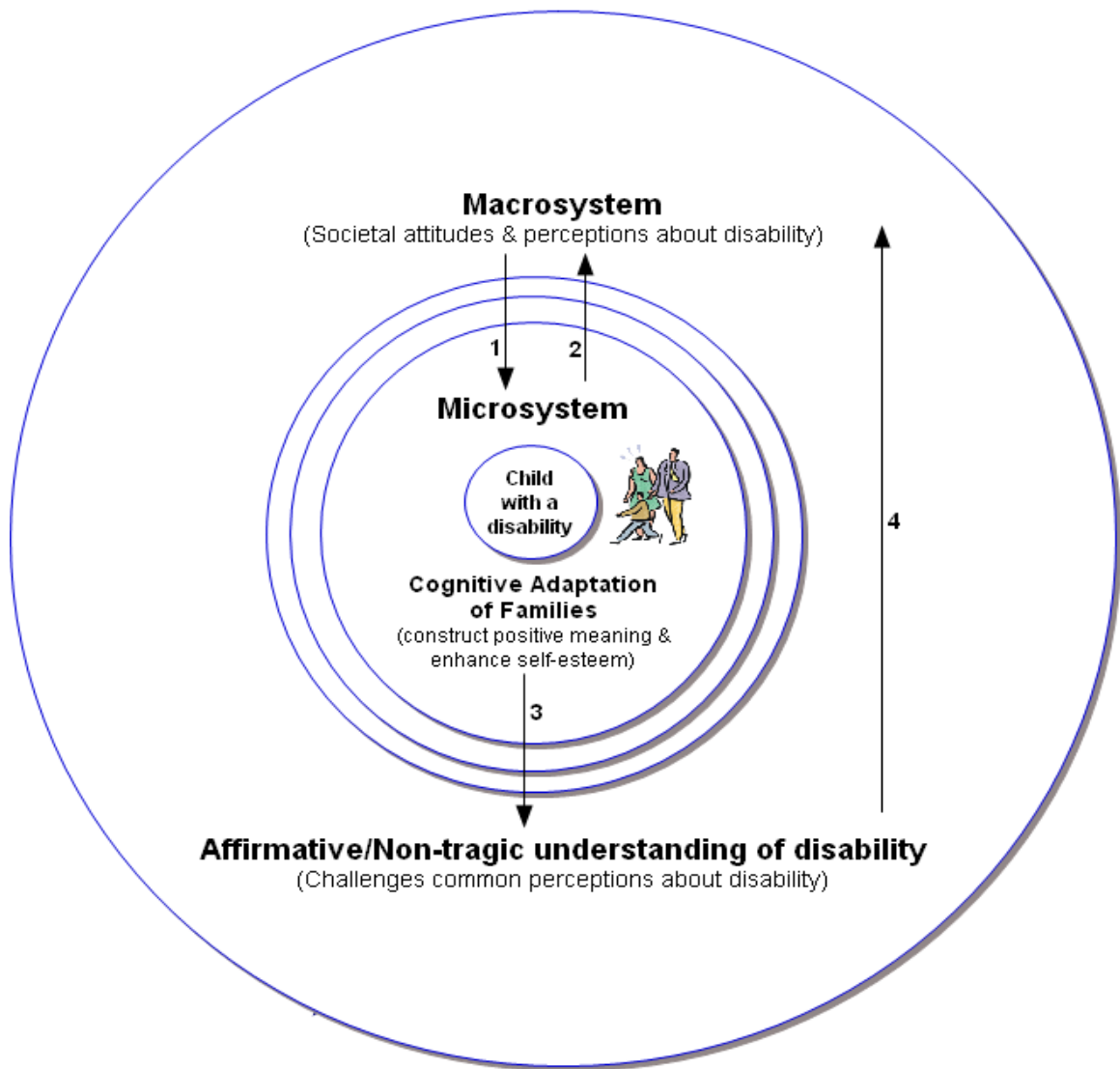
Prior to proceeding, a few notes should be made about the Affirmative Model and its use as part of the integrated conceptual framework. Firstly, the Affirmative Model is an extension of the Social Model of Disability (Oliver, 1983), and both models are incompatible with the view of disability/impairment as a personal tragedy. Yet because the Social Model concerns itself primarily with negative attitudes, discrimination, and prejudice as most harmful to people with disabilities, it has been criticized for not explicitly emphasizing a non-tragic view of disability and for not being explicit in the validation of people with disabilities (Swain & French, 2000). The Affirmative Model, on the other hand, is concerned with directly challenging the notion that the individual or impairment is the problem (Swain & French, 2000, p.578). For this reason – and again because the Dynamic Ecological Systems Model makes a similar argument to the Social Model about the role of society – the Affirmative Model is used as part of the integrated conceptual framework instead of the Social Model.

Secondly, Darling (2003) suggests there is evidence of an increasing number of people with disabilities identifying with an Affirmative Model of Disability. However, she adds, the extent to which the model is being adopted has yet to be determined. Moreover, there is also evidence (Darling, 2003; Watson, 2002) suggesting that a variety of people with disabilities have adopted other ways of viewing themselves as disabled that are not necessarily consistent with the Affirmative Model (e.g. seeing oneself as a normal person who happens to have a disability). Secondly, the Affirmative Model is described as being held by disabled people about disabled people (Swain and French, 2000). However, it

is believed that the model has potential to change more widespread negative attitudes held by non-disabled people by redefining disability/impairment in a more positive light. For this reason, the non-tragic element of the Affirmative Model is the main component being extracted and utilized as part of the integrated conceptual framework. This framework combines the Affirmative Model's non-tragic view with the Dynamic Ecological Systems Model in order to continue to identify society as part of the problem. It also utilizes Taylor's (1983) Theory of Cognitive Adaptation to explain the importance of positive perceptions in the process of cognitive adaptation.

As illustrated in Figure 1 (see page 19), the Dynamic Ecological Systems Model serves as the basis for creating the visual representation for this study's integrated conceptual framework. Figure 1 places the child at the centre of the system, surrounded by his/her immediate family and environment. The figure identifies the process of cognitive adaptation as taking place in the microsystem. The arrow pointing inward to the interior of the circle from the top (see arrow 1) identifies societal attitudes, perceptions, and beliefs about disability and its impact (held at the macrosystem level) as having the potential to affect a family's ability to cognitively adapt to their experience. Cognitive adaptation strategies identified by Taylor (1983) may be used successfully by some families who are able to draw upon positive perceptions of their child and experience. Other families may struggle to find the perceptions needed to adapt. This framework suggests that trouble adapting may be due, at least in part, to negative attitudes

**Figure 1: Integrated Conceptual Framework**



Integrated conceptual framework illustrating the relationship between the Dynamic Ecological Systems Model, the Theory of Cognitive Adaptation, and an Affirmative Model of Disability (Unpublished, Adapted by M. Lodewyks from Bronfenbrenner, 1979)

or other unhelpful perceptions held by people in the child and family's surrounding environment.

Learning from families who have adapted well and view their circumstances in a positive light, and making these perceptions available to the general public, might challenge negative attitudes and beliefs about disability (see arrow 2 pointing upward and outward at the top of the circle). This might also help build a more affirmative, or non-tragic, understanding of disability (see arrow 3 pointing downward and outward at the bottom of the circle). More widespread adoption of a non-tragic model by disabled and non-disabled people might fuel positive change in the ecological context by building on positive attitudes and beliefs about children with disabilities at the macrosystem level (see arrow 4 from the bottom circling around to the top of the circle). These could filter back into the system and affect the well-being of children and families by making positive perceptions more readily available in the adaptation process (again, see arrow 1 pointing inward from the top of the circle).

For the most part, the general public and non-disabled segments of society (and even certain disabled segments) have not yet adopted a non-tragic understanding of disability. This might be because they have not yet had adequate exposure to this alternative way of thinking. Nevertheless, some relatively recent studies have been questioning common assumptions about how disability impacts the family, suggesting that positive perceptions among these families seem to be quite common (Hastings & Taunt, 2002; also see Behr, 1989; Grant et al., 1998; Hastings et al., 2002; Hastings et al., 2005; Kearney & Griffin,

2001; Scorgie & Sobsey, 2000; Stainton & Besser, 1998; Turnbull et al., 1985; Turnbull et al., 1986; Turnbull et al., 1988). There is also evidence that when asked about the positives, many families caring for children with disabilities do report positive perceptions about their child and/or their caring experience alongside certain challenges (Summers et al, 1989; Stainton & Besser, 1998; Hastings et al, 2005). While some families with children with disabilities may report higher levels of stress than other families, there is lack of clear evidence that families with children with disabilities report fewer positive perceptions or positive feelings toward their children (Hastings & Taunt, 2002). Some studies even suggest similar levels of positive perceptions between families with and without children with disabilities (Gupta & Singhal, 2004).

Early reports of positive perceptions and effects or contributions emerged as incidental findings (see Mullins, 1987; Wikler, Wasow & Hatfield, 1983). Other early studies reported positive effects; however, these studies were few and far between (see Dunlap & Hollinsworth, 1977; Grossman, 1972). Focusing primarily on positive perceptions and contributions, some studies have attempted to leave the negatives behind, while some continue to include them. All of these studies, however, contribute to the small body of literature that demonstrates that individuals with disabilities can both enrich and enhance the quality of life for their family members.

Turnbull et al. (1986) conducted one of the first empirical studies on the positive effects of people with disabilities. They interviewed parents of children with disabilities and parents of children without disabilities and asked them to

comment on areas of their lives that they believed were affected by their child, and to describe how they felt their life might be different if the child were not part of it (in Summers et al, 1988). Parents were also asked to discuss what pleased and displeased them about their child, to provide examples of positive and negative experiences, and to discuss possible contributions made by their child. What Turnbull et al (1986) found was that parents of children with disabilities did, in fact, recognize positive contributions made by their children and that these perceived contributions were not all that different from the perceived contributions of children who do not have disabilities. Other studies have come to similar conclusions that many parents view their children with disabilities similarly to the way they view their children without disabilities, as sources of demands but also significant rewards (Sobsey & Scorgie, 2000).

The most common findings about the positive perceptions, contributions, and care-giving experiences raising children with disabilities have been synthesized by Hastings and Taunt (2002). These authors amalgamated findings from Turnbull et al. (1986), Behr et al. (1992), Stainton and Besser (1998), Grant et al. (1998), Scorgie and Sobsey (2000), and Hastings et al. (2002). Findings from Turnbull et al. (1988), Behr (1989), Kearney and Griffin (2001), and Hastings et al. (2005) have also been included in this summary. Overall, family members experienced a sense of pleasure or satisfaction in providing care for the child and a sense of accomplishment in having done one's best for the child. Stories about sharing love with the child were also common. The child was often seen as a source of: (1) increased joy, happiness, blessing, and fulfillment, (2)

greater love, (3) strengthened family ties or marriage (or increased family cohesiveness or closeness), (4) increased spirituality or strengthened religious faith, (5) expanded social and community networks, (6) greater pride and accomplishment, (7) increased personal growth and maturity, or strength or confidence, and (8) greater knowledge about disabilities. Families reported that the child has led to the development of new skills, abilities, or career opportunities, has provided a challenge or opportunity to develop and learn (e.g. tolerance, sensitivity, patience, not to take things for granted, to live life at a slower pace and to make the most of each day, and other life lessons). Others mentioned how their child has given them a new or increased sense of purpose in life, has changed one's perspective on life or clarified what is most important. Lastly, family members reported becoming better people by becoming more compassionate or less selfish as a result of their interaction with their child. Family members also focused on the child's positive attributes (e.g. strengths, talents, special interests) (Turnbull et al, 1988) and spoke of their children with love, admiration, and a sense of optimism (Kearney & Griffin, 2001).

By noting how many interviewed families came to view their disabled family member in terms of the individual's positive characteristics and contributions s/he has made, Turnbull et al. (1985) made an observation that paralleled Taylor's (1983) Theory of Cognitive Adaptation. Turnbull et al. (1985) noted that what became apparent was "the development of a set of beliefs that helped family members adjust to their child's handicap and turn what could be a

very negative situation [based on how the experience is typically perceived] into a positive one” (p.128).

Of the studies whose findings have been synthesized above, two studies stand apart from the rest. Both Stainton and Besser (1998) and Scorgie and Sobsey (2000) make a conscious effort to interview families specifically about positive caring experiences and the positive impacts of the child without also focusing on negative aspects. Stainton and Besser (1998) acknowledged that examining positive impacts is not to suggest that negative impacts do not exist. Yet given the amount of attention paid to the difficulties and challenges associated with caring for a child with intellectual and/or other disabilities, the authors suggested that focusing on positive outcomes was worthwhile. In addition to Stainton and Besser’s (1998) findings previously mentioned, the authors also discovered, while interviewing parents about their positive experiences caring for a child with intellectual disabilities, that several parents viewed their child as a source of increased understanding, increased sense of priorities, and increased community involvement.

Scorgie and Sobsey (2000) found that raising a child with disabilities is about transformational experiences and positive outcomes beyond coping. According to Beck (1999), “transformation involves the disintegration or abandonment of one’s previous life in favor of a new and . . . better way of living” (as cited in Scorgie & Sobsey, 2000, p.198). While most parents did end up discussing the reality of negative changes and impacts in their lives (e.g. stress, health problems, career limitations, difficulty with professionals, reduced



participation in valued social and/or recreational activities), many parents reported personal transformations, relational transformations, and perspectival transformations, all attributed to the presence of a child with a disability. Personal transformations included the acquisition of new roles and vocational changes, as well as positive traits such as compassion, endurance, achievement, control, empowerment, strength, and the ability to be an advocate and to speak out on behalf of their children. Relational transformations included positive changes in attitudes toward people; more openness and support within the family and growth through sibling advocacy were also reported. While some parents reported loss of certain friendships, they also reported expansion of supportive friendship networks with other parents of children with disabilities, health professionals, and personnel from disability agencies.

Unique to Scorgie and Sobsey's (2000) study, however, was their finding that some of the parents associated positive life changes specifically with raising a child with a disability and suggested that these life changes may not occur with parenting a non-disabled child. Studies such as these have made an excellent contribution toward shifting negative attitudes and assumptions about disability and its impact on families. They have also laid important groundwork to further research in a more positive direction.

In an effort to understand the underlying dimensions of positive perceptions, Behr et al. (1992) also developed a tool known as the Positive Contributions Scale (PCS). This was the single scale designed precisely to quantitatively measure parental perceptions of the benefits of having a child with

special needs (Hastings et al., 2005). Several parents in a study by Hastings et al. (2005) reported that filling out the PCS was “the first time that anyone ha[d] asked them about the positive aspects of raising a child with a disability and that they had not fully realized how much their child contributed to their life and their family” (Hastings et al., 2005, p.163). Parents in other studies have also described it an enlightening experience to discuss family strengths and positive aspects of their experiences, as opposed to focusing solely on stress (Bauman, 2004). Findings of this nature suggest that families might benefit from assessments of this sort and that perhaps more researchers should consider ways to build on a tool such as the Positive Contributions Scale.

Despite progress in questioning common assumptions about the impact of disability on the family, there remain at least three gaps in the literature.

- 1) Perceptions of positive contributions made by children with disabilities continues to receive insufficient attention in the research literature, and studies focusing on the positive impact of children with disabilities on family members remain few in number (Hastings & Taunt, 2002; Hastings et al, 2005; Stainton & Besser, 1998).
- 2) With only a few exceptions, studies are not designed specifically to address positive perceptions (Hastings et al, 2002). Often, questions posed to families still tend to be problem-focused, and more effort needs to be made to represent disability in manner that is non-problematic (Shakespeare & Watson, 1998).
- 3) The perceptions of children with disabilities are often not included in research (Shakespeare & Watson, 1998), and their perceived

contributions to family life are missing from the literature. No other research project focusing on positive impacts, other than the present study, has invited children to participate.

To date we have seen that the Affirmative Model of Disability reframes the experience of disability/impairment as non-tragic and therefore could be used as the basis for posing research questions in affirmative ways. The Theory of Cognitive Adaptation highlights the importance of focusing on the positive characteristics of the child, construing personal benefits or gains, and concentrating on the contributions of the child. This could be used to guide families in focusing on the positive outcomes associated with their experience. The Dynamic Ecological Systems Model identifies the potential influence each component of the system can have on its other components, suggesting that changes at one layer can affect other layers. This is important given the potential for positive intervention. Therefore,

- since perceptions of positive contributions made by children with disabilities receives insufficient attention in the research literature, and studies focusing on the positive impact of children with disabilities on family members remain few in number (Hastings & Taunt, 2002; Hastings et al, 2005; Stainton & Besser, 1998), this study adds “narrative depth” (Stainton & Besser, 1998, p.67) to the research area and provides a more positive representation of the experiences of families.
- since most studies are not designed specifically to address positive perceptions (Hastings et al, 2002), this study uses Appreciative

Inquiry methodology to explore disability from a positive standpoint. This methodology has never before been used in the context of interviewing families with children with disabilities.

- since the perceptions of children with disabilities are often not included in research, and their perceived contributions to family life are missing from the literature, this study invites children with disabilities to have a voice in research.

### **Research Questions**

In light of prior research and the gaps in the literature, interviews conducted with participants from this study were designed to answer the following research questions:

- 1) “What are the perceptions of parents regarding the positive effects that their child with a disability has on the family?”, and
- 2) “What are the perceptions of children with disabilities regarding the positive effects they have on the family?”

## METHODOLOGY

### Participant Selection

Purposeful sampling (Patton, 1990), the sampling technique used for this study, is a strategy where specific individuals are intentionally selected in order to provide the researcher with information that cannot be obtained from other sources (Maxwell, 2005). This technique allowed for the recruitment of participants to address the research questions. Thus, families who volunteered to participate already recognized and appreciated the positive effects the child has had on the family.

Prior to recruitment, advertisements and letters (see Appendix B and C) were distributed to a variety of community organizations that work directly with, or provide direct support to, families with children with disabilities. The Children's Coalition of Manitoba, a coalition with which the researcher is involved, was chosen as the recruitment source based on its membership of a variety of disability organizations that associate with families who fit the recruitment criteria (e.g. Community Living Manitoba, Society for Manitobans with Disabilities, Manitoba Down Syndrome Society, Community Respite Service, and The Family Centre of Winnipeg). Recruiting participants via representatives of the coalition allowed for sampling from a wide range of disability groups. Representatives advised interested families to contact the researcher to volunteer for the study or recommended potential participants to the researcher, who then contacted

families by telephone or e-mail. The “snowballing” technique (Babbie, 2001) also occurred as some families were recommended by other participants.

The study was looking to recruit twenty participants; ten parents with at least one child with a disability and ten children with a physical and/or intellectual disability between the ages of 12-17 years. Each set of parent and child participants was required to be from the same family. The children eligible for inclusion had to reside within the family home and have the ability to speak and understand English well enough to answer the interview questions. The ability of a child to participate was assessed based on the recommendations of parents. Each family who volunteered received a letter of recruitment with an overview of the interview questions (see Appendix D and E). Parents were asked to review the questions with their child prior to agreeing to participate.

While thirteen families volunteered, the first ten who met the inclusion criteria were selected (see Table 1 for a summary of the characteristics of study participants by pseudonyms). Twenty-six participants ended up taking part in this study: sixteen parents (six sets and four singles) and ten children, each with a disability, dual diagnoses, or multiple disabilities. Eight of the families were two-parent families (although two of these families chose to only have one parent participate) and two were single parent families. All but one set of parents were the birth parents. Five families had three or more children, four families had two children, and one family had one child. Three families had at least one other child who also had a disability but did not take part in the research.

Table 1: Characteristics of Study Participants by Pseudonyms\*

Family	Parent's Name(s)*	Child's Name*	Gender	Disability	Diagnosis	Age	Family Type	Number Children
1	Eve & Mick	Rayla	Female	Intellectual	Not specified	17	Two-parent	2
2	Louise & Ken	Kevin	Male	Intellectual	Autism	13	Two-parent	2
3	Rachel & Ted	Sandy	Female	Intellectual	Down syndrome	15	Two-parent	2
4	Alana	Cam	Male	Intellectual & Physical	Cerebral Palsy	15	Two-parent	2
5	Rene & John	Neal	Male	Intellectual & Physical	Cerebral Palsy	17	Two-parent	1
6	Judith	Karlee	Female	Physical	Cerebral Palsy	17	Two-parent	3
7	Lilly & Garry	Matthius	Male	Intellectual	Fragile X syndrome	18	Two-parent	3
8	Liza & Phil	Charlie	Male	Intellectual	Asperger syndrome, Tourettes, ADHD, OCD	17	Two-parent	3
9	Heather	Bob	Male	Intellectual & Physical	Not specified, Visual disability	14	Single-parent	4
10	Jean	Claire	Female	Intellectual & Physical	Muscular Dystrophy, Hashimoto's disease	15	Single-parent	3

\* All participants' actual names have been replaced with pseudonyms.

The researcher had hoped for representation from children with a variety of intellectual and/or physical disabilities, from both sexes, and from children of different ages. The ten children who volunteered ranged in age from 13 to 18 years, with the average age being 16 years. While the recruitment criteria specified that child participants be between the ages of 12-17 years, an exception was made for one child who had just recently celebrated his eighteenth birthday but was eager to participate. Six of the children were male and four were female. None of the children's disabilities were acquired disabilities. As specified by parents, five children had intellectual disability only (e.g. Autism, Down syndrome, Fragile X syndrome, a combination of Asperger syndrome, Tourette's, Attention Deficit Hyperactivity Disorder, and Obsessive-Compulsive Disorder), one had physical disability only (e.g. Cerebral Palsy), and the remaining four had both intellectual and physical disabilities (e.g. Cerebral Palsy, Muscular Dystrophy and Hashimoto's disease, unspecified and visual disability).

### **Appreciative Inquiry**

This research was conducted from a positive viewpoint using the philosophy and principles of a research approach known as Appreciative Inquiry (AI). Appreciative Inquiry has been described as a "philosophy of knowing" and as a "methodology for managing change" (Cooperrider & Whitney, 1999a). This method of inquiry was originally designed for organizations, as a business-management tool to be used in the workplace (Cooperrider & Srivastva, 1987). Yet Appreciative Inquiry can have applications both within and outside of



business-management. Appreciative Inquiry was chosen for this study due to the study's focus on positive perceptions regarding families' experiences and the strengths as well as positive impacts of the child. It was also chosen because it has tremendous potential to draw attention to the positive, rather than negative, aspects of disability.

Traditional approaches to research are often based on discourses of human deficit that focus on problems, obstacles, and shortcomings. However, Cooperrider and Whitney (1999a) argue that deficit-based approaches to change restrict human potential, stimulate endless negative vocabulary expansion, and rarely result in a new vision or new knowledge being produced. Therefore, rather than negation, criticism, and spiraling diagnosis, Appreciative Inquiry begins with a conscious choice to concentrate on the positives as the focus of inquiry (Cooperrider & Whitney, 1999a; Cooperrider & Whitney, 1999b; Watkins & Mohr, 2001). By opening the positive core (e.g. strengths, living value, high point experiences) to systematic inquiry, proponents of Appreciative Inquiry argue that they are not dismissing accounts of problems or stress or suggesting that these do not exist (Cooperrider & Whitney, 1999a; Cooperrider & Whitney, 1999b; Watkins & Mohr, 2001; Whitney & Trosten-Bloom, 2003). Rather, they simply do not use these as their basis for inquiry or action and believe that focusing on strengths is more effective and has more potential for positive change (Whitney & Trosten-Bloom, 2003).

Appreciative Inquiry involves "looking at the world with an appreciative eye" (Watkins & Mohr, 2001, p.58) while recognizing that human systems are

best able to thrive under these circumstances (Cooperrider & Whitney, 1999a). It begins with positive presumptions and “assumes that every living system has many untapped and rich and inspiring accounts of the positive” (Cooperrider & Whitney, 1999, p.3). By discovering strengths and focusing on what is valued and positive, Appreciative Inquiry allows us to celebrate successes and exceptional moments. More specifically, Cooperrider (2001) explains:

[Appreciative Inquiry] deliberately seeks to discover people’s exceptionality – their unique gifts, strengths, and qualities. It actively searches and recognizes people for their specialties – their essential contributions and achievements. And it is based on principles of equality of voice – everyone is asked to speak about their vision of the true, the good, and the possible. Appreciative Inquiry builds momentum and success because it believes in people. It really is an invitation to a positive revolution. Its goal is to discover in all human beings the exceptional and the essential. (p.12)

There is no set formula for using Appreciative Inquiry, but there are guiding principles and models to follow. According to Watkins and Mohr (2001) and Whitney and Trosten-Bloom (2003), good appreciative interview questions are stated in positive terms, convey unconditional positive regard, are uplifting and based on the assumption of the glass as half full, are personal and affective, and are invitations to recall high point experiences. They also provide an opportunity to learn and extrapolate deeper meaning from experiences. Often, questions asked in appreciative interviews focus on positive feelings, best experiences, what people value, and wishes for the future. The goal of these types of interviews is to stimulate excitement and delight among participants by initiating positive dialogue and creating opportunities to share “good news” stories (Cooperrider & Whitney, 1999b; Watkins & Mohr, 2001). Interview

questions for this study were designed using Appreciative Inquiry templates. However, rather than tailoring the questions to an organizational setting, the questions were adapted to the context of the family.

### **Data Collection: Appreciative Interviews with Parents and Children**

In line with the Appreciate Inquiry approach, individual, open-ended and semi-structured appreciative interviews were the primary method of data collection for this study. For clarity and consistency, separate interview guides were designed for the parent and child participants (see Appendix F and G). Questions needed to be posed in a slightly different manner depending on the participant group because the vocabulary used in the child interviews needed to be adapted to accommodate the children's needs. Using Appreciative Inquiry (Cooperrider & Whitney, 1999a; Cooperrider & Whitney, 1999b), affirmative interview questions were posed to participants, and participants were engaged to think more deeply about their positive perceptions. The study objective was not to intervene and facilitate cognitive adaptation among families who took part in the study. Nevertheless, it is possible that focusing on aspects central to Taylor's (1983) Theory of Cognitive Adaptation may have helped strengthen a sense of appreciation for the child (O'Connor, 1993; Pearlin & Schooler, 1978; Poyadue, 1993; Turnbull et al., 1988) among families who participated. The hope was to plant the seeds of change with an affirmative topic choice (Cooperrider & Whitney, 1999b), which may promote societal awareness and positive dialogue.

The researcher conducted the interviews in person at each of the participants' homes. Informed consent was obtained from all participants (see Appendix H and I). (Also see Appendix J for the Ethics Approval Certificate.) Each of the children was given the option as to whether they would prefer having their parent(s) present during their interview or participate on their own. Half of the children chose to have their parent(s) present, while the other half chose to be interviewed on their own.

Each of the parent and child interviews lasted between 20-60 minutes and was audio tape recorded and transcribed verbatim. Brief clarification notes were made during some of the interviews to provide valuable information (e.g. non-verbal cues or sources of information) that was not picked up by the tape recorder. These notes were incorporated to provide further context, though the non-verbal components of interviews were not formally measured.

While the interviews served as the primary source of analysis, a research journal was also maintained, as suggested by Miles and Huberman (1994). This journal documented the researcher's reflection and observations immediately following each interview, as well as background information on participants and points for further consideration. Analytic memos (Maxwell, 2005), for instance ideas about potential coding categories, were also documented in order to stimulate new insights on the data. These informal sources of data were taken into consideration during analysis and were handled in the same confidential manner as specified for the interview transcripts (see Appendix H and I).

Tips from the parents were obtained on how to engage the children and rephrase interview questions in ways that accommodated each child's needs and facilitated their understanding. These strategies may have encouraged some of the children to open up and share their stories. At the same time, however, the researcher found it challenging to draw relevant information from some of the children. Attempts were made to conduct the interviews using plain language, yet some questions remained too complex for some children. The researcher also tried to accommodate the schedule of participants, yet some children indicated they had something else that they wished to do at the time of the interview. The children participated, but may have been distracted (e.g. by wanting to watch television or use the computer). The researcher had also offered to meet with families prior to the interviews in hopes of developing rapport with participants. However, all families chose to meet and conduct the interviews in one session given their busy schedules and the convenience of arranging one meeting. This may have resulted in "underdeveloped rapport" (Kelly, 2007, p.73) with some children, which may have influenced the children's comfort level in answering the interview questions.

### **Data Analysis**

A thematic analysis of the interview data was conducted. Previous research, that is interview guides and results from previous studies exploring positive impacts, was used to develop key areas of focus (e.g. marital impact, effects on siblings, specific contributions). Maxwell (2005) refers to these broad

areas of focus incorporated into the interview guides as organizational coding categories and describes their primary function as “bins for sorting the data for further analysis” (p.97).

Once the interviews were transcribed, each transcript was read and reviewed line by line until key words (e.g. good, gift, laugh, happy, helpful, pride, learn, patience, met people, made stronger) emerged from the raw data. These were documented in an Excel spreadsheet, and similar words and meanings were then grouped into substantive coding categories and subcategories (Maxwell, 2005) based on meaningful patterns and themes (Strauss & Corbin, 1990). These substantive categories accounted for unexpected themes that emerged from participant narratives (e.g. perspective changes) and the researcher’s interpretation of the interview context (Maxwell, 2005). Thus, the analysis was a combination of sorting data based on organizational as well as substantive categories.

All coding categories were operationally defined by their situated meanings. Codes for the categories were created and organized into a codebook. As Miles and Huberman (1994) explain, “codes are tags or labels for assigning units of meaning to the descriptive or inferential information compiled during a study” (p.56). These codes were assigned to chunks of data (e.g. key words, phrases, and paragraphs) and assisted in the organization and retrieval of the chunks (Miles & Huberman, 1994, p.57). Microsoft Word was used for coding purposes and to search and retrieve information. Multiple codes were often applied to one segment of text. This was especially the case during the initial

stages of analysis when a word or phrase fit into more than one category based on the category's operational definition. This allowed the researcher to minimize subjective interpretation, to leave intact all segments of text that could potentially be useful to a category, and to compare and contrast the contents of each category before compiling the results. Individual documents were then created for each category containing only the coded segments of text. Reviewing all of the coded segments under their respective categories led to the creation of the themes listed below. The data was analyzed separately for the two groups of participants in case any major differences emerged. The following seven themes were generated from the children's transcripts:

- (1) Helping the family
- (2) Teaching the family
- (3) Changing family members' perspectives and/or awareness (especially regarding disability)
- (4) Specific positive effects on siblings
- (5) Positive feelings evoked in family members
- (6) Additional contributions
- (7) Reflections on the child's overall impact

Similarly, the following twelve themes were generated from parent transcripts:

- (1) Helping the family and enabling parents to help others
- (2) Teaching the family, learning from the child and/or enabling parents to take action to teach/educate other people
- (3) Changing family members' perspectives and/or awareness and/or enabling parents to become more active and/or involved in disability-related causes
- (4) Changing the parents' and/or siblings' inner selves
- (5) Positive effects on the parents' marriage or marital status
- (6) Positive effects on the parents' career or job
- (7) Specific positive effects on the child's siblings
- (8) Positive feelings evoked in family members
- (9) Additional 'contributions'
- (10) Reflections on the child's overall impact
- (11) Positive impacts on others (beyond the immediate family)
- (12) Other/Parting words from parents

As Miles and Huberman (1994) explain, codes and coding categories often need to be revised as new, unanticipated categories emerge and the researcher discovers that certain categories no longer best represent the data. Thus, while the above thematic categories served as the initial basis for organizing the data, it became apparent that the framework needed to be simplified and this extensive list needed to be re-grouped in order to make it more meaningful and fruitful. After having reviewed the initial themes, operational definitions, and overlapping codes, and re-mapping the data, the findings were re-grouped into three broader themes that best reflected the perceptions of the parents and children. These themes were identified as: (1) What the Children Taught the Family or Enabled Family Members to Learn, (2) How the Children Enriched Family Members' Lives and Made Other Contributions, and (3) Messages to Pass Along. Operational definitions were then developed for these themes and sub-themes (see Appendix A).

### **Trustworthiness**

The reliability of this study was strengthened by providing opportunities for participants and independent third party reviewers to corroborate and legitimate, or "to make more certain and to confirm", the data (Miller & Crabtree, 1999, p.136). An opportunity for respondent validation was provided to participants once the interviews had been transcribed. This is where feedback regarding the data is systematically solicited from participants (Maxwell, 2005, p.111). At this point, each participant was asked to verify the accuracy of their transcript and to



make changes to the transcript if they wished to do so. Four families chose not to review their transcripts because they were too busy. Transcripts were sent via e-mail, the preferred method requested by families, to the parents of the remaining six families. While the researcher requested that parents allow the child to review his/her own transcript, or that the parent review the child's transcript with the child, it was often a parent who responded on behalf of the child (or who relayed the child's feedback). Note, however, that in one instance a child provided her own e-mail response. With minor changes or no changes, all six families granted the researcher permission to proceed.

Once the research results had been collated, the researcher also sought external validation by soliciting feedback from three independent third party reviewers. This was done to minimize personal bias and to ensure, as much as possible, the trustworthiness of the data. The reviewers chosen to evaluate the interview data were from diverse backgrounds. One reviewer had a Bachelor of Science degree, another had a background in nursing, and the third had a background in cosmetology. Although this was not a methodological requirement, the reviewers' diverse backgrounds "provided a mix of perspectives on how the participants' responses would be viewed and subsequently categorized" (Klassen, 2007, p.45). The reviewers were introduced to the research study and provided with a list of the major themes and sub-themes that emerged from the data. They were then given a set of guidelines and instructions to follow and were asked to review a series of examples drawn from the interview transcripts (see Appendix K for an example). The reviewers were given the theme for each

set of examples and a corresponding table to complete. Using the list of operational definitions as a guide (see Appendix A), the reviewers were asked to individually categorize the examples according to sub-themes. They were also asked to specify whether examples should be considered common for any child/family or more unique to the family's circumstances. The independent third party reviewers repeated this exercise on their own time for all six tables (representing the three themes that emerged from the data duplicated by the two sets of participants). The reviewers were also asked to identify where the tables, themes, sub-themes, examples, and/or operational definitions lacked clarity or overlapped with others.

Once all three reviewers had completed the above task, the researcher met with them in person to discuss their responses and attempt to reach a consensus. For each table, discussion continued until the researcher and reviewers had reached a consensus. In some instances, a consensus was not reached, and a system for explaining disagreements was worked out. Below each table summary of results, the symbol (\*) is used to indicate that the example was placed where majority agreement occurred (3/4 agreed). In addition, the symbol (\*\*) is used to indicate that the example(s) could potentially fit under a different sub-theme as the vote was split for where the example(s) belonged (2/4 agreed). Details surrounding disagreements are discussed in the results section under notes at the bottom of the page.

## RESULTS

This section highlights results, classified into three major themes, from the parent and child interviews. The first two themes cover (1) What the Children Taught the Family or Enabled Family Members to Learn, and (2) How the Children Enriched Family Members' Lives and Made Other Contributions. Examples that were considered common for any child/family or more unique to these families' circumstances are explored in both themes 1 and 2. What should be noted is that decisions regarding whether a contribution or area of teaching was considered common or more unique were based partly on family members identifying these as such. Decisions were also based partly on the researcher and reviewers reaching consensus that findings were (a) common for any child/family, meaning they could be generalized to families with non-disabled children, or (b) more unique to these families' circumstances, meaning it would be less likely that a non-disabled child would have the same effect or make the same contribution.

The remaining results are presented under theme (3) – Messages to Pass Along. Results presented under this theme are not organized according to commonalities and areas of uniqueness because they do not directly serve to answer the research question but are instead reflections specifically on the families' unique circumstances.

Within each of the three themes, perceptions of the parents are presented first, followed by perceptions of the children. Results are clustered into sub-

themes, and narrative examples are provided from the interview data. See Table 2 for a list of the themes and sub-themes presented in the results.

### **Theme 1: What the Children Taught the Family or Enabled Family Members to Learn (Parents' Perceptions)**

Each of the parents used the words *learn* or *teach* in relation to their child and experience raising their child, or they provided examples of what their child has taught their family. A general example included one parent clearly identifying her child as “a gift for all of us to learn from” and “a gift that teaches you something” (Louise). Another parent reflected, “It’s amazing how much a challenged individual can teach us if we just open our eyes and our ears and observe” (Heather). Rachel also made the following statement regarding her learning experience:

It’s been a huge learning curve for us and I think a huge benefit. I think we’re better people because of what we’ve learnt. It doesn’t make it easy. I think it’s made us better people. I think we’ve learnt so much through this experience.

Three sub-themes revealing what family members have learned or been taught emerged from the interview data. The first sub-theme (New Knowledge) highlights general knowledge parents have learned, including how the child has educated the family about disability and people with disabilities, as well as how parents have been given an opportunity to educate others. Examples also include how the children provided parents the skills to pursue careers in the disability field, and how parents have learned advocacy or activism skills and taught family members new attitudes toward people with disabilities, other

Table 2: List of Themes and Sub-themes Presented in Results

Theme 1: What the Children Taught the Family or Enabled Family Members to Learn (Parents' Perceptions)	p44
Sub-theme 1: New Knowledge Sub-theme 2: New Attitudes Sub-theme 3: New or Enhanced Positive Character Attributes	
Theme 1: What the Children Taught the Family or Enabled Family Members to Learn (Children's Perceptions)	p58
Sub-theme 1: New Knowledge Sub-theme 2: New Attitudes	
Theme 2: How the Children Enriched Family Members' Lives and Made Other Contributions (Parents' Perceptions)	p63
Sub-theme 1: Helpfulness Sub-theme 2: The Children's Positive Character Traits Sub-theme 3: Positive Emotions the Children Evoked in Family Members Sub-theme 4: Other Contributions	
Theme 2: How the Children Enriched Family Members' Lives and Made Other Contributions (Children's Perceptions)	p73
Sub-theme 1: Helpfulness Sub-theme 2: The Children's Positive Character Traits Sub-theme 3: Positive Emotions Children Evoked in Family Members Sub-theme 4: Other Contributions	
Theme 3: Messages to Pass Along (Parents' Perceptions)	p79
Message 1: "It's not all rosy either" Message 2: Reflections of the Bigger Picture, Reframing the Experience, and Understanding my Child and Family Message 3: Would I Change my Family's Circumstances? Message 4: The Importance of Choosing a Positive Attitude and Research Approach	
Theme 3: Messages to Pass Along (Children's Perceptions)	p89
Message 1: What to Understand About Me Message 2: What is Cool, Fun, or Neat about Using a Wheelchair Message 3: What to Understand About my Family	

families, and life in general. It also includes how the children have changed or exceeded family members' expectations. The third sub-theme (New or Enhanced Character Attributes) includes personal character traits gained or enhanced in family members as a result of the experience. These three areas of teaching and learning are explored in detail below, accompanied by examples from the parents' narratives. These results have also been summarized in Table 3.

#### *Sub-theme 1: New Knowledge*

Some family members gained new knowledge because their child educated them on a topic of interest and provided practical knowledge to the family. An example included Ken's family members learning from his son, Kevin, who shared his extensive knowledge about dinosaurs during a family trip to a museum. Similarly, with more knowledge about computers than any other member in the family, Lilly's son Matthias has been able to teach his siblings about different computer programs and share his computer skills.<sup>1</sup> While these examples could be considered common for any child, Liza provided an example that was more uniquely tied to her family's circumstances.<sup>2</sup> She explained that her son Charlie's sister gained knowledge from opportunities she had to attend her brother's occupational and speech therapy appointments, which has been

---

#### **Notes:**

<sup>1</sup> Certain children also enabled parents to realize that the parents could do something they did not initially think they could do. This needs to be noted here given the discrepancy between where the reviewers believed the example belonged. However, it will be covered in more detail under sub-theme 2.

<sup>2</sup> Wherever there is reference made to something being tied more uniquely to the family's circumstances, or more unique circumstances, this is to be understood as the existence of the child's disability.

Table 3: Summary of Parents' Perceptions of What the Children Taught the Family or Enabled Family Members to Learn

Theme 1	Sub-theme	Common for Any Child/Family	More Unique to these Families' Circumstances
<p>What the Children Taught the Family or Enabled Family Members to Learn</p>	<p>(1) New Knowledge</p>	<p>-Child educated family on topic of interest &amp; shared practical knowledge (e.g. dinosaurs, computers)</p>	<p>-Sibling gained knowledge from attending speech and occupational therapy appointments</p> <p>-Family gained knowledge/ understanding about disability &amp; people with disabilities</p> <p>-Child provided knowledge for parents to educate others about disability</p> <p>-Child provided knowledge and skills for parents to pursue career in disability field</p> <p>-Parents learned advocacy and activism skills and how to help others (e.g. fundraising, support groups) *</p>
	<p>(2) New Attitudes</p>	<p>-Child changed or exceeded expectations **</p> <p>-Child taught parents they could do something they did not think they could do *</p> <p>-Parents gained new attitudes toward life (e.g. what is important) and shifted priorities</p>	<p>-Child taught new attitudes toward people with disabilities and towards other families</p>

	(3) New or Enhanced Positive Character Attributes	<p>-Child taught family to be more patient, loving, warm, a better person (general), opened parent's heart, made family more caring, creative, balanced, gentle, calm, outgoing, in touch with their emotions, less selfish *</p> <p>-Child taught sibling to be more responsible &amp; independent</p>	<p>-Child taught family to be more tolerant, accepting, respectful of families with children with disabilities, compassionate regarding people with challenges, in tune with child's development, a better person at work (because of understanding about Asperger syndrome)</p>
--	---	---	--

\* Example was placed where majority agreement occurred (3/4 agreed).

\*\* Example could potentially fit under different sub-theme as vote was split for where example belonged (2/4 agreed). Details will be discussed in notes throughout the text.



beneficial for her development.

The remainder of the examples of new knowledge and skills gained were more uniquely connected to the families' circumstances. For instance, all of the parents perceived their child as responsible for enabling their family to become educated, and gain an understanding, about disability and people with disabilities. In fact, Rachel considered one of the greatest contributions her daughter Sandy has made to her life to be the opportunities she has given her family to learn about Down syndrome. Rachel explained that her family did not know anything about Down syndrome prior to Sandy's birth and felt the education and understanding they received through reading books, attending conferences, meeting people, and being exposed to life experiences has been "phenomenal". When asked to reflect on an area where her daughter has had the biggest positive impact, Rachel elaborated:

...our whole perspective on Down syndrome – not even Down syndrome – on disability in general! That, um, you know having Sandy has thrown us into the world of disability that we would never have been a part of. And most people aren't. And you never give the time of day to think about it, the whole world of disability, but – and I think we might have been one of those kind of people that just wouldn't have thought about it – not in a negative way at all, but just wouldn't have thought about it. We just didn't – wouldn't have the awareness. And we're so aware now. You know, and now we're aware of those who aren't aware!

Learning about disability has also allowed one family to understand the origins and manifestation of their son's genetic disability and taught them not to generalize about people with disabilities. For Liza's family, the learning served as a "gentle lead" into the more severe disabilities witnessed in Charlie's brother, and her experience has given her family "an understanding of what the baseline

could be and how to build in supports”. On a slightly different note, Jean was grateful for her practical experiences which have enabled her to better understand other families.

In addition to becoming educated about disability, Rachel and Lilly have also been able to take the knowledge they have gained from their experience and educate other people about disability. Rachel has taken the many “educational moments” and opportunities her daughter has provided her to address stereotypes and prejudices and to educate others about Down syndrome and people with disabilities. Rachel noted that she never would have taken on the “educational stuff” without the experience she has had raising Sandy, yet realized that she needs to provide people with information in order to change the way they think. Similarly, learning about their son’s disability has enabled Lilly and her husband Garry to teach Matthius’ siblings that “not everyone is the same,” “that you have to value people for their strengths,” and “that they have strengths that maybe you don’t have.” Lilly also recalled the education provided to medical professionals who were unfamiliar with her son’s diagnosis of Fragile X syndrome at the time of his birth:

At the hospital, I was asking doctors and neo-natologists and pediatricians ‘what is this?’ and they didn’t know. So they had to kind of find out and then they would come and tell me. . . I can just remember being in the hospital and having to explain it over and over and over and over to the doctors and nurses, and so. . . I think it really made it – people aware of it, for sure. . . Nobody had ever heard of it. So, it was like we were teaching. We were trying to understand it, and we were having to teach others about it.

In addition to receiving and passing along knowledge about disability, the children determined career paths for four mothers by providing them with the

skills to pursue careers in the disability field. Three of the four mothers initially stayed home with their children but eventually became a Teacher's Assistant, Instructional Assistant, or Special Needs Assistant, respectively, in the school system. Rachel described how her experience landed her a job and how, thanks to her daughter, she has finally figured out what she wants to do with her life (use the knowledge she has gained to help other children). She explained:

I had no idea what I wanted to be when I grew up, couldn't figure it out. And we started analyzing, 'well, where have I spent all these years but in school' – and loved it. And I do so much work with her educationally-wise at home and have all along. You know, right from when the early intervention workers came to the home to show you stuff . . . and then it's up to you to carry on a daily basis. I just loved it. I just reveled in it! And, you know, looking back I think I probably would have enjoyed being a teacher, but nobody directed me that way. And now this is doing what I love to do.

For Liza, however, the effect of her son on her career involved a “big switch” from being a research scientist to being an advocate and educational consultant with a local disability community organization. Liza's husband Phil described the positive outcomes of Liza's career switch:

Way back, Liza had a definite career path outlined and that really changed when we found out that we had kids with disabilities. And over time, I think Liza found a different outlet for her need for a kind of a career. So it's opened up a different avenue that would otherwise have not been there. I think, I mean from my perspective, I think I've seen you [addressing Liza] quite fulfilled in terms of making a contribution and making a difference not only in our family, but more broadly, a greater impact. . . She's made a contribution to kids as a whole.

Beyond a direct career impact, half of the parents also learned advocacy and activism skills and became more involved in disability-related causes or volunteer work. While learning these types of skills and becoming involved in volunteer work may not necessarily be unique to families with children with

disabilities, the examples provided by the parents were connected to the family's more unique circumstances. Examples ranged from starting a parent support group, taking on new roles within disability agencies or associations, sponsoring, initiating, or participating in fundraising efforts for people with disabilities. In becoming more involved, some parents talked about the value of helping others. For instance, Lilly noted that "you just want to help, like all of sudden you just want to do what you can to help other people". Referring to his and Lilly's experience, Garry added: "I think it's great for us that we were able to have this [experience] because . . . we've probably helped a lot of people". These parents believed that a desire to help was common among many families with children with disabilities.

Learning new knowledge and how to help others, however, was only part of the picture. Families also reported gaining new attitudes or experiencing attitude changes as a result of parenting their children.

### *Sub-theme 2: New Attitudes*

A few parents thanked their children for teaching their family new attitudes toward people with disabilities and other families. Some of these attitudes were tied to the family's more unique circumstances and reflected an ability to more readily recognize and appreciate the value, potential, and strengths of a person with a disability. For instance, Charlie "opened the awareness of people with disabilities and that there is a value inherently, intrinsically in those people" and gave his dad Phil a "more balanced appreciation for what people are about".

Similarly, Judith's daughter made her family look at people with disabilities differently and changed her mother's view of how people with disabilities ought to be treated. Judith explained:

We've all seen disabled people all over the place and don't have any prejudice or anything. But now when I see somebody with a disability, I just think there's so much more to them than what you see. I guess I didn't think about it too much before, but now it makes you think about it more. And you wonder if they've got all those big strengths and inner qualities going on too that people don't see.

Judith also commented on how she looks at other families differently:

If I see a family with a kid with a disability, I feel like I know them already, and I feel like I understand a lot more about them. So, it's, um – you just don't know it until you live in that situation, and it gives you a lot of respect for the other families and what they have to do to keep it all together.

Similarly, Jean talked about her experience having given her a new perspective on how to help the individuals she works with who also have disabilities. She learned not to place limits on people or to tell them what they can or cannot do based on their disability but instead to help people strive for self-improvement. Other parents described their child as having taught family members attitudinal changes in terms of the following: heightening a sibling's comfort level around kids with disabilities (Alana), not being afraid of somebody who has challenges (Heather), and discovering a new-found enthusiasm for getting to know people with disabilities (Eve).

In addition, just under half of the parents described their children as having changed or exceeded parents' expectations in a positive way.<sup>3</sup> Some

---

**Notes:**

<sup>3</sup> Reviewers did not reach consensus on where this example belonged. Two felt that it belonged under this sub-theme, while two felt that it belonged under sub-theme 3. Yet the example is only included here given the flow of results and the fact that the researcher could not provide

parents identified characteristics of the children that did not comply with what is typical for their diagnoses and explained how their children are nothing close to the worst case scenarios predicted by their doctors. For example, Ken explained what his son has taught his family as a result of his accomplishments not being anticipated by doctors:

So if Kevin can learn all that about dinosaurs. Kevin can learn all that about history – Kevin can go out and simply read books – which they said he would never do – Kevin can go out and write – which they said he would never do – all this stuff. He’s taught us, well, you can do it.

Not only did parents learn that their children were often capable of more than labels suggest; the children also enabled certain parents to realize they, too, could do something they did not think they could. For instance, John shared the following while reflecting on his learning and growth:

When Neal was first born, he had to stay in hospital until he reached a certain weight and he was in the hospital for like 6 weeks. And during that time we would go there every day, and we’d spend all day there with him. And you’d think you couldn’t do this [referring to seeing his son in a fragile state], but in the end it had to be done, and you did it . . . I wasn’t expecting that, as a father, to do something like that. But we did . . . and I think I grew from that, that I could do it.

In addition to realizing that both they and their children could do something unexpected, a few parents also gained new attitudes toward life as a result of the awareness they have gained and the perspective their child has brought to the family. (See theme 2 for more on perspectives added to the family.) Heather’s son, for instance, has taught her to actively look for positives in any given situation, to reframe her perspective of a difficult situation (e.g. the death of her

---

justification for including it under a different sub-theme. Also, while a number of examples pertained to the family’s more unique circumstances, this was not always the case. Some examples were considered common for any child.

mother), and to “focus on what is good and right with the world.” Her son’s ability to say something cute and off-topic when she has had a difficult day has also served to remind her that “life isn’t really that bad.” Similarly, Lilly’s son opened her eyes and made her realize that there are a lot of people going through so much more. Along similar lines, some parents realized what is important in life thanks to their child. For instance, Louise explained that her husband no longer “sweat[s] the small stuff, like little stuff at work, or dealing with family and friends” because he realizes “there’s bigger things in life to worry about.”

A change or shift in priorities thanks to the child was also mentioned by a few parents. For instance, both John and Garry described their jobs as no longer being their number one priority. Garry explained: “it came to a point where Matthius and his comfort level was more important than getting jobs in Toronto and Calgary, Vancouver, which now I would say was a great thing.” His wife Lilly added that, as a result of their family’s choice to stay in Winnipeg, her husband is now a lot more family-driven, which she perceived to be a good thing.

### *Sub-theme 3: New or Enhanced Positive Character Attributes*

In addition to having learned new knowledge and attitudes, all of the parents perceived themselves as having acquired new or enhanced positive character attributes as a result of raising their child. Parents acknowledged that they possessed certain traits prior to having the child, but the child heightened some of these. Some examples could be considered common to any family,

while others were considered by parents to be tied more uniquely to their circumstances.

Attribute changes considered common to any family included family members learning to open their hearts, be more caring, creative, balanced, gentle, calm, outgoing, responsible, independent, and less selfish. Parents also perceived their children as responsible for teaching family members to be more patient, loving, and warm. The enhancement of the above character attributes was, for the most part, considered common for any family, although in some instances, the families' more unique circumstances were perceived as influential. For instance, Judith connected her family's learned patience to her daughter's physical disability, explaining:

It takes longer to do things and longer to get somewhere. Not that that's a big deal, but families just jump in the car and take off. And we're still getting it together in the house, and stuff like just keeping up takes longer but nobody cares. Like, so what, we all start getting ready earlier it's not that big of deal. But yeah, the kids have to be really patient because it seems to take longer. They're [referring to the child's siblings] both really kind and tolerant people and very easygoing, so I think they've become that way because of our situation.

Similarly, Ken made a distinction between how loving and warm his spouse became after the diagnosis of their second son, explaining:

With Louise, it's definitely made her more loving. Louise was more the – it was a little bit more not let you in, that type of person. Not that Louise wasn't loving, but having a child was going to change that – obviously. But with Kevin, he just totally changed everything. I mean, my friends call Louise mom! She's just turned into the ultimate mom. It's amazing because I really think – I mean, first child, sure, that softens you, but even with the diagnosis of Kevin it's just totally changed her, that she's – just become so incredibly warm to everybody.



A few of the children were also perceived as having put their parents more in touch with their emotions. For instance, Lilly and Garry talked about how raising their son has brought out a sensitive and gentle side in Garry as well as an emotional side that he never dreamt he would ever have. Similarly, Phil admitted how while growing up he was “never really much into feelings and emotions,” but that having Charlie has enabled him to open up to “the emotional side of people and of life” and to find “a softer side.”

The most commonly reported positive attribute change that was tied to the existence of disability and to the family’s more unique circumstances was having learned to be more tolerant and accepting. As Mick explained, he “was pretty intolerant growing up with people that are different” and his daughter has given him the ability to be non-judgmental. Family members also learned acceptance of diversity and of people’s behaviors, acceptance of “people being a little bit different and [that] it’s okay to be different” (Lilly), and acceptance of what is (Eve). Recalling his words to an elderly man who was going through the “why me thing” following his grandson’s diagnosis of Autism, Ken recalled his journey to acceptance, explaining: “You just get to a point where you can just say ‘why not me?’”

Other parents saw themselves as more respectful of families of children with disabilities (Judith), more compassionate regarding people with challenges, and “more in tune” with their child’s development than with the development of their non-disabled child (Rachel). Just under half of the parents perceived their child as having made them an overall “better person”, “better parent”, or made

family members "better people" (e.g. because of what they have learned). In some cases, nothing was mentioned about the child's disability and there was no direct link to the family's more unique circumstances. For instance, Heather shared:

All through the years of having him, I don't think there's ever been a time where I haven't been able to learn to be a better person because of Bob. And I think that about sums it up. I have become a better person because of Bob or because of what Bob has brought into my family and my home.

In other cases, the child's disability was identified as influential. For instance, Phil perceived himself as a "better person at work" because of the understanding his son has given him about Asperger syndrome. This understanding has enabled him to "relate to staff and other people in a different sort of way" and to understand and interpret for other people the behavior of a coworker who also has Asperger syndrome.

### **Theme 1: What the Children Taught the Family or Enabled Family Members to Learn (Children's Perceptions)**

While each of the parents used the words *learn* and *teach* or provided examples of what they felt their child has taught their family or enabled family members to learn, this was not the case for every child. A few of the children indicated that they did not know, could not come up with anything, or simply had no response. Nevertheless, the majority of the children did comment on teaching family members. Two sub-themes emerged from the data that reveal what the children perceived they have taught family members or enabled them to learn. The first sub-theme (New Knowledge) includes how the children have educated

family members on topics of interest and provided them with practical knowledge, including knowledge about disability and assistive equipment. The second sub-theme (New Attitudes) includes how the children have taught family members new attitudes, primarily toward people with disabilities. It also includes how they felt they have changed or exceeded family members' expectations. These two areas of teaching and learning are explained in detail below, accompanied by examples from the children's narratives. These results have also been summarized in Table 4.

#### *Sub-theme 1: New Knowledge*

A couple of the children perceived they have been able to educate family members on topics of interest to the child and provide family members with practical knowledge. For instance, Charlie described a time when his family was listening to a science CD, and he was able to help "explain some of the finer points when they didn't get it". Similarly, Karlee talked about how she has been able to educate her family on Russian history, medicine, and Juvenile Diabetes because these are all topics that she likes to research. Thirdly, describing himself as neat, clean, and organized, Matthius perceived that his family has learned "to clean up [and] to clean more" because of him.

An area connected more uniquely to raising a child with a disability involved being able to provide family members with knowledge about disability and assistive equipment. Following a prompt from her mom, for instance, Sandy mentioned that her mom "had to learn about Down syndrome" and agreed that

Table 4: Summary of Children's Perceptions of What the Children Taught the Family or Enabled Family Members to Learn

Theme 1	Sub-theme	Common for Any Child/Family	More Unique to these Families' Circumstances
What the Children Taught the Family or Enabled Family Members to Learn	(1) New Knowledge	<p>-Child educated the family on topic of interest (e.g. science, medicine)</p> <p>-Child shared practical knowledge (e.g. cleaning)</p>	<p>-Child educated the family about disability and assistive equipment</p>
	(2) New Attitudes	<p>-Child taught family new attitude toward environment (to be more globally/ environmentally conscious)</p>	<p>-Child taught family new attitudes toward people with disabilities and exceeded family's expectations based on diagnosis</p> <p>-Child has shown family "how it's really possible to persevere in a big way" (despite physical challenges) *</p> <p>-Child taught family about potential of person with a seemingly difficult life to make a positive impact</p>

\* Example was placed where majority agreement occurred (3/4 agreed).

she made her mom smarter as a result. Similarly, believing that his family did not know anything about Cerebral Palsy before he came along, Cam also felt that he has taught his family “some things they don’t know” (e.g. how to get a wheelchair and accessible parking pass).

### *Sub-theme 2: New Attitudes*

Two children took the notion of teaching about disability one step further by illustrating how they felt family members have learned new attitudes toward people with disabilities (e.g. what people with disabilities can do and are capable of). Claire, for instance, perceived that she has taught her family “that people with disabilities can be more than they think, because some people think oh, just because you’re like disabled you can’t do this or that.” When asked how she has shown her capabilities, she elaborated: “I wasn’t supposed to really walk after grade 5 or 4, my doctor said, but I’m still walking and I can do gym and everything. And I was supposed to get, like, a spine surgery, and I never had to because I wasn’t that bad”. Karlee also explained how she has taught her family about the potential of people with disabilities and what it means (or does not mean) to be disabled.

I don’t know what my parents would have thought about people with disabilities before I came around, but I think it’s just kind of shown them that it really doesn’t mean that much, like in the scheme of things, like you can still be productive and still have goals and not really let anything stop you as hard as that is sometimes.

Karlee’s insight into how she has been able to change her family’s attitudes extended beyond the other children. For instance, she perceived that her family

has learned “that people don’t always fit into a box”, that she is not necessarily like another person who has Cerebral Palsy, and that “being disabled is different for every person who is disabled”. Karlee added: “I think that any idea that they might have had before I came along about how this is what a person with Cerebral Palsy or in a wheelchair is like, it’s definitely shattered that”. She also pointed out that while there are some disappointments that accompany her physical disability, she has shown her family that “it’s really possible to persevere in a big way”. Lastly, Karlee described how she has been able to help other people by doing volunteer work and getting involved in her community, and added with regard to her family: “I hope that they’ve learned that you can make a positive impact on other people’s lives, even if yours seems really difficult”.

In a more general sense, Karlee also felt that she has been able to get her family “thinking differently” in terms of being more globally and environmentally conscious. This is an example that would not necessarily be unique to the child’s circumstances but could be considered more common to any child.

While a separate sub-theme was created in the parent results to account for positive attribution changes in family members, only one child referred to an attribution change in a family member. When asked to reflect on the most important thing she has helped her mother learn or understand, Claire responded: “to be patient, I guess”. However, it was unclear whether Claire truly felt that she has taught patience, because her comment was made with hesitancy and followed a prompt by her mom. As a result, this sub-theme was not included in the child results.

## **Theme 2: How the Children Enriched Family Members' Lives and Made Other Contributions (Parents' Perceptions)**

This theme includes segments from the interviews that reflect the parents' perceptions of how their child has enriched family members' lives and made other contributions (beyond those previously identified). The parents' perceptions clustered into the following four sub-themes: (1) Helpfulness, (2) The Children's Positive Character Traits, (3) Positive Emotions the Children Evoked in Family Members, and (4) Other Contributions. Similar to theme 1, many examples provided in this section could pertain to the experience of raising any child and are not necessarily unique to a child with a disability. However, in certain instances, parents referred to the uniqueness of their experience. As with theme 1, these commonalities and areas of uniqueness are explored here. These results have also been summarized in Table 5.

### *Sub-theme 1: Helpfulness*

The majority of the parents perceived that their child has helped the family. For instance, when asked what she appreciates most about her child, Lilly replied: "Very helpful! . . . [He] never says no when I ask [him] to do something. He's always very willing to help." Some children were described as helpful when it came to household chores (e.g. laundry, dishes, making supper). For instance, Heather described what it meant to her when her son took initiative when it came to cleaning and helping family members complete chores:

Table 5: Summary of Parents' Perceptions of How the Children Enriched Family Members' Lives and Made Other Contributions

<b>Theme 2</b>	<b>Sub-theme</b>	<b>Common for Any Child/Family</b>	<b>More Unique to these Families' Circumstances</b>
How the Children Enriched Family Members' Lives and Made Other Contributions	(1) Helpfulness	<p>-Child helps with chores</p> <p>-Child provides other types of practical help (repairs bikes, babysits siblings, helps recall dates and phone numbers, consoles sibling, helped parents parent other sibling)</p>	<p>-Child calms sibling with similar diagnoses, helped sibling develop faster by giving her opportunity to accompany him to therapy appointments &amp; enabling her to have access to specialists &amp; services at clinic</p>
	(2) The Children's Positive Character Traits	<p>-Child is fun, funny, hilarious, has sense of humor, brings smile to face, makes family laugh, lights up room *</p> <p>-Other traits: caring, compassionate, happy, joyful, affectionate, loving, positive, gentle, sensitive, thoughtful, generous, appreciative, reliable, adventuresome, focused, honest, creative, interesting, knowledgeable, good attitude, good listener, neat person to talk to, appealing personality</p> <p>-Child sets good example or role model for siblings **</p>	



	(3) Positive Emotions the Children Evoked in Family Members	<p>-Child made parents proud, impressed, inspired, motivated, encouraged, uplifted, appreciate, enjoy, happy, joyous, excited (general), blown away, thrilled, floored</p> <p>-Family feels fortunate, privileged, lucky, blessed *</p> <p>-Child shifted parents' emotions from negative to positive</p>	-Parent derives more excitement in life (from little things) given unique circumstances
	(4) Other Contributions	<p>-Family met people, gained friendships, made connections thanks to child</p> <p>-Child made parent or family stronger &amp; improved communication among parents*</p> <p>-Child adds perspective, insight &amp; dimension, brings out good things in parent, brings sanity, slows or relaxes family *</p>	-Child opened parent to a different place in the world (world of disability)

\* Example was placed where majority agreement occurred (3/4 agreed).

\*\* Example could potentially fit under different sub-theme as vote was split for where example belonged (2/4 agreed). Details will be discussed in notes throughout the text.

He came down on Saturday morning and he said, 'Mom, you're not cleaning the bathroom today. I made myself a note yesterday'. And he wrote on there. 'Clean bathroom!' And he's gone several times already . . . 'No, I've got my note, mom. I've got to clean the bathroom'. You know, it didn't matter that it wasn't spelled correctly or anything, but what mattered was that he had the consideration to go and write himself a note that that was a chore that needed to be done that day. And he went and did it.

In contrast, Liza identified her son as not "a particularly helper-outer with the chores" explaining that he does not instinctively recognize the need to help around the house, although he is generally willing to help when asked.

Beyond helping with household chores, half of the parents also mentioned other types of practical help their child provided. Examples included repairing family members' bikes, recalling important dates and phone numbers, and consoling or babysitting siblings. Louise focused on how her son, Kevin, has also helped her and her husband parent Kevin's brother. An example considered more unique to the family's circumstances was provided by Liza, who explained that Charlie and his brother share similar diagnoses and this has enabled Charlie to relate to his brother in a unique way. This has helped not only the sibling but the entire family. In addition, Charlie has also helped his younger sister develop at a faster rate by giving her the opportunity to accompany him to occupational and speech therapy appointments and enabling her to have access to specialists and services at a particular clinic.

### *Sub-theme 2: The Children's Positive Character Traits*

Each parent described a variety of positive character traits their child possessed. Each of the parents (with exception of one) described their child as

funny, humorous, hilarious, or as having a good or wonderful sense of humor. These were considered contributions. Similarly, parents talked about how their child “likes to joke,” “likes to get the humor going,” “brings a smile to your face,” and has “brought a lot of laughs” when the family needed it. Ken elaborated: “I’ll come in from a tough day at the office, and he looks at me and says the funniest things sometimes, and I just start laughing. I can’t help it.” On a similar note, over half of the parents described their child as fun or lots of fun, or talked about having fun as a family.<sup>4</sup>

Parents also described other character traits family members valued that could be considered common to any child (refer back to Table 5). With these characteristics in mind, half of the parents talked about how their child sets a good example and has been a good role model or mentor for siblings.<sup>5</sup> One child’s role modeling was reflected in his willingness to help out, his cleanliness and conscientiousness, his ability to be responsible, and his sociable nature. Another parent considered her daughter “the epitome of what Jesus wants us to be” because her actions come straight from the heart.” She also believed that being a good example extended beyond the child’s sibling to everyone else around her.

---

**Notes:**

<sup>4</sup> One might consider these examples to have evoked positive emotions in family members. However, because these responses were most often provided as examples of the child’s best qualities or what parents appreciate most about their child, they have been included under this particular sub-theme.

<sup>5</sup> Reviewers did not reach consensus on where this example belonged. Consequently, the example was placed here, where the majority consensus occurred.

*Sub-theme 3: Positive Emotions the Children Evoked in Family Members*

In addition to parents valuing their children's positive character traits, all ten parents also reported positive emotions their children have evoked in family members. A sense of pride was the most common, as all ten parents described times they felt pleased with or proud of their children for something they did or accomplished. Lilly recognized that some of the things that evoke a sense of pride "may not be the same as what other people [her son's age] are doing at the same time". Yet she maintained that there are still numerous reasons to be proud. Other parents agreed that there have been countless moments of pride and other special moments in parenting, but identified that "you'd have to have an endless memory" to recall all of these (Heather).

Over half of the parents were proud of their children for demonstrating a sense of independence. Examples revolved around milestone events such as the child finally learning to walk, learning to tie his shoes, and learning to ride a bike independently. More individualized examples included a child operating his computer without assistance, taking the bus, starting a job, spending his own money, and being able to take care of him/herself. Parents were also proud of their children for academic reasons (e.g. doing well in school despite challenges), as well as sports achievements and other non-academic awards. Referring to his son's team, John described his feelings during one of his proudest moments:

One of my proudest moments was when they won the championship in wheelchair hockey this year. And it was really a hard fought playoff and we won. And he was very happy to get his award as the most improved player. It was totally surprising – it blew me away! When he got it I was very happy because, you know what, I won that when I was a kid.

Often in conjunction with feelings of pride, parents felt excited, impressed, surprised, blown away, thrilled, and floored by their children. Some parents were proud of or impressed by their child's intelligence, knowledge, or creativity, their good sense of right and wrong, their ways of overcoming fears, and their willingness to participate in public speaking events (which one parent identified as something not too many children are necessarily comfortable doing). Other parents were proud of or impressed by their children for showing responsibility, putting their minds to something and taking a chance, and for being their own advocates. While these examples were considered common for any child, Rachel felt that she derives more excitement from the "little things" in life than many other people do and that she "celebrate[s] things that other people don't even think about celebrating" because of her daughter's more unique circumstances.

Jean also explained:

Disability-wise, I'm very proud of her because she hasn't let her disability control her life. She's got multiple disabilities . . . And she doesn't let that slow her down. And she has to work really hard at school, and she doesn't let that slow her down. She knows she's not dumb . . . and she can do the work, and she does it. I'm very proud of her for that, because it would be too easy to say, 'Oh, I can't do this' and give up, right? She's always willing to push the limits and do the best that she can and at least try it.

Other positive emotions considered common for any child to evoke in family members were also mentioned. For instance, parents felt inspired, motivated, encouraged, uplifted, happy (e.g. with the person the child is becoming), and joyous. Jean explained with regard to her daughter: "When you're grumpy or you've had a bad day, she's the first one to notice and to come over to you and to try to make you feel happy, whether it's by being silly or telling

you a joke, she's the first one to come over". Enjoying time with and appreciating the child were also mentioned by parents.

In addition, more than half of the parents expressed feeling fortunate, privileged, lucky, and blessed to have their son or daughter in their life. For a few parents, these comments were attached to a perception of their child as high-functioning, not as severely disabled as others, "healthy", not "typical" for their disability, not having as many medical issues as other families, or to an acknowledgement that "there's a lot of people that are going through so much more" (Lilly). For the remainder of the parents, however, there was no mention of the child's level of ability or disability as playing an influential role with regard to the family feeling fortunate, privileged, lucky, or blessed.

Several parents also identified how certain emotions they experienced shifted from negative to positive over the years. For instance, Heather explained:

You have various emotions. You have various feelings. Like, um, there was a period of time when I thought I was being punished by having two mentally and cognitively challenged kids, and [now] I'm glad that I had them. It's just been that much of a joy raising them.

Similarly, once Liza got past grieving about giving up her previous career, she felt fulfilled because of the broad impact she has been able to have.<sup>6</sup>

#### *Sub-theme 4: Other Contributions*

Shifting away from positive emotions, yet still exploring how the children have enriched their families' lives, parents discussed other contributions not

---

#### **Notes**

<sup>6</sup> While these two examples have do to with the parent's experience with disability, having emotions shift from negative to positive was not considered by the reviewers as unique to these families' circumstances.

listed above. For instance, the majority of the parents were asked whether they felt their child has had a positive effect on the parents' social network. Two parents perceived that their child has not had an effect on their social network, yet the remainder talked about having met people, gained friendships, and made new connections thanks to their child. While it is believed that any child can expand a family's social network, certain instances were attributed to the family's more unique circumstances. Eve explained:

I've met people through her – lots of people, very nice people – that I would have never met otherwise. And we're all kind of in the same boat, and it's like a different social group that I would have never met.

For some parents, this meant meeting other children with disabilities or families with children with disabilities. For instance, Ken described having his social circle widened and having other parents with children with special needs “come out of the woodwork” since his son was diagnosed. Through the creation of a support network of parents with similar experiences, Ken and his wife Louise have also been able to offer support to parents who have approached them for advice and guidance.

On a slightly different note, despite challenges identified by parents (see theme 3, message 1) and one parent noting that having a child with a disability may make some families “fall apart”, the most common positive marital impact shared by the majority of parents was the following. Many parents perceived that their child strengthened their marriage, made the parents or family stronger, or brought the parents closer together. On a similar note, in describing one of the greatest contributions her daughter has made, Judith expressed that having

Karlee in her life has made her family “more of a team” and “one unit and strong together”. Two parents also felt they had become better at communicating and sharing with their spouse thanks to the child. For instance, Garry talked about the difficulty he and his wife experienced when their son was first diagnosed and described the role each of them played in helping the other get through the “tough part”. Their experience, however, has made him and his wife “more free to talk about things and feelings”, thus improving their communication with one another. This positive outcome could be attributed to the family’s more unique circumstances; however, the reviewers considered the example common for any family.

Among other contributions, a few parents felt that their child added a fresh perspective or insight to the family. For instance, Louise described that her son Kevin “still has that innocent perspective of things” which she appreciates. Her husband Ken also commented on the value of Kevin’s insight and identified this as something he appreciates most about his son:

His insight into things is so different than anybody else. He thinks different than we do – um, traditionally do – and I love hearing his insight. He adds such a dimension to our house that, you know, I just can’t imagine not having that dimension in our home. It’s just – it’s such a core of who we are in this house. He’s so amazing.

Lastly, parents added that their child “brings out all the good things” in his dad (Rene), has “brought a lot of sanity” to the family when they needed it (Jean), slows the family down (which is sometimes “a good thing”), and relaxes the family (because some things take longer). Again, the previous examples may not necessarily be considered more unique to the family’s circumstances. Referring



to the world of disability, however, Alana thanked her son for opening her up “to a whole different place in the world” that she likely never would have “stepped in” if it were not for her son.

## **Theme 2: How the Children Enriched Family Members’ Lives and Made Other Contributions (Children’s Perceptions)**

This theme includes segments from the interviews that reflect the children’s perceptions of how they have enriched their family members’ lives and made other contributions to the family (beyond those previously identified). The children’s perceptions clustered into the same four sub-themes as the parents: (1) Helpfulness, (2) The Children’s Positive Character Traits, (3) Positive Emotions the Children Evoked in Family Members, and (4) Other Contributions. These results have also been summarized in Table 6.

### *Sub-theme 1: Helpfulness*

All ten children felt as though they have helped their families in some way or considered themselves helpful. The most common example provided by the children was helping with household tasks and chores (e.g. cleaning, folding laundry, making food, setting the table, taking care of the family dog). In contrast, one child admitted that he does not help around the house unless he can bargain for something in return. Beyond household chores, some children also felt they provided other types of practical help. Examples included fixing the computer and helping family members figure out “technical computer glitches” (Karlee), fixing

Table 6: Summary of Children's Perceptions of How the Children Enriched Family Members' Lives and Made Other Contributions

<b>Theme 2</b>	<b>Sub-theme</b>	<b>Common for Any Child/ Family</b>	<b>More Unique to these Families' Circumstances</b>
How the Children Enriched Family Members' Lives and Made Other Contributions	(1) Helpfulness	-Help with household chores  -Other practical help (fixes bikes or computer, takes responsibility for siblings, helps run garage sales, talked family through difficult situation)	-Helps sibling with similar diagnoses  -Helps family deal with surgeries & pain
	(2) The Children's Positive Character Traits	-Child is fun, funny, a comedian, has good sense of humor, makes family laugh	
	(3) Positive Emotions the Children Evoked in Family Members	-Child made parents proud, happy, glad  -Child brightens family's day **	
	(4) Other Contributions	-Child brings different perspective or way of thinking (keeps things interesting), promotes interesting dinner conversations *  -Child has connections, counterbalances the mellowness in her family	-Child composes and plays music for his family (attributes talent to Asperger syndrome) *

\* Examples were placed where majority agreement occurred (3/4 agreed).

\*\* Example could potentially fit under different sub-theme as vote was split for where example belonged (2/4 agreed). Details will be discussed in notes throughout the text.

family members' bikes, and helping run garage sales. Charlie also agreed with his mom's suggestion that taking responsibility for his siblings has been helpful, adding "that, I definitely did well". Meanwhile, another child felt as though his helpfulness came in the form of talking his family through a difficult situation (e.g. the death of his grandfather).

While the above examples could be considered common for any child, some children referred specifically to their helpfulness in terms of their more unique circumstances. For instance, Charlie explained that, because of the common diagnoses he and his brother share, they can relate to each other and "understand each other better than anybody else". Prompted by his mother, he added how he can typically calm his brother down when he gets upset and can do this more easily than anyone else.

Cam also provided an example that was unique due to having to go through a variety of surgical procedures because of his disability. Having been through more than ten surgeries, he explained "let's say I, like, need surgery and they have a hard time dealing with that, I uh help them get through it if I'm in pain".

### *Sub-theme 2: The Children's Positive Character Traits*

While a perception of helpfulness was apparent among the children, the majority of the children also described themselves as having a good sense of humor, as funny or comedic, or as able to make their families laugh. Kevin perceived that his family "love[s] me being funny" and agreed with his parents'

statement that he “add[s] laughter to the house”. Karlee also felt that her family thinks fondly of her for similar reasons, explaining:

Oh, I make them laugh! Because I can't tell a joke without laughing hysterically, and then that makes them laugh and it's just like, I have a really strange, sarcastic sense of humor sometimes, and they just laugh and think of me fondly for all the little idiosyncrasies that I have!

*Sub-theme 3: Positive Emotions the Children Evoked in Family Members*

In addition to acknowledging character trait contributions, all ten children reported positive emotions they felt they evoked in family members. For instance, more than half of the children provided examples of times they felt they made their family proud for something they did or accomplished.<sup>7</sup> Examples included receiving awards and trophies for hard work through physical exercise and sport (e.g. power wheelchair hockey), school accomplishments, and achievements towards increasing their independence. While pride could be considered an emotion that any child might evoke in family members, Cam provided an example of a moment that was more unique to his physical circumstances. He explained:

We have friends down the street. . . and they told me I would get to do something if I actually walked all the way to their house. I forget what, um, it was, but I – it took me about an hour but I walked all the way in a walker – I borrowed a walker. My mom was there but I was telling her to be quiet because I was sweating and I knew if I sat down I wouldn't be able to make it all the way, so it took me an hour, but I finally got there. I was sweating like a pig!

---

**Notes:**

<sup>7</sup> Of the four children who did not provide examples, two were unsure, did not know, or had no response. The other two were not posed the question due to the flow of the conversation.

Although it does not serve to answer the research question directly, all ten children also provided examples of times when they felt good about or proud of themselves for something they did or accomplished.

In attempts to tap into a similar emotion, half of the children were asked whether they felt they made their families happy and their families are glad to have them around. Four children responded yes, while others were uncertain (e.g. “sometimes,” “I think so”). Cam provided insight into his perception that his degree of disability played a role in making his family happy, explaining: “I have friends that are way, um – have Cerebral Palsy way worse than I do, so they’re glad that I have it the way I do because I can do most things that normal people can do”. Reasoning from the others behind why family members were happy or glad revolved around the child being funny, having a good sense of humor, making the family laugh, having a good day at school, loving her mother, and being cheerful, tidy, and helping around the house.<sup>8</sup>

#### *Sub-theme 4: Other Contributions*

Other contributions not included under helpfulness, character traits, or positive emotions were also mentioned by the children. For instance, referring to his natural gifts when it comes to writing and composing music, Charlie described a contribution that he attributed to his disability. He explained how having

---

#### **Notes:**

<sup>8</sup> Some questions were introduced differently to the children, and therefore not all the children were posed this question. Additionally, Claire felt that she “brightens” her family’s day, yet no consensus was reached on where this example belonged. One reviewer felt that it belonged under sub-theme 2, and another felt that it belonged under sub-theme 4. The example was placed here where majority consensus occurred.

Asperger syndrome has given him the ability to be hyper-focused, to work harder than he otherwise would, and to be more successful with his music. He concluded: “I think the music is a positive impact. It can impact everyone else too if they hear it.”<sup>9</sup> Other contributions included being able to draw on “friends that have connections” when the family needed something (Cam) and bringing “a different perspective” and way of thinking<sup>10</sup> to the family which “keeps things interesting” (Karlee). When asked how she makes a difference in her family, Karlee replied: “I suppose it would be a little less lively without me. There wouldn’t be as many interesting dinner conversations”. She also referred to “the whole yin and yang thing” and to how she counterbalances the mellowness in her family. Similarly, Neal perceived that his family would be missing out on “lots” if he were not around.

As mentioned at the beginning of the results section, interview participants not only discussed what the children taught their families and the various contributions the children have made. Participants also shared a series of messages they wished to pass along to other people. These have been included under the final theme below.

---

**Notes**

<sup>9</sup> While all the reviewers agreed that this example belonged under the sub-theme 4, two reviewers argued that it could also be included under sub-theme 2 given that the child is musically gifted. Nevertheless, the example is only mentioned here because of the context in which it is presented.

<sup>10</sup> This comment is not mentioned under theme 1, sub-theme 2 because the child noted this as something she felt helps her family but did not connect it to an attitude change in family members.

### **Theme 3: Messages to Pass Along (Parents' Perceptions)**

The parents expressed not only the positive aspects of their lives and experiences raising their children but also acknowledged that not every aspect of their experience has been, or should be conceived of as, positive. For instance, Rachel commented that “as wonderful as it is to work on the positives, it’s not all rosy either” while Judith recognized that “you can’t appreciate the positive stuff without thinking of the difficulties”. Therefore, to accurately reflect the data, this data is also included. Parents’ messages were, then, sub-categorized as: (1) “It’s not all rosy either”, (2) Reflections of the Bigger Picture, Reframing the Experience, and Understanding my Child and Family (3) Would I Change my Family’s Circumstances?, and (4) A Positive Attitude and Research Approach is Important. These messages are explained in detail below accompanied by examples from the parents’ narratives. These results have also been summarized in Table 7.

#### *Message 1: “It’s not all rosy either”*

Each of the parents experienced one or more of the following throughout the course of raising their child: “challenges” (e.g. dealing with stubbornness), “struggles”, “problems” (e.g. medical), “issues” (e.g. behavioral), “obstacles”, “difficulties”, “bad days”, and “tough days” or “tough times”. Parents also referred to segments of their experience as “work” or “hard work”, a “long haul”, “trying”, “time and energy-consuming”, and as not having been easy. Feelings of stress (e.g. around the time of diagnosis), worry (e.g. about the child’s future),

Table 7: Summary of Parents' Messages to Pass Along

Theme 3	Sub-theme	Examples
Messages to Pass Along	(1) "It's not all rosy either"	<p>-There have been struggles, problems, issues, obstacles, difficulties, tough or hard times, it has been trying, time, energy-consuming, "it's been a long haul", it is hard work</p> <p>-We have felt stress, worry, tired, sad, frustrated, overwhelmed, punished, concerned and have experienced disappointment, mourning, grief, denial</p> <p>-Raising our child has been a "real test" on our marriage, it has "stretched" us, we had to downsize work hours, our marriage is work, my marriage broke up</p> <p>-Note: Mad feelings we experienced were caused by ignorance of others, crisis was caused by blame from others</p>
	(2) Reflections of the Bigger Picture, Reframing the Experience, and Understanding my Child and Family	<p>-Reflections of the bigger picture: There have been more good times than bad, you get over the hard times, there are stresses but it has been working out, getting better or easier</p> <p>-Reframing the experience: Our child is a gift instead of burden, does not hold us back or add to difficulties, our child's difference is actually exciting, we are not sorry for it, it is not a tragedy or catastrophe, our experience has been good, great, positive, rewarding, beneficial, a privilege, our child is a godsend, blessing, joy, we do not know what we would do without our child</p> <p>-Understanding my child: Take time to get to know my child, they are individuals, labels do not define a person, stop devaluing their lives, our children have something really special to offer, my child can give a lot to society and deserves respect</p>



		-Understanding my family: We're a 'normal' family, 'just like any other family', do not make assumptions or judgments about our family
	(3) Would I Change my Family's Circumstances?	-We would not change the fact that our child has a disability -We would consider changing the fact that our child has a disability -We would change the fact that our child has a disability
	(4) The Importance of Choosing a Positive Attitude and Research Approach	-A positive attitude is a choice, and kids with disabilities do have a positive impact "if people allow it to be that way [and] if they see it that way"

disappointment (e.g. that the child could not play certain sports), grief, mourning, and denial were also mentioned. A couple of parents reported feeling frustrated, overwhelmed, tired, sad, and punished. One parent also described how his daughter's special needs caused him to feel more concerned about her than her non-disabled sibling.

Three parents also shared negatives regarding effects on their marriages. For instance, Liza talked about how her experience has been a "real test" of her marriage and how she and her husband have been "stretched" in ways they did not think they could have been stretched "or didn't necessarily want to be stretched". Note, however, that this parent then proceeded to mention that her marriage has also been strengthened as a result (see theme 2, sub-theme 4). In addition, Jean, a single-parent with two children with disabilities, described how her marriage broke up around the same time that her daughter was diagnosed, adding her perception that "very few marriages with disabled children survive". Yet she then proceeded to mention that the break up more likely resulted from "a whole bunch of things" rather than one specific cause.

Judith was the only parent to identify that her experience had not had a positive effect on her career. However, she did not specify that the effect on her career had necessarily been negative. Explaining how she simply felt that it was important to stay at home with her daughter, she replied regarding her career: "I've just pushed that somewhere else".

It is important to note that some of the parents perceived certain emotions and aspects of their experience as caused by someone other than the child. For example, Eve explained:

There was no question, that period of time where you struggle with it – a bit of a denial thing. Well, you almost grieve, but you come to the conclusion that those feelings are more about you, and what you thought, or what other people might be thinking.

Similarly, Rachel described feeling angry with other people because of their ignorance toward her daughter, and Liza identified that what led to her nervous breakdown was other people's insinuations that she had badly parented her child.

Elaborating on other people's perceptions as problematic, Heather suggested that people should reconsider their use – or misuse – of words and labels. While people with intellectual disabilities are often labeled as hindered in some way, she explained: "the hindrance is very often on the so-called 'normal' people for lack of understanding them". Referring to her son, she elaborated:

I think if we all would try to understand people like Bob and people with Down syndrome, and whatever other labels they've got for these individuals. If we would just try to understand them, we could really – if we would start living like them – start making the world a better place to live in. They can just contribute so much, and yet so often I see them pushed aside because they're labeled as retards. . . . And I. . . looked up retarded in the dictionary, and the definition of retarded is to be hindered, to be confined. And the so-called normal people are hindered and confined within their own belief system, whereas Bob isn't. He sees the world as a wide open opportunity for life. And, so I mean, if we want to really go by the Webster's Dictionary of retarded, all the rest of us are!

The examples above were used to illustrate the possibility that problems encountered by families do not always or necessarily stem from the child but that other people can be problematic, and it is important to recognize this.

*Message 2: Reflections of the Bigger Picture, Reframing the Experience, and Understanding my Child and Family*

Beyond identifying that other people can sometimes be problematic, half of the parents also made an effort to place negative aspects of their experience in context of the bigger picture. In doing so, parents identified that there have been “more good times than bad” and that you “get over” the hard times (Rene), that there are stresses and concerns but things have been working out (Alana, Judith), and that things have been getting better and easier over time (Louise, Rachel, and Liza). Jean contextualized her experience in the following way:

I know that my friends who don't have children with disabilities have absolutely no idea how much hard work it is . . . They really don't understand the stress and the energy and the time and the commitment it takes . . . I don't think people know how hard it is sometimes. But they also don't know how rewarding it is and how full your life is and how much joy and funniness comes into your life from some of the wacky things that happen. Like, I don't think they really realize that.

Efforts were made by some parents to dispel negative assumptions they felt others might associate with their child or experience. Parents described their experience “as a gift instead of a burden” (Eve) and talked about how they are not sorry for the way their child has changed their life (Rachel). Others insisted that their child “doesn't hold us back” (Rachel), “doesn't add to the difficulties” (Liza) and how they know “a lot of normal kids who are a lot more challenging

and harder to deal with” (Jean). Eve utilized the negative assumptions of other people as opportunities to identify her daughter’s difference as exciting, explaining:

It is not a source of anything negative. It’s very positive. And some people will look at us as if, oh you know, ‘you’re doing so much for her’, and I say ‘no, she’s doing so much for me.’ ‘Oh, she’s so lucky to have you.’ ‘No, this is our privilege to raise her’. It is not anything negative to have her and people like her in your family.

Reflecting on the public perception of disability as tragic, Ken reframed the experience raising a child with a disability in the following way:

You want a catastrophe? You want tragedy? You know what, let me pick up a paper and show you about somebody who died in a car accident. Let me show you about a young mother that was killed. Let me show you about the tsunami. Those are tragedies. This is a curveball. All you got to do is learn how to hit curves, and you’ll be fine, right? And it’s not easy, but you learn to grow with it.

The majority of the parents also used a variety of positive words to describe life with their child (e.g. good, great, positive, rewarding, gift, godsend, blessing, privilege, benefit, joy to have around). A few mentioned not knowing what they would do without the child. For instance, John shared the following with regard to his son:

He completes our family. I don’t know what we would do if we didn’t have Neal. It would become quieter around here. I mean, our day is so full because of Neal. We’re very active. We’re going from 5 o’clock in the morning to 10 o’clock at night every day. And sometimes you get tired, but we love it because if it wasn’t for Neal, we’d be – what would we be doing? . . . He completes us. Uh, you might say that sounds corny, but it’s not.

In addition, four parents (Eve, Louise, Rene, Heather) were adamant in their belief that there is a reason they were given their child. For instance, three felt as though they were specially chosen by God.

At the end of the interviews, parents were asked what they would like people to understand about their child. Responses were varied. The most common requests were that assumptions not be made about the child based on his/her disability and that people look beyond the disability, recognize the child's ability and potential, and take the time to get to know the child. Louise explained:

The one thing that we always tell him is 'Autism doesn't make me special. I'm special just because' he's who he is. The word *special needs* or the word *Autism*, or anything else is a label. It doesn't mean that's the person. You can read all you want on Autism – doesn't mean you're going to read about Kevin. They're all individuals. And if anything, get to learn the kid by talking to him. Don't just assume, because he's an awesome kid.

Parents also insisted that their children can give a lot to society and deserve respect (Rene) and requested that people make an effort to listen to and learn from their children. Elaborating on this point, Rachel cautioned:

I was just thinking in terms of the impact of all people with Down syndrome on the world, or what's going on right now. We've been trying to basically eradicate this group of people by all the blood testing and stuff. It devalues the lives that they have. And they have something to offer that we just don't have. They've got something really special that we need to sit up and take note of because we could learn a lot from them. . . They've got something *really* special to offer! And all we see is the disability.

At the end of the interviews, parents were also asked what they would like people to understand about their family. Requests included that assumptions and judgments not be made about their family and that others view their family as "normal" or "just like any other family" (Leslie). One parent acknowledged the experience of being a family with a child with a disability as different but clarified that "most importantly what stays the same is the love and respect for one another that makes a family" (Rene).

*Message 3: Would I Change my Family's Circumstances?*

On a slightly different note, three parents reflected on whether or not they would change the fact that their child has with a disability if given the opportunity to do so. Each had a different opinion. For one parent, there was no question that she would change her son's circumstances. Alana explained:

I don't think any parent with a child – or with anybody with a disability – I mean, if you could tell me I could [snaps fingers] go like that and change it, I would but I'm just saying there are positives and there are negatives but, I mean, just for him now he's asking questions, like 'Why – why me? Why did I get this?' You know, and you're sort of going, well Cam, that's the way it is. 'Well, why didn't [sibling] get it?' Well, it didn't happen that way. You know, so I have to deal with his questions too, and – this is what we got, kiddo! And this is what we got to go with, but like I told him, if I could go like that [snaps] and change it I would, but you got to work with what you have.

For Ken, the choice was not so straightforward. While he mentioned that he would not change his child's circumstances for the world, he admitted that for the sake of opportunities for his child he might consider it:

I remember the day we were told, and it was like, 'why me?' And now I'm like, 'thank you'. And you know what, you know the old cliché, 'I wouldn't change it for the world'? I wouldn't. Selfishly, I wouldn't. Now, maybe, for opportunities for Kevin, I might. Maybe I'd say, well, I'd be a bad parent if I didn't – if I couldn't change it, right? But selfishly, he's been a godsend. He's amazing, absolutely amazing, and for all of us – Louise, [Sibling], and myself – and this house. It's just incredible... It's just made both of our lives so much better.

The third set of parents was adamant about not wanting to change anything:

We wouldn't change things. No, we wouldn't change anything – and that's one thing that Garry and I have talked about. We said 'You know what, if things could have been different and Matthias wouldn't have had Fragile X, what do you think? How would you have felt?' . . . And we both said, you know, he's just such a great guy that if not having Fragile X meant that he would be different in any way, then we wouldn't want him not to have Fragile X . . . Garry has said even if, you know, they come up with this treatment – and that was the first thing I can remember you [addressing her husband] saying to Dr. [unclear]; 'Is that going to change

their personality?’ Because [Garry] was afraid of that, he said . . . ‘If it’s going to change who he is, I don’t want it’. (Lilly and Garry)

Near the end of each interview, a question was posed to parents regarding whether or not they perceived their experience to have changed their life for the better and whether or not their experience has changed their view of the world. Yet because the question was two-fold, which component the parent was responding to was unclear. For this reason, responses have not been included in the results.

*Message 4: The Importance of Choosing a Positive Attitude and Research Approach*

For a couple of parents, it was clear that a positive attitude with regard to their circumstances played an important role in their life, and these parents wanted others to appreciate the power of a positive outlook. Rachel suggested that attitude, to a large extent, is a matter of choice. Meanwhile, Ken shared that “80 % of your success comes from your attitude” and advised that “if you do nothing else right but have a positive attitude, it will bring you the things you never dreamed you could have”. Ken’s wife, Louise, shared her frustration with society’s overemphasis on the “negative stuff” and expanded on the importance of focusing on the “positive stuff”. She pleaded:

There’s so many more children being diagnosed with specifically Autism, and all these people think their lives are over. When everybody knows about the negatives, isn’t it time – with so many people being diagnosed – that we tell people, you know what, there is hope despite, you know, high functioning or low functioning. At the end of the day, it is what it is, and you were dealt the hand. You know what; people need to know about the



positive stuff. And I will shout at the top of my voice of positive stuff because I am so tired of hearing negative stuff, there's always positives.

In concluding the interviews, some parents emphasized the importance of drawing research attention to the positives aspects of raising a child with a disability. For instance, Rachel described an incident when a medical professional publicly devalued the lives of children with Down syndrome who died after heart surgery complications. This professional allegedly claimed that losing the children "wasn't much of a loss" because "they didn't have much of a life anyway". Rachel used this example to illustrate the need to provide additional education to professionals in the medical field. She also insisted that, contrary to what some people believe, her daughter and a lot of other children with disabilities do have a positive impact "if people allow it to be that way [and] if they see it that way".

It was apparent from the interviews with parents that they had a lot to share in terms of messages to pass along to other people. Similarly, the children also had messages they wished to share with others. These have been summarized in the final theme below.

### **Theme 3: Messages to Pass Along (Children's Perceptions)**

The children had three messages they wanted to pass along to others: (1) What to Understand About Me, (2) What is Cool, Fun, or Neat about Using a Wheelchair, and (3) What to Understand About my Family. Their messages are explained below, accompanied by examples from the children's narratives.

These results have also been summarized in Table 8.

Table 8: Summary of Children's Messages to Pass Along

Theme 3	Sub-theme	Examples
Messages to Pass Along	(1) What to Understand About Me	<p>-I have disabilities, but I am not a worse person for it.</p> <p>-I can still do some of the same things as anyone else. Do not assume that my disability means I cannot do something.</p> <p>-I know a lot about the world and what is going on, my disability has not stopped me and does not make me unaware, I have big ambitions and a bright future. Do not feel sorry for me.</p>
	(2) What is Cool, Fun, or Neat about Using a Wheelchair	<p>-Having the opportunity to play power wheelchair hockey</p> <p>-Having the opportunity to travel via Dreams Take Flight</p> <p>-Wheelchair as a "conversation piece" – "fun to use it as an opportunity to. . . let them know that there's way more to me than the wheelchair"</p>
	(3) What to Understand About my Family	<p>-My family is nice, fun, caring, loving, understanding, inviting, welcoming, happy</p> <p>-We are a normal family, just like any other</p>

*Message 1: What to Understand About Me*

In closing the interviews, all of the children were asked what they would like other people to understand about them. Five responded without assistance from parents. Responses from three of the children pertained specifically to their experience with disability. For instance, Charlie wanted others to “understand that I have disabilities, but I’m not a worse person for it.” Meanwhile, Claire wanted others to know “that just because I have Muscular Dystrophy that I can do some of the things you can. . . And that it’s not fair to say, ‘oh, you can’t do that’.” Lastly, Karlee responded with the following:

First of all, lots of people have the perception that I’m kind of slow and everything like that. And I want them to know that I really do know a lot about the world and what’s going on, and it hasn’t stopped me – having Cerebral Palsy, being in a wheelchair doesn’t mean I don’t – I’m not an unaware person. And also that I have big ambitions and a bright future, and just that I’m looking forward to big things in my life. What I mean is I don’t want them to feel sorry for me because I think I’m going to have a really good and interesting and fun life.

*Message 2: What is Cool, Fun, or Neat about Using a Wheelchair*

Beyond explaining something about themselves in relation the perceptions of others, three children were also asked what they perceived was cool, fun, or neat about using a wheelchair. Responses included having the opportunity to play power wheelchair hockey, to travel with Dreams Take Flight, and to use her wheelchair as a communication tool. Karlee elaborated:

I don’t like sitting around in it all day, but the thing I like about it is, like, it’s sort of a conversation piece in some strange way . . . people are interested, and it’s kind of fun to use it as an opportunity to sort of let them know that there’s way more to me than the wheelchair.

### *Message 3: What to Understand About my Family*

In addition to sharing about themselves and the benefits they associated with their disability, each child was also asked what they would like other people to understand about their families.<sup>11</sup> The children who responded described their families as nice, fun, caring, loving, understanding, inviting, welcoming, and happy. Again, Karlee summed up her response in the following way:

I want people to understand that my family is really just like any other, and as different as it may seem to other people, my family still faces the same up and downs and times of utter craziness that anyone else's family would. I think it's important for other people to know that we are a normal family. My having a disability is not the main focus of our lives.<sup>12</sup>

### **Summary of Parent and Child Results**

In summary, all of the parents and children interviewed identified a variety of positive effects that the children have had on their families and contributions the children have made to their families. The children taught their families and enabled family members to learn new knowledge, new attitudes, and new or enhanced positive character attributes. They also enriched family members' lives, and made contributions to their families in terms of helpfulness, their positive character traits, and positive emotions they evoked in family members. Participants also had a variety of messages they wished to pass along regarding

---

#### **Notes:**

<sup>11</sup> This question was added after half of the interviews had been conducted based on a conversation with one family. Therefore, it ended up being posed to half of the families via e-mail. Four of the children who were posed the question via e-mail had parents respond on their behalf, and for this reason responses are included in parent results. Note also that one child's response was not recorded due to complications with the tape recorder.

<sup>12</sup> It might be worthwhile to note that while some parents reflected on changing their circumstances, none of the children did this. Yet given Alana's discussion around Cam's "why me" comments, one might suspect that Cam might consider changing his circumstances. However, because Cam did not mention anything on this topic, nothing has been included here.

the following: negative aspects encountered, the bigger picture and reframing their experience, what they wanted others to understand about the child and family, whether or not they would consider changing their circumstances, benefits they associated with disability, and the importance of choosing a positive attitude and research approach. Overall, the participants identified certain effects and contributions that were considered common for any child/family (summarized in Table 9) and others that were considered more unique to these families' circumstances (summarized in Table 10).

Table 9: Summary of Positive Contributions & Areas of Teaching Considered Common for Any Child/Family

Theme	Sub-theme	Common Contributions & Areas of Teaching (Parents' Perceptions)	Common Contributions & Areas of Teaching (Children's Perceptions)
(1) What the Children Taught the Family or Enabled Family Members to Learn	(1) New Knowledge	-Child educated family on topic of interest & shared practical knowledge	-Child educated the family on topic of interest -Child shared practical knowledge
	(2) New Attitudes	-Child changed or exceeded expectations ** -Child taught parents they could do something they did not think they could do * -Parents gained new attitudes toward life (e.g. what is important) & shifted priorities	-Child taught family new attitude toward environment (more globally/ environmentally conscious)
	(3) New or Enhanced Positive Character Attributes	-Child taught family to be more patient, loving, warm, better people, opened heart, made family more caring, creative, balanced, gentle, calm, outgoing, in touch with emotions, less selfish*, taught sibling to be more responsible & independent	
(2) How the Children Enriched Family Members' Lives & Made Other Contributions	(1) Helpfulness	-Child helps with chores -Child provides other types of practical help	-Child helps with chores -Child provides other types of practical help

	(2) The Children's Positive Character Traits	<p>-Child is fun, funny, hilarious, has sense of humor, brings smile to face, makes family laugh, lights up room *</p> <p>-Other traits: caring, compassionate, happy, joyful, affectionate, loving, positive, gentle, sensitive, thoughtful, generous, appreciative, reliable, adventuresome, focused, honest, creative, interesting, knowledgeable, good attitude, good listener, neat person to talk to, appealing personality</p> <p>-Child sets good example **</p>	<p>-Child is fun, funny, a comedian, has good sense of humor, makes family laugh</p>
	(3) Positive Emotions the Children Evoked in Family Members	<p>-Child made parents proud, impressed, inspired, motivated, encouraged, uplifted, appreciate, enjoy, happy, joyous, excited (general), blown away, thrilled, hyper, floored</p> <p>-Family feels fortunate, privileged, lucky, blessed *</p> <p>-Child shifted parents' emotions from negative to positive</p>	<p>-Child made parents proud, happy, glad</p> <p>-Child brightens family's day **</p>
	(4) Other Contributions	<p>-Family met people, gained friendships, made connections</p> <p>-Child made parent or family stronger, improved communication among parents*</p> <p>-Child adds perspective, insight &amp; dimension, brings out good things in parent, brings sanity, slows or relaxes family *</p>	<p>-Child brings different perspective or way of thinking, keeps things interesting, promotes interesting conversations *</p> <p>-Child has connections, counterbalances mellowness</p>

\* Example was placed where majority agreement occurred (3/4 agreed).

\*\* Example could potentially fit under different sub-theme as vote was split for where example belonged (2/4 agreed). Details were discussed in notes throughout the text.

Table 10: Summary of Positive Contributions and Areas of Teaching Considered More Unique to these Families' Circumstances

Theme	Sub-theme	More Unique Contributions & Areas of Teaching (Parents' Perceptions)	More Unique Contributions & Areas of Teaching (Children's Perceptions)
(1) What the Children Taught the Family or Enabled Family Members to Learn	(1) New Knowledge	<ul style="list-style-type: none"> <li>-Sibling gained knowledge from attending speech &amp; occupational therapy appointments</li> <li>-Family gained knowledge/ understanding about disability &amp; people with disabilities</li> <li>-Child provided knowledge for parents to educate others about disability</li> <li>-Child provided knowledge &amp; skills for parent to pursue career in disability field</li> <li>-Parents learned advocacy and activism skills and how to help others in similar circumstances *</li> </ul>	<ul style="list-style-type: none"> <li>-Child educated family about disability &amp; assistive equipment</li> </ul>
	(2) New Attitudes	<ul style="list-style-type: none"> <li>-Child taught new attitudes toward people with disabilities &amp; other families</li> </ul>	<ul style="list-style-type: none"> <li>-Child taught family new attitudes toward people with disabilities &amp; exceeded family's expectations based on diagnosis</li> <li>-Child showed family "how it's really possible to persevere in a big way" (despite physical challenges) *</li> </ul>



			-Child taught family about potential of person with seemingly difficult life to make positive impact
	(3) New or Enhanced Positive Character Attributes	-Child taught family to be more tolerant, accepting, respectful of families with children with disabilities, compassionate regarding people with challenges, in tune with child's development, better person at work (because of understanding about Asperger syndrome)	
(2) How the Children Enriched Family Members' Lives and Made Other Contributions	(1) Helpfulness	-Child calms sibling with similar diagnoses, helped sibling develop faster by providing opportunity to accompany to therapy appointments & enabling access to specialists & services at clinic	-Child helps sibling with similar diagnoses -Child helps family deal with surgeries & pain
	(2) Positive Emotions the Children Evoked in Family Members	-Parent derives more excitement in life from little things given unique circumstances	
	(3) Other Contributions	-Child opened parent to a different place in world (world of disability)	-Child composes & plays music for family (attributes talent to disability) *

\* Example was placed where majority agreement occurred (3/4 agreed).

\*\* Example could potentially fit under different sub-theme as vote was split for where example belonged (2/4 agreed). Details were discussed in notes throughout the text.

## DISCUSSION

The discussion section begins by acknowledging certain negative aspects of families' experiences and placing these in context of the broader findings. Findings of positive effects and contributions considered common for any child/family or more unique to a child with a disability are then explored, followed by discussion around the children's recognition of their effects and contributions. Lastly, findings are linked back to the Affirmative Model of Disability and to the Dynamic Ecological Systems Model, and comparisons are made based on disability, age, and gender.

It is important to address the finding that certain negative aspects of families' experiences similar to those mentioned in previous literature (Drew, Logan & Hardman, 1984; Naseef, 2001; Olshansky, 1962) were described by parents in this study (e.g. challenges, struggles, feelings of stress, grief, mourning, disappointment, sadness). It could be argued that some challenges experienced by some families may be associated more specifically with the child's disability (e.g. medical issues) and may not necessarily be encountered as commonly by other families. The integrated conceptual framework did not account for the characteristics of the child or issues associated specifically with disability as problematic. However, the methodology made it possible not to deny that negative components of an experience might exist but to make a conscious choice not to focus on these. Nevertheless, recognizing certain challenges families mentioned as valid and real is important in ensuring that families obtain

the programs and services that they need. However, as Scorgie and Sobsey (2003) identified, what is important to note is that “although parents of children with disabilities [may be] presented with additional challenges, most of them freely acknowledge that their lives have been enriched by their disabled offspring” (Scorgie & Sobsey, 2003 cited in McPherson & Sobsey, 2003, p.1247). Also interesting to note was a mother’s commentary that despite her daughter’s disabilities which people often assume cause problems for her family, she knows a lot of so-called “normal” or non-disabled children who are lot more challenging to deal with. It is plausible, then, that at least some of the stresses and challenges mentioned (e.g. stubbornness, behavioral issues) are experienced by many parents throughout the course of raising any child.

Regardless, this study confirms findings from the few previous studies suggesting that children with disabilities have a variety of positive effects on individual family members and on the family as a whole (Behr, 1989; Grant et al., 1998; Hastings & Taunt, 2002; Hastings et al., 2002; Hastings et al., 2005; Kearney & Griffin, 2001; Scorgie & Sobsey, 2000; Stainton & Besser, 1998; Turnbull et al., 1986; Turnbull et al., 1988). It also yields interesting findings not reported in prior literature.

### **Common Contributions and Areas of Teaching**

Previous research concluded that the perceived contributions reported by parents of children with disabilities were not all that different from those reported by parents of children who do not have disabilities (McPherson & Sobsey, 2003;

Sobsey & Scorgie, 2000; Turnbull et al, 1986). The data from this study also outlined that a child with a disability can enable some of the same types of learning and make some of the same important contributions as any other child (refer back to Table 9). Highlighting these similarities is critical given the tendency for children with disabilities to be distinguished from non-disabled children and to be viewed as less likely to impact their families in positive ways (Fotheringham et al., 1971; Tausig, 1985).

As explained in the results section, the children were able to teach family members new or enhanced character attributes, for instance to be more patient, loving, caring, responsible, and independent, less selfish, and overall better people. Family members also learned to shift priorities and gained new attitudes toward life and what is important. These findings are similar to previous research summarized in the review of literature. Findings not reported in previous research, however, included the children educating their families on topics of interest and sharing practical knowledge, changing and exceeding family members' expectations, teaching parents they can do something they did not think they could do, and teaching family members to be more creative, balanced, gentle, calm, outgoing, and in touch with their emotions.

Statements about parents feeling proud, happy, lucky, fortunate, privileged, and/or blessed make major contributions to this study by supplementing some of the older literature that limited itself to reporting negative emotions (Naseef, 2001). These statements also stand in contrast to Naseef's (2001) suggestion that all of the positive feelings are deflated when a parent has

a child with a disability. As noted in the results, certain parents described feelings of pride that may have been attached to a certain level of ability, independence, or intellect, or talked about feeling lucky, fortunate, privileged, or blessed because their child's disability is less severe than others or they are dealing with less than other families. Equally worthy of mention, however, is that parents were proud of their children for talents, strengths, and abilities and considered themselves blessed to have the child, period. The fact that families also described themselves as happy, contrasts with the literature that focuses on "chronic sorrow" (Crnic et al., 1983; Olshansky, 1962) and suggests that families with children with disabilities are not typically happy.

As indicated in the review of literature, studies have blamed the presence of a child with a disability for strained family relations, higher levels of parental marital stress, and marital dissolution (Blacher & Hanneman, 1993; Eyman et al, 1972; Jordan, 1962; Tausig, 1985). A few parents from this study talked about having their marriages "tested" and "stretched", which might appear to support previous literature. Yet the majority of parents – including those who made reference to being "tested" and "stretched" – confirmed findings from more recent studies (summarized in the review of literature) suggesting that families have actually grown stronger and closer thanks to the child. Additionally, the parent who speculated about her daughter's possible role in her marital break up noted that her daughter was not likely the specific cause. This causes one to question reports of higher levels of strain caused directly by the child and supports

Havens' (2005) comment regarding the inconclusiveness of studies reporting higher rates of divorce or separation.

### **More Unique Contributions and Areas of Teaching**

Referring back to the literature, Scorgie and Sobsey (2000) found some significant positive life changes associated with raising a child with a disability that may not be associated with parenting a non-disabled child. Aside from Scorgie and Sobsey's (2000) research, however, no other study has suggested that positive changes in family members' lives occur specifically as a result of parenting a child with a disability. The data from this study supports Scorgie and Sobsey's (2000) findings by suggesting that a child with a disability can enable some more unique types of learning and make some more unique contributions to the family (refer to back to Table 10). Previous research (again, summarized in the review of literature) has noted such positive effects as gaining knowledge about, and new attitudes toward, people with disabilities, learning to be more tolerant, accepting, and compassionate regarding people with challenges, and gaining advocacy skills, skills to educate other people about disability, and skills to pursue careers in the disability field. However, with the exception of Scorgie and Sobsey (2000), prior research has not explicitly identified any of these as being more unique to the families' circumstances. Explicitly identifying these may be critical, given the tendency for the unique impacts of children with disabilities to be overlooked by the general public.

This study also adds to the literature because none of the findings classified under enriching family members' lives and making other contributions in more unique ways had been reported in previous research. Previous research may have reported family members considering the children helpful. However, no reports were made regarding the benefits associated with a child's ability to calm his/her sibling with similar diagnoses, to help a sibling develop faster by having opportunities to accompany the child to therapy appointments, or to provide the family access to specialist services. Similarly, while previous research may have reported families experiencing excitement, a mother from this study expressed deriving more excitement in life from the little things given her daughter's circumstances. Also interesting was that in showing her family how it is "really possible to persevere in a big way," despite physical challenges, a child reported a unique area of teaching that no previous literature had reported.

Talking to families and discovering a variety of positive impacts potentially unparalleled (at least not to the same degree) by non-disabled children, and also not reported in previous research, provides reason to believe that other positive and unique effects or contributions might be discovered upon interviewing other families.

### **The Children's Recognition of their Positive Effects**

This study allowed children with disabilities an opportunity to be active participants in the research process and to have their voices heard. It also sought to determine whether the children were aware of the positive effects they have

and the contributions they make to their families. Some children hesitated with their responses, claimed that they were unsure or did not know how to answer a question, or deferred questions to parents. In turn, parents suspected that the children may not have given a lot of thought to the topic area or that “maybe kids just don’t realize what they give” (Rene) to the same extent that parents do. The data obtained from the children was not as elaborate as the data obtained from parents. However, what was interesting was that the children’s perceptions paralleled the parents’ in a variety of ways. This provides validation for both sets of participants’ responses and reinforces the findings. This may have been a result of some families reviewing the questions together ahead of time. Yet the fact that not all families did this and some children came up with responses on their own suggests the children do recognize their positive influence. This was made more interesting given the diversity of the children’s disabilities.

Conclusions cannot be drawn regarding the extent to which participating in the interviews may have contributed to an increase in the children’s positive self-images. This is something that a future study might consider. Yet it is possible that some of the children’s awareness of their effects and contributions may have increased by being encouraged to think about their influence and hearing their parents’ responses. For example, some children admitted to never having thought about their positive impacts yet came up with responses, sometimes to their own surprise. It might be worthwhile to mention here that each of the children was interviewed prior to interviewing their parents which made it unlikely that the children simply mimicked their parents’ responses.



### **Linking Findings Back to the Affirmative Model of Disability**

Noting the positive effects and contributions of the children who participated in this study is particularly helpful in upholding a non-tragic view of disability/impairment. In this respect, findings support the central tenet of the Affirmative Model of Disability – the affirmation of “the value and validity of life as a person with an impairment” (Swain & French, 2000, p.578).

The extent to which the children considered their disability/impairment important to their sense of identity, however, was unclear. Most children acknowledged the existence of their disability/impairment but perceived themselves as able to do normal things and contribute to their families in normal ways. Perhaps this is not surprising, given the extent to which both the parents and children identified effects and contributions considered common for any child/family. Each child also revealed a sense of pride in himself or herself. Yet, for the most part, it was unclear whether this pride was grounded, as Swain and French (2000) describe, in actively celebrating their differences. In these regards, and in so far as the Affirmative Model requires a person with a disability to reject the ideology of normality, some of the children may not have adopted the model as strictly defined by Swain and French (2000). Yet as some researchers argue for the demolition of the “false dividing line between ‘normal’ and ‘disabled’ [meaning impaired]” (Shakespeare & Watson, 2002, p.26), the results suggest that the children saw themselves as both disabled and normal.

Nevertheless, no child indicated that they wished to be other than they are or appeared to perceive their existence or influence as tragic. In the opinion of

the researcher, this was most important. At least four of the children also noted direct benefits to their lifestyle that they associated specifically with their disability/impairment. It is possible that more children may have identified similar benefits had they been asked. However, only three were posed the question about whether there is something positive about being disabled (e.g. whether there is anything cool, fun, or neat about using a wheelchair). Nevertheless, those who made a direct connection between their disability/impairment and a specific benefit to themselves provided direct support for the Affirmative Model.

Moreover, it is recognized that it was not the original intent of the Affirmative Model to be applied by non-disabled people about disabled people. However, the parents in this study, who know firsthand what it is like to live with a child with a disability, each also provided support for a non-tragic understanding of disability.

As mentioned in the results, it needs to be reiterated here that one parent admitted that she would change the fact that her son has a disability if given the opportunity to do so. This comment does seem to support a tragic mindset. Nevertheless, this parent still reported a variety of ways her son has impacted her family positively. The remainder of the parents expressed nothing that supported the tragedy model. This could be understood as a sign of progress that non-disabled people are expressing a more affirmative view. Considering that this non-tragic element was the component of the Affirmative Model that was extracted for the purpose of the study, the model remains useful as part of the integrated conceptual framework.

### **Linking Findings Back to the Dynamic Ecological Systems Model**

As several participants reiterated the problematic role of other people in their surrounding environment, the findings support the Dynamic Ecological Systems Model. Study participants did reveal some negative emotions similar to those reported in previous literature (Bristor, 1984; Drew et al., 1984; Frude, 1992; Naseef, 2001). Yet parents were clear that by no means were their emotions limited to negative emotions. Also noteworthy was the finding that parents did not necessarily hold the child responsible for negative aspects of their experience but 'pointed a finger' at other people and the larger social system. Families talked about the stresses and frustrations with the system, the ignorance of other people, and how predictions of medical professionals regarding a child's prognosis can be overly pessimistic. There is no doubt that information provided by certain medical professionals can be helpful to families. However, these findings reiterate what has been mentioned in previous literature (Gupta & Singhal, 2004; Kearney & Griffin, 2001; Singer & Powers, 1993; Woolfson, 2003) regarding the problematic role that other people and their perceptions can play in how families feel about or adjust to their circumstances.

Kearney and Griffin (2001) found that certain negative feelings experienced by parents originated largely from having to deal with recurring messages of negativity and hopelessness from other people. Evidence for this was provided by a study participant who admitted that struggles adjusting to a child's disability had less to do with the child than with other people's preconceptions and the parent's own feelings regarding what her experience

would be like. Other participants insisted that their anger, nervous breakdowns, and crises resulted from having to deal with the ignorance of other people and a general lack of understanding, more so than from the child. These findings support Woolfson (2003) and Gupta and Singhal's (2004) statements that negative attitudes toward disability and other public perceptions can be transmitted to parents' views of, and beliefs about, their disabled children and to their parenting from outside sources. As previously explained, these may be damaging to a family's ability to think positively about, and adapt to, their circumstances. Findings of this nature are particularly interesting because they provide an opportunity to draw attention away from viewing the child and his/her disability as the problem. They also force us to think about preconceptions of disability that may not be accurate and the influence these may have.

Overall, there did not appear to be notable differences between participant responses based on disability (intellectual disability, physical disability, or intellectual and physical disability). It could be noted that the one child with physical disability only provided more elaborate responses than the rest of the children. Yet it could be argued that her personality and level of comfort with the researcher, rather than her type of disability, may have been responsible for this. Also, one might suspect that the children with physical disabilities might be less helpful with household tasks and chores. However, the data revealed that the helpfulness factor was not associated with a specific disability type. Age and gender of the children did not appear to play a notable role in the types of responses the children provided.

Similarly, no notable differences emerged among parents based on their child's type of disability. There were, however, apparent differences based on the gender of the parents. For instance, the mothers were more likely to identify their careers as having been determined or influenced by their child. While there appeared to be some impact on fathers' careers, on no occasion did a child appear to determine a father's career choice. It was much more common for fathers to report positive effects on already existing careers. Fathers were also more likely than mothers to report the child as having put them more in touch with their emotions. Overall, however, it was apparent that both the mothers and fathers who participated in the study perceived a variety of ways the child impacted the family positively.

### **Summary**

This research revealed that, like a number of researchers (Behr, 1989; Grant et al., 1998; Hastings et al., 2002; Hastings et al., 2005; Hastings & Taunt, 2002; Scorgie & Sobsey, 2000; Stainton & Besser, 1998; Turnbull, Turnbull et al., 1986), parents were frustrated with society's overemphasis on the "negative stuff." Discussing dangers associated with screening for certain disabilities (Garel, Gosme-Seguret, Kaminski & Cuttini, 2002; Green, 1995; Shakespeare, 1998; Shakespeare & Watson, 2002; Swain & French, 2000), a mother insisted that her daughter and other children with disabilities have "something really special to offer." Not surprisingly, no study participant espoused a view that

certain individuals with disabilities are “unworthy of life” (Naseef, 2001; Singer, 2000). In contrast, the majority of the parents felt that:

- (1) their child made their lives better,
- (2) they are not sorry for the way their child has changed their life,
- (3) their child is not a burden or source of anything negative, at least not any more than any other child
- (4) they do not know what they would do without their child, and
- (5) they would not change their circumstances or seek a cure if it were to change who the child is.

These study findings have important implications which are explored in the conclusion.

## CONCLUSION

Historically, children with disabilities have been portrayed as sources of stress and negativity, and disability has been portrayed in Western society as a tragedy to be avoided. Yet this study revealed that children with disabilities can have some of the same effects and make some of the same contributions as any other child. It also revealed that children with disabilities can have unique effects and make unique contributions potentially unparalleled by their non-disabled peers.

The findings from this study can have implications in a variety of areas. Firstly, the findings can provide medical professionals, particularly those involved in prenatal screening and diagnosis, with practical and positive information to share with families when a family is informed that their child has a disability. New parents have the right to this information (Scorgie & Sobsey, 2000). They need to be made aware that raising a child with a disability can be enriching and rewarding, perceptions that allow them to look at their circumstances in a positive light. This would help fill a gap identified in previous literature (Garel et al, 2002) regarding the lack of availability of information for medical professionals to share with parents.

Secondly, the findings might benefit other parents currently raising a child with a disability by encouraging them to focus more closely on what their child adds to their life (Stainton & Besser, 1998). For instance, new parents might be assisted in developing positive but realistic expectations of their children by being

put in touch with other parents who have already been positively impacted (Scorgie & Sobsey, 2000). As mentioned in the review of literature, focusing on positive impacts and the child's contributions may serve to control the meaning and level of stress associated with the experience (Pearlin & Schooler, 1978). There is also evidence that being in contact with a positive attitude may assist some parents in making a positive attitude shift of their own (Singer, Marquis, Powers, Blanchard, Divenere, Santelli, Ainbinder, Sharp, 1999). This suggests that the development or expansion of more programs that promote and nurture the positive perceptions of families may be helpful. Advocating for these programs does not suggest that families are not in need of the resources, supports, and services that address certain challenges they may face. It is doubtful that even the families interviewed for this study would deny additional programming and assistance offered to them. However, while families continue to be provided with programs that address certain issues, the development of more programs that enhance the positive aspects of their circumstances is an area where more attention might be beneficial.

Thirdly, given the problematic role that negative attitudes and assumptions of the larger social system may play in parents' initial reactions to their children, and in their ability to draw on positive perceptions in adapting to their circumstances, these findings need to be shared with the general public. Through advocacy or activism, some families are already involved in the process of educating the public. This study hopes to build on the efforts of parents to promote awareness of the value inherent in every person. Making the findings



available does not suggest that everything will automatically improve for families who might be struggling. However, if society started taking more responsibility for the ways it negatively impacts children and families, by adopting more positive attitudes and attributing more value to the contributions of people with disabilities, it is believed that this could have beneficial effects. It is hoped that as people increasingly recognize and value what children with disabilities can bring to other people's lives, families might have easier access to positive perceptions that they can draw upon in the adaptation process. Perhaps if more families see their experiences in a positive light, they too can influence what happens in other parts of the system (e.g. alter perceptions of the impact of disability, provide additional support to new parents, relieve some of the fear and anxiety about giving birth to a child with a disability).

### **Study Limitations**

It is important to note the limitations of this study. First, the study may have been limited by the small sample size and the fact that eight of the ten families were two-parent families and the majority seemed to have adapted well. As such, this study may not have been representative of a wider population of families since those who volunteered were attracted to the research topic. Nevertheless, similar findings from recent studies (Stainton & Besser, 1998) support the findings of this study. Second, the children who participated in this study had the verbal skills and intellectual capacity to answer the interview

questions. Time and resource constraints made it difficult to include children who did not fit these criteria.

Third, having parents present during some of the children's interviews may have limited this study. The presence of a parent may have increased a child's comfort level and provided an opportunity to rephrase questions in ways the child understood. However, because the children were sometimes prompted by their parents, it is difficult to determine whether certain responses actually reflected the perceptions of the children or of their parents. Similarly, the process of respondent validation (Maxwell, 2005, p.111) may have been undermined by the fact that the researcher relied on parents to review the transcripts with their children and relay the children's feedback. This was also largely due to time and resource constraints.

Fourth, this study may have been limited by the fact that the interview guides were not piloted, and participants were only interviewed once. Piloting the interviews may have provided an opportunity to identify questions which were unclear and to find a more effective way of phrasing questions. In addition, interviewing families on more than one occasion may have provided an opportunity to clarify certain responses and have participants elaborate on others. Because there was no follow up interview, some comments remained unclear in the analysis.

Furthermore, this study is limited in that there were no apparent cultural differences among participants.

## Future Research

Similar to families who participated in studies conducted by Hastings et al. (2005) and Bauman (2004), families from this study commented on the infrequency with which they are asked about the positive aspects of raising a child with a disability. Many participants were enthusiastic about this study and admitted this was an area they had never analyzed to the extent they did in their interviews. One child also spontaneously announced she was glad she participated. This feedback suggests there is a need for more studies that address positive perceptions. Future research might consider further use of the Appreciative Inquiry methodology and the development of tools for qualitatively measuring perceptions of the benefits of having a child with special needs (Hastings et al., 2005). Another researcher seeking to build on this study might consider either posing different interview questions and/or interviewing the parents prior to the children. This might provide a sense of the child's impact from the parent's point of view first and offer ideas to better prompt the child.

Future research might consider interviewing siblings, extended family, and friends in order to "enhance and broaden our understanding of the effects of disability" (Stainton & Besser, 1998, p.68). Given more time and resources, researchers might consider interviewing families with children who were excluded from this study, as well as families from different ethnic or cultural backgrounds. This may shed light on the extent to which culture or ethnicity may play a role in perceptions of disability.

While little is known about the process of identity formation around the disability experience (Darling, 2003), and this was not explored with the children in this study, this is perhaps another area where future research is warranted. Future research might also explore strategies for better enabling children and their families to focus on positive aspects of disability. Future research might also consider to what extent children might benefit from participating in research that explores their positive effects and contributions and how to promote positive self-images among children.

This study is based on the premise that external factors can influence a family's ability to cognitively adapt to disability. While the impact of these societal and ecological factors are noted in Behr's (1990) literature review, "a more critical look at professional impacts and the impact of external factors on family perceptions and coping is needed" (Stainton & Besser, 1998, p.67). Given the implications this study may have for the medical profession, it may be useful to conduct further research on the point of "first disclosure of disability to the family" and on the attitudes of medical professionals toward disability (Stainton & Besser, 1998, p.68). Interviewing families with children with disabilities about their experiences with prenatal diagnosis and "new reproductive technologies" (Stainton & Besser, 1998, p.68) is another area worthy of further investigation.

While this study is also based on the premise that positive perceptions play an important role in making families strong and resilient, more research attention needs to be paid to the exact role of positive perceptions and other psychological resources in adapting to disability (Hastings et al., 2002; Summers

et al., 1988; Woolfson, 2001). Focusing on positive perceptions is not to suggest these are the only – or even the most important – factors leading to adaptation and resilient families. It is important for future research to continue exploring the characteristics of strong and resilient families in the hopes of discovering effective strategies for transferring these to other families.

Despite study limitations and the avenues that remain for future research, this study explored disability from an alternative standpoint using a methodology that has not been used in a similar context. In doing so, it provided additional understanding of the impacts of disability and a more positive representation of the experiences of families raising children with disabilities. This study also added “narrative depth” (Stainton & Besser, 1998, p.67) to the research area, shed light on positive effects not reported in previous research, and provided unique insight into the perceptions of children with disabilities. In doing so, it has laid important groundwork for future research. It is hoped that this study may have planted the seeds of change with an affirmative topic choice (Cooperrider & Whitney, 1999b), which may promote societal awareness and positive dialogue around disability.

## REFERENCES

- Abbott, D.A., & Meredith, W.H. (1986). Strengths of parents with retarded children. *Family Relations*, 35, 371-375.
- Babbie, E. (2001). *The Practice of Social Research*, 9<sup>th</sup> Edition. Belmont, CA: Wadsworth/Thomson Learning.
- Bauman, S. (2004). Parents of children with mental retardation: Coping mechanisms and support needs. Abstract from unpublished doctoral dissertation, University of Maryland. Retrieved October 12, 2006, from <https://drum.umd.edu/dspace/bitstream/1903/1954/1/umi-umd-1903.pdf>
- Behr, S. (1989). The underlying dimensions of the construct of positive contributions that individuals with developmental disabilities make to their families: A factor analytic study. Unpublished doctoral dissertation. University of Kansas.
- Behr, S. (1990). Literature review: Positive contributions of persons with disabilities to their families. Robert Hoyt (Ed.). Lawrence: Beach Centre on Families and Disability.
- Behr, S. K., Murphy, D. L., & Summers, J. A. (1992). *User's manual: Kansas Inventory of Parental Perceptions (KIPP)*. Lawrence: University of Kansas, Beach Centre on Families and Disability.
- Behr, S. K., & Murphy, D. L. (1993). Research progress and promise: The role of perceptions in cognitive adaptation to disability. In A.P. Turnbull, J. M. Patterson, S. K. Behr, D. L. Murphy, J. G. Marquis & M. J. Blue-Banning (Eds.), *Cognitive coping, families, & disability* (151-163). Baltimore: Paul H. Brookes Publishing Co.
- Bogdan, R. & Biklen, D. (1993). Handicapism. In M. Nagler (Ed.). *Perspectives on disability*. Palo Alto: Health Markets Research.
- Blacher, J. & Hanneman, R. (1993). "Out-of-home placement of children and adolescents with severe handicaps: behavioral intentions and behavior". *Research in Developmental Disabilities*, 14, 145-160.
- Booth, T.A. (1978). From normal baby to handicapped child: Unravelling the idea of subnormality in families of mentally handicapped children. *Journal of the British Sociological Association*, 12, 203-221.

- Bristor, M.W. (1984). The birth of a handicapped child – A wholistic model for grieving. *Family Relations*, 33, 25-32.
- Bronfenbrenner, U. (1979). *The ecology of human development: Experiments by nature and design*. Cambridge, MA: Harvard University Press.
- Canadian Coalition for Family Supportive Policy. (2004). Declaration overview: Securing a good life for family members with a disability. Retrieved June 6, 2006, from [http://www.plan.ca/documents/CCFSP.summary\\_june04.pdf](http://www.plan.ca/documents/CCFSP.summary_june04.pdf)
- Cole, D. A. (1986). "Out-of-Home Child Placement and Family Adaptation: A Theoretical Framework". *American Journal of Mental Deficiency*, 91 (3), 226-236.
- Cole, K.A., Clark, J.A., & Gable, S. (2001). Promoting family strengths. Retrieved June, 10, 2006 from <http://muextension.missouri.edu/explore/hesguide/humanrel/gh6640.htm>
- Cooperrider, D. L. (2001). Why Appreciative Inquiry? In S.A. Hammond & C. Royal (Eds.), *Lessons from the field: Applying Appreciative Inquiry* (12). Plano, TX: Thin Book Publishing Co.
- Cooperrider, D. L., & Srivastva, S. (1987). Appreciative Inquiry in Organizational Life. *Research in Organizational Change and Development*, 1, 129-169.
- Cooperrider, D. L., & Whitney, D. (1999a). A positive revolution in change: Appreciative Inquiry (Draft). Retrieved September 30, 2006, from: <http://appreciativeinquiry.case.edu/uploads/whatisai.pdf>
- Cooperrider, D. L., & Whitney, D. (1999b). *Collaborating for change: Appreciative Inquiry*. San Francisco, CA: Berrett-Koehler Communications Inc.
- Cooperrider, D. L., Whitney, D., & Stavros, J. M. (2005). *Appreciative Inquiry Handbook: The First in a Series of AI Workbooks for Leaders of Change*. Bedford Heights, OH: Lakeshore Communications Inc. & Berrett-Koehler Publishers.
- Crnic, K. A., Friedrich, W. N., & Greenberg, M. T. (1983). Adaptation of families with mentally retarded children: A model of stress, coping, and family ecology. *American Journal of Mental Deficiency*, 88 (2), 125-138.
- Darling, R. B. (2003). Toward a Model of Changing Disability Identities: a proposed typology and research agenda. *Disability & Society*, 18 (7), 881-895.

- Datta, S. S., Russell, P. S., & Gopalakrishna, S. C. (2002). Burden among the caregivers of children with intellectual disability. *Journal of Learning Disabilities, 6* (4), 337-350.
- Shaffer, D. R. (1999). *Developmental Psychology: Childhood and Adolescence*, (5<sup>th</sup> Ed.). Pacific Grove, CA: Brooks/Cole Publishing Company.
- Drew, C. J., Logan, D. R., & Hardman, M. L. (1984). *Mental Retardation – a life cycle approach*. Toronto: Times Mirror/Mostle College Publishing.
- Duncan, S. (2001). Building family strengths. Retrieved June, 10, 2006 from <http://familycenter.byu.edu/newarticles.aspx?id=5>
- Dunlap, W. R., & Hollinsworth, J.S. (1977). How does a handicapped child affect the family? Implications for practitioners. *The Family Coordinator, 26* (3), 286-293.
- Dunst, C. J., Trivette, C. M., & Deal, A. G. (1988). *Enabling and empowering families: Principles and guidelines for practice*. Cambridge, MA: Brookline Books.
- Dunst, C. J., Trivette, C. M., & Mott, D. W. (1994). Strengths-based family-centered intervention practices. In C. J. Dunst, C. M. Trivette, & A. G. Deal (Eds.), *Supporting & strengthening families* (115-131). Cambridge, MA: Brookline Books.
- Eyman, R. K., O'Connor G., Tarjan, G., & Justice, R. S. (1972). Factors determining residential placement of mentally retarded children. *American Journal of Mental Deficiency, 76* (6), 692-698.
- Folkman, S., & Mascowitz, J. T. (2000). Positive affect and the other side of coping. *American Psychologist, 55* (6), 647-654.
- Fotheringham, J. B., Skelton, M., & Hoddinolt, B. (1971). *The retarded child and his family: The effects of home and institution*. Toronto, Ontario, Canada: Institute for Studies in Education.
- French, S. (1994). The Disabled Role. In French S. (Ed.) *One Equal Terms: Working with disabled people*. Butterworth-Heinemann. Oxford.
- French, S. & Swain, J. (2004). Whose Tragedy? Towards a personal non-tragedy view of disability. Retrieved January 3, 2007, from <http://www.leeds.ac.uk/disabilitystudies/archiveuk/swain/affirmative%20chapter.pdf>
- Frude, N. (1992). *Understanding family problems: A psychological approach*. Chichester: John Wiley.



- Garel, M., Gosme-Seguret, S., Kaminski, M. & Cuttini, M. (2002). Ethical decision-making in prenatal diagnosis and termination of pregnancy: a qualitative survey among physicians and midwives. *Prenatal Diagnosis*, 22, 811-817.
- Glidden, L.M. (1993). What we do not know about families with children with disabilities: Questionnaire on resources and stress as a case study. *American Journal on Mental Retardation*, 97, 481-495.
- Grant, G., Ramcharan, P., McGrath, M., Nolan, M., & Keady, J. (1998). Rewards and gratifications among family caregivers: Towards a refined model of caring and coping. *Journal of Intellectual Disability Research*, 42 (1), 55-71.
- Greer, F.A., Grey, I. M., & McClean, B. (2006). Coping and positive perceptions in Irish mothers of children with intellectual disabilities. *Journal of Intellectual Disabilities*, 10 (3), 231-248.
- Grossman, F. K. (1972). Brothers and sisters of retarded children. New York: Syracuse University Press.
- Gupta, A., & Singhal, N. (2004). Positive perceptions in parents of children with disabilities. *Asia Pacific Disability Rehabilitation Journal*, 15 (1), 22-35.
- Hastings, R. P., Allen, R., McDermott, K., & Still, D. (2002). Factors related to positive perceptions in mothers of children with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 15, 269-275.
- Hastings, R. P., Beck, A., & Hill, C. (2005). Positive contributions made by children with an intellectual disability in the family: Mothers' and fathers' perceptions. *Journal of Intellectual Disabilities*, 9 (2), 155-165.
- Hastings, R. P., & Taunt, H. M. (2002). Positive perceptions in families of children with developmental disabilities. *American Journal on Mental Retardation*, 107 (2), 116-127.
- Havens, C. A. (2005). Becoming a resilient family: Child disability and the family system. Retrieved September 21, 2006, from <http://www.ncaonline.org/monographs/17family.shtml>
- Helff, C. M. & Glidden, L. M. (1998). More positive or less negative?: Trends in research on adjustment of families rearing children with developmental disabilities. *Mental Retardation*, 36, 457-464.

- Jordan, T.E. (1962). Research on the handicapped child and the family. *Merrill-Palmer Quarterly*, 8, 243-260.
- Kazak, A.E., & Marvin, R.S. (1984). Differences, difficulties and adaptation: Stress and social networks in families with a handicapped child. *Family Relations*, 33, 67-77.
- Kearney, P. M., & Griffin, T. (2001). Between joy and sorrow: being a parent of a child with developmental disability. *Journal of Advanced Nursing*, 34 (5), 582-592.
- Kelly, C. (2007). *The Role of Mandates/philosophies in Shaping Interactions between People with Disabilities and their Support Providers*. Unpublished master's thesis, University of Manitoba, Winnipeg, Manitoba, Canada.
- Klassen, K. (2007). *Career Exploration Experiences for Children with Disabilities*. Unpublished master's thesis, University of Manitoba, Winnipeg, Manitoba, Canada.
- Maxwell, J. A. (2005). *Qualitative research design: An interactive approach* (2<sup>nd</sup> Ed.). Thousand Oaks: Sage Publications.
- McAndrew, I. (1976). Children with a handicap and their families. *Child: Care, Health & Development*, 2, 213-237.
- McCubbin, H. I., Joy, C. B., Cauble, A. E., Comeau, J. K., Patterson, J. M., & Needle, R. H. (1980). Family stress and coping: A decade review. *Journal of Marriage and the Family*, 42, 855-871.
- McCubbin, H. I., McCubbin, M. A., Thompson, A. I., Han, S.-Y., & Allen, C. T. (1997). Families under stress: What makes them resilient. Adapted from the 1997 American Association of Family and Consumer Sciences Commemorative Lecture. Retrieved June 1, 2006 from: <http://www.cyfernet.extension.umn.edu/research/resilient.html>
- McCubbin, M. A., & McCubbin, H. I. (1987). Family stress theory and assessment: The T-Double ABCX model of family adjustment and adaptation. In H.I. McCubbin, & A.I. Thompson (Eds.), *Family assessment inventories for research and practice* (3-25). Madison, Wisconsin: University of Wisconsin-Madison.
- McCubbin, M.A., & McCubbin, H.I. (1996). Resiliency in families: A conceptual model of family adjustment and adaptation in response to stress and crisis. In H.I. McCubbin, A.I. Thompson, & M.A. McCubbin (Eds.). *Family assessment: Resiliency, coping and adaptation – Inventories for research and practice* (1-64). Madison, WI: University of Wisconsin System.

- McPherson, G. W. & Sobsey, D. (2003). Rehabilitation: Disability ethics versus Peter Singer. *Arch Phys Med Rehabilitation*, 84, 1246-1248.
- Miles, M. B., & Huberman, A. M. (1994). *Qualitative data analysis: An expanded sourcebook* (2<sup>nd</sup> Ed.). London: Sage Publications.
- Miller, W. L. & Crabtree, B. F. (1999). The Dance of Interpretation. In B. Crabtree & W. Miller (Eds.), *Doing Qualitative Research* (2<sup>nd</sup> Ed.). Thousand Oaks, CA: Sage Publications.
- Morris, J. (1991). *Pride Against Prejudice*. The Womens Press. London.
- Mullins, J. B. (1987). Authentic voices from parents of exceptional children. *Family Relations*, 36, 30–55.
- Nagler, M., & Nagler, A. (1997). *Yes you can!: A guide for parents of children with disabilities*. Toronto: Stoddart.
- Naseef, R. A. (2001). *Special children, challenged parents: The struggles and rewards of raising a child with a disability*. Secaucus, N.J.: Carol Publishing Group.
- Nelson Canadian Dictionary of the English language: An Encyclopedic Reference. (1997). ITP Nelson, Toronto.
- O'Connor, S. (1995). 'We're all one family': The positive construction of people with disabilities by family members. In S. J. Taylor, R. Bogdan, & Z. Lutfiya (Eds.), *The variety of community experience: Qualitative studies of family and community Life* (68-77). Baltimore: Paul H. Brookes Publishing Co.
- Oliver, M. (1983). *Social work with disabled people*. Basingstoke: Macmillan.
- Oliver, M. (1990). *The politics of disablement*. London: MacMillan.
- Oliver, M. & Sapey, B. (1999). *Social work with disabled people* (2<sup>nd</sup> Ed.). Macmillan, London.
- Olshansky, S. (1962). Chronic sorrow: A response to having a mentally defective child. *Social Work*, 43, 190-193.
- Paquette, D. & Ryan, J. (n.d.). Bronfenbrenner's Ecological Systems Theory. Retrieved May 25, 2006, from: <http://pt3.nl.edu/paquetteryanwebquest.pdf>
- Patton, M.Q. (1990). *Qualitative evaluation and research methods* (2<sup>nd</sup> Ed.). Newbury Park, CA: Sage Publications.

- Pearlin, L. I., & Schooler, C. (1978). The structure of coping. *Journal of Health and Social Behavior*, 19, 2-21.
- Poyadue, F. S. (1993). Cognitive coping at parents helping parents. In A.P. Turnbull, J. M. Patterson, S. K. Behr, D. L. Murphy, J. G. Marquis, & M. J. Blue-Banning (Eds.), *Cognitive Coping, Families, & Disability* (95-109). Baltimore: Paul H. Brookes Publishing Co.
- Rangaswami, K. (1995). Parental attitude towards mentally retarded children. *Indian Journal of Clinical Psychology*, 22, 20-23.
- Reynolds, A.R. (1979). Some social effects of the mentally retarded child on the family. *Australian Journal of Mental Retardation*, 5, 214-218.
- Rioux, M. (1997). When myths masquerade as science: Disability rights from an equality-rights perspective. In L. Barton & M. Oliver. (Eds.), *Disability studies: Past, present, and future*. Leeds: The Disability Press.
- Rousey, A. B., Blacher, J. B., & Hanneman, R. A. (1990). Predictors of out-of-home placement of children with severe handicaps: A cross-sectional analysis. *American Journal on Mental Retardation*, 94 (5), 522-531.
- Scorgie, K., & Sobsey, D. (2000). Transformational outcomes associated with parenting children who have disabilities. *Mental Retardation*, 38 (3), 195-206.
- Shakespeare, T. (1998). Choices and rights: Eugenics, genetics and disability equality. *Disability & Society*, 13 (5), 665-682.
- Shakespeare, T., & Watson, N. (1998). Theoretical perspectives on research with disabled children. In C. Robinson, & K. Stalker (Eds.), *Growing up with Disability* (13-27). London: Jessica Kingsley Publishers.
- Shakespeare, T., & Watson, N. (2002). The social model of disability: an outdated ideology? *Research in Social Science and Disability*, 2, 9-28.
- Singer, G.H., Marquis, J., Powers, L. K., Blanchard, L., Divenere, N., Santelli, B., Ainbinder, J. G. & Sharp, M. (1999). A multi-site evaluation of parent to parent programs for parents of children with disabilities. *Journal of Early Intervention*, 22, 217-229.
- Singer, G.H., & Powers, L.E. (1993). Contributing to resilience in families: An overview. In G.H. Singer, & L.E. Powers (Eds.), *Families, disability, and empowerment: Active coping skills and strategies for family interventions* (1-26). Baltimore: Brookes.
- Singer, P. (2000). *Writings on an ethical life*. New York: HarperCollins.

- Sobsey, D. (1990). Too much stress on stress? Abuse and the family stress factor. *Quarterly Newsletter of the American Association on Mental Retardation*, 3 (2), 8.
- Stainton, T., & Besser, H. (1998). The positive impact of children with an intellectual disability on the family. *Journal of Intellectual & Developmental Disability*, 23 (1), 57-70.
- Strauss, A., & Corbin, J. (1990). *Basics of qualitative research: Grounded theory procedures and techniques*. Newbury Park, CA: Sage Publications, Inc.
- Summers, J. A. (1988). Family adjustment: Issues in research on families with developmentally disabled children. In V.B. Van Hasselt, P.S. Strain, & M. Hersen (Eds.), *Handbook of developmental and physical disabilities* (79-90). Elmsford, NY: Pergamon.
- Summers, J. A., Behr, S. K., & Turnbull, A. P. (1988). Positive adaptation and coping strengths of families who have children with disabilities. In G. H. Singer, & L. K. Irvin (Eds.), *Support for caregiving families: Enabling positive adaptation to disability* (27-40). Baltimore: Paul H. Brookes Publishing Co.
- Swain, J., & French, S. (2000). Towards an affirmative model of disability. *Disability & Society*, 15 (4), 569-582.
- Tausig, M. (1985). Factors in family decision-making about placement for developmentally disabled individuals. *American Journal of Mental Deficiency*, 89 (4), 352-361.
- Taylor, S. E. (1983). Adjustment to threatening events: A theory of cognitive adaptation. *American Psychologist*, 38, 1161-1173.
- Nhat Hanh, Thich. (n.d.). Retrieved March 8, 2009, from [http://www.brainyquote.com/quotes/authors/t/thich\\_nhat\\_hanh.html](http://www.brainyquote.com/quotes/authors/t/thich_nhat_hanh.html).
- Trute, B., & Hauch, C. (1988). Building on family strength: A study of families with positive adjustment to the birth of a developmentally disabled child. *Journal of Marital and Family Therapy*, 14 (2), 185-193.
- Turnbull, A. P. (1988). Positive contributions that members with disabilities make to their families. Paper presented to the AAMD 109<sup>th</sup> Annual Meeting, Philadelphia.

- Turnbull, A. P., Behr, S. K., & Tollefson, N. (1986, May). Positive contributions that persons with mental retardation make to their families. Paper presented at American Association on Mental Deficiency, Denver, CO.
- Turnbull, A.P., Brotherson, M.J., & Summers, J.A. (1985). The impact of deinstitutionalization of families. In R. Bruininks & K. Lakin (Eds.) *Living and learning in the least restrictive environment*. Baltimore: Paul H. Brookes.
- Turnbull, H. R., Guess, D., & Turnbull, A. P. (1988). Vox populi and baby doe. *Mental Retardation*, 26, 127–132.
- Vasta, R, Miller, S.A., Ellis, S., Younger, A., & Gosselin, P. (2006). *Child psychology (Canadian Edition)*. Mississauga, ONT: John Wiley & Sons Canada, Ltd.
- Vohs, J. (1993). On belonging: A place to stand, a gift to give. In A.P. Turnbull, J. M. Patterson, S. K. Behr, D. L. Murphy, J. G. Marquis, & M. J. Blue-Banning (Eds.), *Cognitive coping, families, & disability* (pp51-66). Baltimore: Paul H. Brookes Publishing Co.
- Walsh, F. (2003). Family resilience: A framework for clinical practice. *Family Process*, 42 (1), 1-18.
- Watkins, J. B., & Mohr, B. J. (2001). *Appreciative Inquiry: Change at the speed of imagination*. San Francisco, CA: Jossey-Bass/Pfeiffer.
- Webster's Third New International Dictionary. (1960). Cambridge, Massachusetts: Merriam-Webster Inc.
- Whitney, D., & Trosten-Bloom, A. (2003). *The power of Appreciative Inquiry: A practical guide to positive change*. San Francisco, CA: Berrett-Koehler Publishers, Inc.
- Wolbring, G. (2002). Science Technology and the Triple D (Disease, Disability, Defect). Retrieved November, 2004, from <http://www.bioethicsanddisability.org/nbic.html>.
- Woolfson, L. (2001). Cognitive change and effective parenting of disabled children. *Proceedings of the British Psychological Society*, 9 (2), 277.
- Woolfson, L. (2003). Disabled children, parents and society: a need for cognitive reframing. *Proceedings of the British Psychological Society*, 11 (1), 5.
- The Free Dictionary by Farlex. (n.d.). Retrieved September 1, 2008, from <http://www.thefreedictionary.com/attitude>.

## **APPENDICES**

Appendix A: Glossary of Terms / Operational Definitions

Appendix B: Recruitment Advertisement

Appendix C: Recruitment Letter

Appendix D: Overview of Appreciative Interview Questions for Parents

Appendix E: Overview of Appreciative Interview Questions for Children

Appendix F: Parent Interview Guide

Appendix G: Child Interview Guide

Appendix H: Informed Consent Form for Parents

Appendix I: Informed Consent/Assent Form for Children

Appendix J: Ethics Approval Certificate

Appendix K: Guidelines / Instructions for Third Party Reviewers

## Appendix A: Glossary of Terms / Operational Definitions

**Advocacy:** The “act of pleading for or supporting” (Webster’s Third New International Dictionary, 1960). (Synonyms: backing, sponsorship, promotion.)

**Advocate:** “To plead in favor of; to defend by argument, before . . . the public; to support” (Webster’s Third New International Dictionary, 1960). (Synonyms: endorse, defend.) Includes how family members have been given an opportunity to defend their child or other people with disabilities through educating others.

**Attitude:** The way a family member thinks (their mind-set or point of view) or behaves (or their disposition to act or respond in a particular way) towards a given person or situation ([www.thefreedictionary.com](http://www.thefreedictionary.com)). This includes how the child teaches family members new ways of thinking toward people with disabilities, other families, life in general, and how the child has changed or exceeded family members’ expectations.

**Character Attribute:** A personal quality, characteristic, trait, or feature (e.g. loving patient, tolerant) that a family member has acquired, or that has been enhanced in a family member, as a result of the child.

**Character Trait:** An aspect of the child’s personality or character, or inner qualities of the child, that parents valued and felt the child contributed to the family. These typically consisted of short or one word descriptors (e.g. funny, happy, loving, thoughtful).

**Contribution:** “The perceived benefits attributed to the presence of a family member with a disability by parents, siblings, and others in the family system” (Behr, 1989, p7). More specifically, what the child has done for, brought to, or added to the family. Examples include chores and other forms of helpfulness, positive character traits, positive emotions evoked in family members, and other contributions.

**Disability / Impairment:** While distinctions can be made between the terms *disability* and *impairment*, this study did not focus on these distinctions. The families interviewed did not distinguish between the two terms at any point. Therefore, since the participants used the term *disability*, it is used throughout the study. Also, for the purposes of this paper, the terms *child with a disability* and *disabled child* are used interchangeably. This choice is intentional. Using the term *child with a disability* is consistent with people first language of Canada and the language of the participants. Using the term *disabled child* reflects terminology used in the UK that acknowledges that the child can be disabled by society.



**Effect:** For the purposes of this paper, the term *effect* is considered synonymous with the term *impact*, and is therefore used interchangeably throughout the text. *Effect* or *impact* is used to explain the influence of a child with a disability on the family. This influence can be understood in negative or positive terms. When exploring the positive impacts of a child, researchers sometimes also discuss positive contributions. In the context of this paper, an *effect* refers to something the child has done for the family, as in an outcome or consequence of the child (e.g. taught), whereas a *contribution* refers to something the child has added to the family.

**Emotion:** A family member's way of feeling toward the child, toward aspects of their experience, or toward their overall experience living with the child.

**Enrich:** To improve or enhance the lives of family members.

**Family:** The term *family* refers to "two or more people... related by blood [or] marriage" (Canadian Coalition for Family Supportive Policy, 2004, p.1). For the purposes of this paper, the term *family* refers to immediate relatives (parents and siblings) who care for at least one child with an intellectual and/or physical disability within the family home.

**Helpfulness:** Ways the child assists in direct (e.g. chores) and indirect (e.g. access to services) ways and is (or has been) willing to lend a hand to family members. Examples reflect instances when a parent specifically used the words *help* or *helpful*.

**It's not all rosy either:** Acknowledges negative aspects associated with families' experiences, including challenges, struggles, emotions (e.g. stress, disappointment), and other perceived negative effects of the child. It also includes parents' reflections on negative emotions (e.g. grief) or problems (e.g. crisis) encountered by family members stemming from other people rather than the child.

**Knowledge:** Information, education, understanding, wisdom, or skill a family member has learned from the child regarding disability, people with disabilities, assistive equipment, other families, and topics of interest to the child (e.g. dinosaurs, computers, science, medicine).

**Learning:** "The process through which our experiences produce relatively permanent changes in our feelings, thoughts, and behaviors" (Developmental Psychology: Childhood and Adolescence, 1999). (Synonyms: be taught, be trained, become skilled at, gain knowledge of, realize, or understand.)

**Other Contributions:** Additional contributions that do not specifically have to do with helpfulness, the children's positive character traits, or ways family members

feel. Examples include the expansion of social networks, family members being strengthened, and the child improving communication within the family.

**Teach:** “To impart knowledge of, skill in, or information or understanding... to cause to learn by example or experience” (Nelson Canadian Dictionary of the English language, 1997). (Synonyms: to educate, explain, or show.)

**The Importance of a Positive Attitude and Research Approach:** Includes parents’ reflections on the significance of a positive attitude choice and allowing oneself to see the positive impact and contributions their child can make.

**Reflections of the Bigger Picture, Reframing the Experience, and Understanding my Child and Family:** Includes efforts made by parents to place negative aspects of their experience in the context of the bigger picture and to dispel negative assumptions others might associate with their child or experience. Also includes a variety of positive words used by parents to describe life with their child (e.g. rewarding) and examples of what parents would like people to understand about their child and their family.

**Would I Change my Family’s Circumstances?:** Includes, and is limited to, parents’ reflections on whether or not they would consider changing the fact that their child has a disability, if given the opportunity to do so.

**What is Cool, Fun, or Neat about Using a Wheelchair:** Includes examples of what three children perceived is cool, fun, or neat about using a wheelchair (e.g. playing power wheelchair hockey, having an opportunity to travel on ‘Dreams Take Flight’, using it as a communication tool).

**What to Understand about Me:** Includes examples of what the children would like other people to understand about them.

**What to Understand About my Family:** Includes examples of what the children would like other people to understand about their families.

## **Appendix B: Recruitment Advertisement**

### **PARENT & CHILD / YOUTH INVITATION TO PARTICIPATE IN A RESEARCH PROJECT**

#### **Parent & Child Perceptions of the Positive Effects that a Child with a Disability can have on the Family**

*Affiliation: University of Manitoba*

#### **What is This Study About?**

The purpose of this study is to learn more about the perceptions of parents of children with disabilities, as well as the perceptions of children themselves, regarding the positive effects that a child with a disability can have on the family.

#### **This Study is Open to:**

- Parents who provide care at home to at least one child/youth with a physical and/or intellectual disability
- Parents who would like to share their positive experiences raising a child/youth with a disability
- Children/Youth with disabilities (12-17 years) who currently reside at home and who would like to be interviewed

#### **This Study Offers an Opportunity to:**

- Appreciate the positive impacts of children with disabilities by exploring disability from a positive standpoint
- Talk about positive experiences and positive aspects of disability
- Change negative attitudes towards people with disabilities by promoting positive perceptions
- Encourage children/youth with disabilities to have a 'voice' in research

**If you are a parent of a child with a disability and want to share your positive experiences, or you are a child/youth with a disability who would like to share your perspective, or want more information, please call Michelle Lodewyks (204-xxx-xxxx) or e-mail me at xxx@cc.umanitoba.ca. Please also feel free to contact my research supervisor, Dr. Christine Blais, at 204-xxx-xxxx or xxx@cc.umanitoba.ca. We would be happy to answer any questions you have!**

**Children/Youth will receive two Cinema City 8 free movie passes for participating.**

This study is being conducted by **Michelle Lodewyks**  
Interdisciplinary Masters Program in Disability Studies  
Department of Graduate Studies  
University of Manitoba

*(Note: For the actual study, the recruitment advertisement was printed on university letterhead.)*

## Appendix C: Recruitment Letter

**Research Project Title:** Parent & Child Perceptions of the Positive Effects that a Child with a Disability can have on the Family

**Researcher:** Michelle Lodewyks

**Research Supervisor:** Dr. Christine Blais (Associate Professor, Disability Studies)

**University of Manitoba Committee Members:** Dr. Nancy Hansen (Director, Disability Studies), Dr. Emily Etcheverry (Director, School of Medical Rehabilitation), Dr. Roberta Woodgate (Assistant Professor, Faculty of Nursing)

**Affiliation:** University of Manitoba

May 15, 2007

Dear Parent(s) and Children,

Hello, my name is Michelle Lodewyks. I am a Master's student at the University of Manitoba in the Interdisciplinary Masters Program in Disability Studies. I am writing to tell you about a research project that I am working on for my thesis. My study has been approved by the University of Manitoba's Research Ethics Board, and this letter has been sent to you on my behalf by \_\_\_\_\_ (name of individual) at \_\_\_\_\_ (name of organization).

The name of my study is *Parent & Child Perceptions of the Positive Effects that a Child with a Disability can have on the Family*. The purpose of the study is to learn more about the perceptions of parents of children with disabilities, and children themselves, regarding the positive effects that a child with a disability can have on the family. What I learn from parents and children I interview will be presented in my Master's thesis. The study will provide children with disabilities a voice in research, and the information will hopefully help foster more positive perceptions of people with disabilities in general.

I am inviting 10 parents and 10 children from a total of 10 families to take part in my study. In order to participate, the children must have a physical and/or intellectual disability, must be between 12-17 years old, must currently live at home, and must speak and understand the English language well enough to understand the interview questions. Parents and children will be invited to take part in individual interviews that will be arranged at a time and place that is convenient for you. I would also like to meet with you to get to know you before the interviews. I am estimating that each interview will take anywhere from 20-60 minutes to complete. Parent and child interviews will be separate, unless a child prefers to have a parent present for the interview. Each participant will be provided with an overview of the interview questions prior to the interview, and parents will be asked to review these questions with their children. I will ask you to read and sign a consent form, and you will be provided with a copy of the consent form to keep. The interviews will be audio-tape recorded and transcribed. If you choose to participate, please be assured that there are no

right or wrong answers to the questions and that all information will be kept confidential. This means that your name (as well as your child's name) will not be connected in any way with your answers in any reports about the study. Should you and/or your child wish to withdraw from the study, or refuse to answer any questions, you may do so at any time without penalty. Once the study is complete, you will receive a summary of the findings if you so wish.

If you and your child are interested in participating in the study, or want more information, please feel free to contact me at xxx-xxx-xxxx or at my e-mail address: xxx@cc.umanitoba.ca. You may contact my research supervisor, Dr. Christine Blais, at xxx-xxx-xxxx or at xxx@cc.umanitoba.ca. If you would feel more comfortable, you may also feel free to return the enclosed response card to \_\_\_\_\_ (name of individual at organization) at \_\_\_\_\_ (address of organization), or you may mail it to me directly at the following address: xxxxxxxxxxxx, Winnipeg, MB xxx xxx.

If you are interested in the study and are willing to share your positive experiences with me, please let me know as soon as possible or by June 30, 2007. Your decision to participate is completely voluntary. Children will receive two Cinema City 8 movie passes for participating in the study.

Thank you in advance for your time and consideration. Once again, if you have any questions or are interested in learning more about the study, please contact me by phone, e-mail, or by returning the response card (below). I look forward to hearing from you and learning about your positive experiences!

Sincerely,

---

**Michelle Lodewyks**

M.A. Candidate, Interdisciplinary Master's Program in Disability Studies  
University of Manitoba

---

**Dr. Christine Blais**

Research Supervisor  
University of Manitoba

*\*Please see attached response card if you wish to use it to request more information or to volunteer for the study.*

**RESPONSE CARD:**

My name is \_\_\_\_\_, and my son's / daughter's (circle) name is \_\_\_\_\_.  
We are interested in Michelle's study on "Parent & Child Perceptions of the Positive Effects that a Child with a Disability has on the Family".

We would be willing to have Michelle contact us by phone / e-mail (circle) to find out more about her study before we agree to participate.

We would prefer to be contacted by telephone.

**Phone:** \_\_\_\_\_ (home) / \_\_\_\_\_ (work) \_\_\_\_\_ (cell).

(The best time to reach us is between \_\_\_\_ - \_\_\_\_ (time) on a \_\_\_\_ (day of week).

We would prefer to be contacted by e-mail.

**E-mail address:** \_\_\_\_\_

## Appendix D: Overview of Appreciative Interview Questions for Parents

### Main Questions:

The main question I would like you to think about for your interview is: *“What positive effects has your child with a disability had on you and/or your family?”* Below are some additional questions I may ask you during your interview to assist me in gathering more information or to clarify my understanding of your experience. Please feel free to ask me for clarification on any questions before or during the interview.

- 1) Tell me a bit about yourself, your family (e.g. children, living arrangements), and your child with a disability (e.g. age, sex, type of disability – only if you want to).
- 2) Using only positive words, how would you describe \_\_\_\_\_ (name) (e.g. best qualities, positive traits, talents, strengths)?
- 3) Think about times you have really felt good about, pleased with, or proud of your child. Describe what made these times exciting or meaningful.
- 4) Describe other positive aspects (e.g. rewards, gratifications) of parenting \_\_\_\_\_ (name).
- 5) In what ways does your child contribute to your family? What is the greatest contribution s/he has made to your life and/or your family (area child has had the biggest positive impact)?
- 6) Describe to me in what ways, if any, your child has had a positive impact on: (a) your marriage, (b) your spouse, (c) your job/career, (d) your social network, (e) his/her sibling(s), (f) extended family.
- 7) Have there been other positive changes experienced (or additional family strengths discovered) as a result of having \_\_\_\_\_ (name) in your family?
- 8) Describe a time of personal growth from your experience raising your child.
- 9) Has your experience raising \_\_\_\_\_ (name) changed your view of the world or your life/ family’s life for the better? Explain.
- 10) If you could have other people understand 3 things about your child, what would these be?

***Thank you for taking part in my study!***

## Appendix E: Overview of Appreciative Interview Questions for Children

### Main Questions:

The main question I would like you to think about for your interview is: *“What positive effects do you (as a child with a disability) feel you have had on your family?”* I may also ask you to talk about some of the questions below to help me better understand your experience. Please feel free to ask me any questions you might have before or during your interview.

- 1) Tell me a bit about yourself (e.g. age, school, likes, dislikes, disability – optional) and your family (e.g. parents, living arrangements, siblings, and getting along).
- 2) What are some good things you can tell me about yourself (e.g. best qualities, talents, things you are good at, what you like best about yourself)?
- 3) What do you think your family would say are the 3 things they like best about you?
- 4) Describe to me what, if anything, you find is cool/fun/neat about having \_\_\_\_\_ (disability).
- 5) Think about times you have really felt good about or proud of yourself (where you did something good or accomplished something important). Tell me a story about one of these times. Tell me about some things you do (or have done) that you think make your family happy/proud.
- 6) What is the biggest contribution\* your think you have made to your family (e.g. something you have helped a family member learn or understand)?
- 7) If you could have other people understand 3 positive things about you, what would these be?

***Thank you for taking part in my study!***



## Appendix F: Parent Interview Guide

*Below is an outline of the topics and types of questions that may be covered during the interview with parent participants. These questions are intended to promote open conversation based on the philosophy of Appreciative Inquiry. The research question to guide discussion is: "What positive effects has your child with a disability had on you and/or your family?" Prompts may be used to encourage parents to provide more detail.*

### Profile / Identity

- Tell me a bit about yourself, your family, and \_\_\_\_\_ (child's name).
  - *Prompts: number/age/sex of children, living arrangements, getting along, age/sex of child with disability, type of disability (avoiding labels common to medical model).*

### Positive Feelings, Perceptions, Experiences & Contributions

- Thinking about the positive effects \_\_\_\_\_ (name) has had on your family, how would you describe those effects? Using only positive words, how would you describe \_\_\_\_\_ (name)?
  - *Prompts: Tell me the good things about \_\_\_\_\_ (name) (e.g. best qualities, positive traits, talents, strengths). Tell me the 3 best things about your child (what you appreciate most).*
- Think about times you have really felt good about, pleased with, or proud of your child. Describe what made these times exciting or meaningful.
  - *Prompts: Tell me a story about a special moment parenting \_\_\_\_\_ (name). What made it memorable? What strengths/talents did you and/or your child display? Describe other positive aspects (e.g. rewards, gratifications) of parenting \_\_\_\_\_ (name).*
- What is the greatest contribution \_\_\_\_\_ (name) has made to your life and/or your family (area child has had the biggest positive impact)?
  - *Prompts: In what other ways does \_\_\_\_\_ (name) contribute to your family? Describe to me in what ways your child has had a positive effect on: (a) your marriage, (b) your spouse, (c) your job/career, (d) your social network, (e) his/her sibling(s), (f) extended family. Have there been other positive changes*

*experienced (or additional family strengths discovered) as a result of having \_\_\_\_\_ (name) in your family? Describe a time of personal growth from your experience raising your child. Has your experience raising \_\_\_\_\_ (name) changed your view of the world or your life/family's life for the better? Explain.*

## **Conclusion**

- If you could have other people understand 3 things about your child, what would these be?
- Are there other areas which you feel we have not covered but you feel are important, or anything else you would like to add, change, dispute, or clarify before concluding the interview?

## Appendix G: Child Interview Guide

*Below is an outline of the topics and types of questions that may be covered during the interview with child participants. These questions are intended to promote open conversation based on the philosophy of Appreciative Inquiry. The primary research question to guide discussion is: "What positive effects do you feel you have had on your family?" Prompts may be used to encourage the children to provide more detail.*

### Profile / Identity

- Tell me a bit about yourself (e.g. age, school, likes, dislikes, type of disability – if volunteered)
- Tell me a bit about your family (e.g. parents, living arrangements, siblings, and getting along)

### Positive Feelings, Experiences, Contributions & Perceptions of Self

- What are some good things you can tell me about yourself?
  - *Prompt: Using only positive words, how would you describe yourself (e.g. best qualities, talents, strengths, things you are good at, what you like best about yourself). What do you think your family would say are the 3 things they like best about you? Describe to me what, if anything, you find is cool, fun, or neat about having \_\_\_\_\_ (disability).*
- Think about times you have felt good about or proud of yourself (where you did something good or accomplished something important/exciting). Tell me a story about one of these times.
  - *Prompt: How did you feel? What made it exciting? Tell me about some other things you have done that made your family happy/proud. Are there ways you feel you help your family? Describe how you are helpful at home.*
- What is the biggest contribution\* your think you have made to your family?
  - *Prompt: Do you feel you have changed\* your family for the better? Explain. In what ways do you feel you have had a positive influence\* on your: (a) parents' marriage, (b) parent's job(s)/career(s), (c) family's social network\*, (d) siblings, (e) other*

*relatives. Describe what you think is the most important thing you have helped a family member learn or understand.*<sup>13</sup>

## **Conclusion**

- If you could have other people understand 3 positive things about you, what would these be?
- Is there anything else that you feel we have not covered but you feel is important, or anything else you would like to add, change, or clarify (explain better) before ending the interview?

---

### **Notes:**

<sup>13</sup> Other than asking the children whether they felt they changed their family for the better, the remainder of these prompts was omitted from the child interviews. This was done after the first interview revealed how awkward it was to pose these questions to child participants.



UNIVERSITY  
OF MANITOBA

## Appendix H: Informed Consent Form for Parents

**Research Project Title:** Parent & Child Perceptions of the Positive Effects that a Child with a Disability can have on the Family

**Researcher:** Michelle Lodewyks (M.A. Candidate, Disability Studies)

**Research Supervisor:** Dr. Christine Blais (University of Manitoba)

**University of Manitoba Committee Members:** Dr. Nancy Hansen (Director, Disability Studies), Dr. Emily Etcheverry (Director, School of Medical Rehabilitation), Dr. Roberta Woodgate (Assistant Professor, Faculty of Nursing)

**This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more details about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.**

I, \_\_\_\_\_ (parent's name), understand that the purpose of this study is to learn more about the perceptions of parents of children with disabilities, and of children with disabilities themselves, regarding the positive effects that a child with a disability can have on the family. The purpose is also to explore disability from a positive standpoint. I understand that the information I provide will be combined with other parents' and children's perceptions to explore relevant patterns and themes. The information may also contribute to a more positive representation of the experiences of families.

I understand that this study is being conducted by Michelle Lodewyks, a master's student at the University of Manitoba, in order to fulfill her thesis requirement in the Interdisciplinary Masters Program in Disability Studies. Parents caring for at least one child with a disability and children with disabilities, 12-17 years of age, are being asked to participate in the study.

I understand that in order to obtain the information needed for the study, I am being asked to take part in an individual, face-to-face, open-ended and semi-structured interview which is expected to take anywhere from 20-60 minutes. This interview will take place at a location that has been agreed upon by me and the researcher prior to the interview. I understand that Michelle will conduct the interview and record notes as required. The interview will be audio-tape recorded to allow Michelle to review and transcribe the discussion. During the interview, I understand that I will be asked a series of questions inviting me to discuss the positive effects that my child with a disability has had on me and my family, as well my more general positive perceptions toward my child. At this time, I have been provided with an overview of the questions to be addressed in the interview and have been given the opportunity to review these questions.

I understand that my participation in the study is voluntary and that if I choose not to participate or to withdraw from the study at any time, I may do so without prejudice or consequence. I may also refuse to answer any interview questions. If anything is unclear, I should feel free to ask Michelle to provide clarification. I understand that Michelle does not anticipate that there will be any discomforts or increased risks associated with my participation in the study and that the study is not designed to elicit information that is deemed sensitive, personal, or potentially distressing to participants.

I understand that only Michelle and her research supervisor (Dr. Christine Blais) will have access to the transcripts, and all information will be kept confidential. Stories and/or quotes from my interview may be used in the final report, however I will be asked to choose a pseudonym that will be used to refer to me in this report. Therefore my actual name will not be used or associated with any of my responses, and my identity will remain confidential. I understand that Michelle is required by law to report the abuse of children or individuals receiving care to the legal authorities should this information arise during my participation in the study.

I understand that the data Michelle collects (the audiotapes and interview transcripts) will be stored in a locked filing cabinet that only she and Dr. Blais will have access to. I also understand that information collected in my interview may be included in a final report that Michelle will write in the form of a Master's thesis. The information may also eventually be published in a journal.

I understand that if I decide to participate in the study, a summary report of the findings will be provided to me if requested. (If requested, I can expect to receive the report by June 30, 2009.) I understand that I will not be identified in this report (except by my pseudonym if I choose to have one). Once the final report has been completed, all identifying information and audio materials used in the research will be destroyed. It is expected that the transcripts will be shredded and the tape-recording of the interview will be erased by June 30, 2009.

I understand that if I have any further questions about the study, I may contact the researcher, Michelle Lodewyks, at 204-xxx-xxxx or by e-mail at xxx@cc.umanitoba.ca. I may also contact her research supervisor, Dr. Christine Blais (University of Manitoba) at 204-xxx-xxxx or by e-mail at xxx@ms.umanitoba.ca. This research has been approved by the Joint-Faculty Research Ethics Board at the University of Manitoba. If I have any concerns or complaints about the project I may contact any of the above-named persons or the Human Ethics Secretariat, Margaret Bowman, at 204-474-xxxx, or e-mail xxx@umanitoba.ca. A copy of this consent form has been given to me to keep for my records and reference.

My signature on this form indicates that I have understood to my satisfaction the information regarding participation in the research project and

agree to participate. In no way does this waive my legal rights nor release the researcher or involved institutions from their legal and professional responsibilities. I understand that my continued participation should be as informed as my initial consent, so I should feel free to ask for clarification or new information throughout my participation.

**I give my permission for an audio-tape recorder to be used during the interview. YES \_\_\_ NO \_\_\_.**

**I have chosen \_\_\_\_\_ as my pseudonym, and I give permission for the researcher to use this name to refer to me in her final report. YES \_\_\_ NO \_\_\_.**

**I would like to obtain a summary report of the findings. YES \_\_\_ NO \_\_\_.** (If yes, please provide your contact information and how (e.g. e-mail, surface mail) you would like to obtain the report.)

**Parent / Guardian's signature** \_\_\_\_\_  
Parent / Guardian's name (print) \_\_\_\_\_  
Contact Information \_\_\_\_\_  
Date \_\_\_\_\_

**Researcher's signature** \_\_\_\_\_  
Date \_\_\_\_\_

*(Note: For the actual study, all consent forms were printed on university letterhead.)*



UNIVERSITY  
OF MANITOBA

## Appendix I: Informed Consent / Assent Form for Children

**Research Project Title:** Parent & Child Perceptions of the Positive Effects that a Child with a Disability can have on the Family

**Researcher:** Michelle Lodewyks (M.A. Candidate, Disability Studies)

**Research Supervisor:** Dr. Christine Blais (University of Manitoba)

**University of Manitoba Committee Members:** Dr. Nancy Hansen (Director, Disability Studies), Dr. Emily Etcheverry (Director, School of Medical Rehabilitation), Dr. Roberta Woodgate (Assistant Professor, Faculty of Nursing)

I, \_\_\_\_\_ (child's name), state that I am \_\_\_ years old and I would like to take part in this study. I understand that a researcher by the name of Michelle Lodewyks is working on a project for school, and she is hoping to learn more about the positive ways that children with disabilities can affect their families. I understand that other children (12-17 years) and their parents will also be asked to take part in the study and that the reason Michelle is writing her report is to help people better understand my family. I understand that my parents and people at the University of Manitoba feel that this study is safe for me to take part in, if I want to.

I understand that I am being invited to take part in an interview which will take anywhere from 20-60 minutes. I understand that I can make the interview shorter or longer if I want depending on how much I have to say and what I feel like sharing. If I choose to take part in Michelle's study, I understand that I have the choice of having a parent come with me to talk to Michelle. I understand that I can also choose where and when I would like to meet with Michelle, and we will agree on a time and place that I am comfortable with.

I understand that during the interview, Michelle will ask me a number of questions. She will ask me to tell her about some of the things I am good at (my talents and strengths), things I like best about myself, things I am proud of and my family is proud of me for (my accomplishments). She will also ask me about good experiences with my family and things I feel I have helped my family learn. When I talk to Michelle, I do not have to worry because there is no right or wrong answers to the questions she will ask. I understand that she just wants to know what I think. Michelle has given me a list of the questions so I can think about them ahead of time. I understand that if there are any questions that I do not want to answer, I can just let her know and I do not have to answer them.

I understand that during the interview, Michelle may use notes to help her remember things. She will also use an audio-tape recorder so that she can remember everything we talk about. I understand that if at any point I want Michelle to turn the tape off, she will turn it off for me. If I feel uncomfortable about something and do not want to answer questions, this is okay too. If I need a break or more time to think about my answers, I can let Michelle know, and she will be patient with me. I understand that if I have any questions at any time or



feel that something is not clear, I can ask Michelle to explain. In order to make this easier for me, I understand that Michelle will give me a red 'stop' card that I can use to let her know that I have a question, need a break, or do not want to answer a question.

I understand that only Michelle and her research supervisor (Dr. Christine Blais) will read what I say. When Michelle writes her report, she may write about some of the things I talked about, but no one will know who said it. Only Michelle, Dr. Blais, and I will know who said what because I may pick a pretend name rather than using my real name. I understand that the information that Michelle collects (the audiotapes and interview transcripts) will be stored in a locked filing cabinet that only Michelle and Dr. Blais will have access to. No one will be told what we talked about including my parents, family, or friends (unless I want them to). I understand that if I become upset about something during the interview, and would like to talk to someone who may be able to help me, Michelle can tell me or my parents how to contact a counselor or specialist for help.

I understand that taking part in this study is my choice and that if I decide not to be in the study, no one will be upset with me. I also understand that even if I decide to be in it, I can quit at any time by telling Michelle or my parents. I will not get in trouble.

I understand that if I have any questions or worries about the study, I can ask Michelle or my parents. If my parents do not know an answer, they will know who we can ask.

I understand that if I decide to participate in the study, Michelle will thank me by offering me two Cinema City 8 free movie passes.

I understand that what is learned from the study will be presented in a paper Michelle will write called a Master's thesis. The information may also be published in a journal. I understand that my name will not be revealed in any of these. Once the project is complete, Michelle will share with me what she found, if I ask her to. I understand that it is up to me if I want to be in this project. I have read the information (or have had a parent read it to me), and Michelle has also read it to me. My signature below tells you that I am interested in taking part in the study.

**I give my permission for an audio-tape recorder to be used during the interview. YES \_\_\_ NO \_\_\_.**

**I have chosen \_\_\_\_\_ as my pretend name, and I give permission for Michelle to use this name to refer to me in her final report. YES \_\_\_ NO \_\_\_.**  
(Note: I can pick any name I want, as long as Michelle agrees it is acceptable.)

**I would like to find out what was learned from the project and want Michelle to send me a summary report of the findings. YES \_\_\_ NO \_\_\_.** (If yes, please provide your contact information.)

*(In situations where informed consent cannot be obtained in writing due to the nature of a disability, tape-recorded or e-mail consent will be accepted.)*

**Child's signature** \_\_\_\_\_  
Contact Information \_\_\_\_\_  
Date \_\_\_\_\_

**Parent / Guardian's signature** \_\_\_\_\_  
Parent / Guardian's name (print) \_\_\_\_\_  
Relationship to child \_\_\_\_\_

**Researcher's signature** \_\_\_\_\_  
Date \_\_\_\_\_

*(Note: For the actual study, all consent forms were printed on university letterhead.)*



UNIVERSITY  
OF MANITOBA

**Appendix J: Ethics Approval Certificate**

OFFICE OF RESEARCH  
SERVICES

Office of the Vice-President (Research)

CTC Building  
208 - 194 Dafoe Road  
Winnipeg, MB R3T 2N2  
Fax (204) 269-7173  
www.umanitoba.ca/research

**APPROVAL CERTIFICATE**

09 May 2007

**TO:** Michelle Lodewyks (Advisor C. Blais)  
Principal Investigator

**FROM:** Wayne Taylor, Chair  
Joint-Faculty Research Ethics Board (JFREB)

**Re:** Protocol #J2007:059  
"Parent & Child Perceptions of the Positive Effects that a Child with a Disability can have on the Family"

Please be advised that your above-referenced protocol has received human ethics approval by the **Joint-Faculty Research Ethics Board**, which is organized and operates according to the Tri-Council Policy Statement. This approval is valid for one year only.

Any significant changes of the protocol and/or informed consent form should be reported to the Human Ethics Secretariat in advance of implementation of such changes.

**Please note:**

- if you have funds pending human ethics approval, the auditor requires that you submit a copy of this Approval Certificate to Kathryn Bartmanovich, Research Grants & Contract Services (fax 261-0325), including the Sponsor name, before your account can be opened.
- if you have received multi-year funding for this research, responsibility lies with you to apply for and obtain Renewal Approval at the expiry of the initial one-year approval; otherwise the account will be locked.

**The Research Ethics Board requests a final report for your study (available at: [http://umanitoba.ca/research/ors/ethics/ors\\_ethics\\_human\\_REB\\_forms\\_guidelines.html](http://umanitoba.ca/research/ors/ethics/ors_ethics_human_REB_forms_guidelines.html)) in order to be in compliance with Tri-Council Guidelines.**

## Appendix K: Guidelines / Instructions for Third Party Reviewers

My study explored *Parent and Child Perceptions of the Positive Effects that a Child with a Disability can have on the Family*. The results from the interviews I conducted with 16 parents and 10 children have been classified into 3 major themes with the following sub-themes.<sup>14</sup>

### Parent Results: List of themes and sub-themes

Theme 1: What the children taught the family or enabled family members to learn

Sub-theme 1: New knowledge

Sub-theme 2: New attitudes

Sub-theme 3: New or enhanced positive character attributes

Theme 2: How the children enriched family members' lives and made other contributions

Sub-theme 1: Helpfulness

Sub-theme 2: Child's positive character traits

Sub-theme 3: Positive emotions child evoked in family members

Sub-theme 4: Other contributions

Theme 3: Messages to pass along

Message 1: "It's not all rosy either"

Message 2: Consider the bigger picture, do not make assumptions, and what to understand about my child and family

Message 3: Changing my family's circumstances?

Message 4: People's perceptions can be problematic

Message 5: A positive attitude is important

### Child Results: List of themes and sub-themes

Theme 1: What the children taught the family or enabled family members to learn

Sub-theme 1: New knowledge

Sub-theme 2: New attitudes

Theme 2: How the child has enriched family members' lives and made other contributions

Sub-theme 1: Helpfulness

Sub-theme 2: Child's positive character traits

Sub-theme 3: Positive emotions child evoked in family members

Sub-theme 4: Other contributions

---

#### Notes:

<sup>14</sup> The names of some of the sub-themes changed following the process of seeking external validation from the three independent third party reviewers.

## Theme 3: Messages to pass along

Message 1: What to understand about me

Message 2: What is cool, fun, neat about using a wheelchair?

Message 3: What to understand about my family

A table has been created to summarize each parent theme and each child theme, and therefore a total of 6 tables will be presented to you. For each table, the results have been clustered into sub-themes, and narrative examples have been drawn from the interview data. Using the list of operational definitions as a guide, you will be asked to categorize a list of examples provided. Note: Some examples could be considered common for any child/family (meaning they could be generalized to families with non-disabled children) while other examples could be considered different (or more unique) to the family's circumstances (meaning it would be less likely that a non-disabled child would have the same effect or make the same contribution).

Table 1: Parent Perceptions of What the Children Taught the Family or Enabled Family Members to Learn

**The following are examples (numbered 1-14) of what the parents perceived their children taught their family or enabled family members to learn.**

Please review the examples and write the number that corresponds to the example(s) in the appropriate box in Table 1 (the box that you feel best represents the example). Please choose only 1 box per example (but make a note if you feel that an example could belong in more than 1 box). Once all 3 judges have completed this task, we will review each judge's responses and attempt to reach a consensus. Please be prepared to explain your choices and to provide suggestions for clarification or revisions.

*Examples, numbered 1-14, to review and insert in appropriate box in Table 1:*

- (1) Child opened parent's heart, taught family to be more caring, creative, balanced, gentle, calm, outgoing, in touch with their own emotions, less selfish
- (2) Sibling gained knowledge from speech & occupational therapy appointments
- (3) Family gained knowledge about disability, people with disabilities, and other families
- (4) Child taught parents they could do something they did not think they could do
- (5) Child provided knowledge for parents to educate others
- (6) Child changed or exceeded expectations in positive way

- (7) Child educated family on topic of interest and shared practical knowledge
- (8) Child taught sibling to be more responsible and independent
- (9) Child provided knowledge & skills for parent to pursue career in disability field
- (10) Parents learned advocacy and activism skills and how to help others
- (11) Parents learned new attitudes toward life and what is important
- (12) Child taught new attitudes toward people with disabilities and other families
- (13) Child set good example, good role model for siblings
- (14) Child taught family to be more patient, loving, warm, better people, tolerant, accepting, respectful, and compassionate, in tune with child's development

Table 1: Summary of Results: Parent Perceptions of What the Child Taught the Family or Enabled Family Members to Learn

Theme	Sub-theme	Common for Any Child/Family	More Unique to these Family's Circumstances
What the Children Taught the Family or Enabled Family Members to Learn	New Knowledge		
	New Attitudes		
	New or Enhanced Positive Character Attributes		