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# Family *life*

CHILDREN WITH DISABILITIES AND THE  
FABRIC OF EVERYDAY FAMILY LIFE



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# Children with Disabilities and the Fabric of Everyday Family Life

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# Contents

<i>Executive Summary</i> .....	7
<i>Section 1.</i>	
The family life project .....	14
Broadening the research agenda .....	16
Participant narratives	
Can you help us? .....	22
An empty shell .....	23
I used to be so mousy and shy .....	25
If you gave us a pill to cure the Autism .....	26
A mixed bag of successes and frustrations .....	27
There are things that you have to sacrifice .....	28
You give me hope .....	30
Normal families go out to Boston Pizza .....	34
Sleeping with one eye open .....	36
I am going to tell you about the celebrations .....	38
Our tilt table .....	40
We are your neighbour, your sister, your friend, your daughter .....	43
The balancing act at the heart of family life .....	46
<i>Section 2.</i>	
Sustainable family care for children with disabilities .....	54
Appendix A .....	73
<i>Section 3.</i>	
Rethinking resilience in families of children with disabilities .....	78
<i>Section 4.</i>	
Benefit-finding or finding benefits? The positive impact of children with disabilities .....	96
Appendix B .....	111
<i>Section 5.</i>	
Resilience in families raising children with disabilities and behaviour problems .....	117
Appendix C .....	134
<i>Section 6.</i>	
Recruiting parents as interventionists: parent adherence and adverse effects .....	143
<i>The Family Life Survey</i> .....	161



## List of Tables

### Executive Summary

Table 1. Child, parent-carer and family characteristics .....	8
---	---

### Section 2. Sustainable family care for children with disabilities

Table 1. Child, parent-carer and family characteristics .....	62
Table 2. Placement propensity by child age group .....	65
Table 3. Zero-order correlation matrix .....	66
Table 4. Standardized direct, indirect and total effects with bootstrap standard errors ...	68
Table 5. Multinomial logistic regression: parameter estimates .....	68

### Section 3. Rethinking resilience in families of children with disabilities

Table 1. Child, parent-carer and family characteristics .....	83
---	----

### Section 4. Benefit-finding or finding benefits?

Table 1. Child, parent-carer and family characteristics .....	103
Table 2. Zero-order correlation matrix with imputed data .....	105
Table 3. Multi-group moderation test: path coefficients .....	108

### Section 5. Resilience in families raising children with disabilities and behaviour problems

Table 1. Child, parent-carer and family characteristics .....	123
Table 2. Zero-order correlation matrix .....	124
Table 3. Behaviour profile: low and high behaviour problem groups .....	126
Table 4. Standardized direct, indirect and total effects with bootstrap standard errors ...	129
Table 5. Multi-group moderation tests: standardised regression weights .....	130

### Section 6. Recruiting parents as interventionists: parent adherence and adverse effects

Table 1. Child, parent-carer and family characteristics .....	151
Table 2. Correlation matrix using imputed, standardized data .....	153
Table 3. Standardized direct, indirect and total effects with bootstrap standard errors ...	155

## List of Figures

### Executive Summary

Figure 1.	Placement propensity by sustainability of the daily routine.....	9
Figure 2.	Family related accommodations by sustainability group.....	11
Figure 3.	Community related accommodations by sustainability group.....	11
Figure 4.	Work related accommodations by sustainability group.....	12

### Section 1. The Family life project

Figure 1.	The Ecocultural Project of Family Life .....	20
Figure 2.	Families caring for children with a diverse range of conditions .....	21
Figure 3.	The BIG four challenges.....	46

### Section 2. Sustainable family care for children with disabilities

Figure 1.	Placement propensity by diagnosed condition .....	63
Figure 2.	CFA with bootstrap, standardised path coefficients .....	64
Figure 3.	Placement propensity by family life congruence .....	64
Figure 4.	Path model predicting placement propensity .....	67
Figure 5.	Child characteristics as predictors of sustainability .....	69
Figure 6.	Selected indicators of resource-fit as predictors of sustainability .....	69

### Section 4. Benefit-finding or finding benefits?

Figure 1.	Parent reported benefits .....	104
Figure 2.	SEM analysis: Corroborating parent claims, and the benefit-finding hypothesis .....	106
Figure 3.	SEM analysis: The true, deep and lasting change hypothesis .....	106
Figure 4.	SEM analysis: The 'stress-buffering' and 'motivation to persevere' hypotheses .....	107

### Section 5. Resilience in families raising children with disabilities and behaviour problems

Figure 1.	Latent factors with items loadings .....	125
Figure 2.	Relationship between ASD, child behaviour problems and family life congruence ....	126
Figure 3.	Relationship between child behaviour problems and family life congruence .....	126
Figure 4.	Child behaviour problems, social support and family life congruence .....	127
Figure 5.	Child behaviour problems, financial hardship and family life congruence .....	127
Figure 6.	Cumulative advantage and family life congruence .....	128
Figure 7.	Path model: Direct & indirect effects of child-specific & social-ecological factors .....	128
Figure 8.	Path model: Moderating effects of social support and financial hardship .....	129

### Section 6. Recruiting parents as interventionists: parent adherence and adverse effects

Figure 1.	CFA: Family life congruence.....	152
Figure 2.	Predictors of parent adherence.....	154
Figure 3.	Implementation and family wellbeing: a path model.....	154

## Executive Summary

The focus of this study was on the everyday challenge and accomplishment of sustaining a routine of family life that accommodates the needs and interests of a child with disabilities *and* all other family members. One objective was to examine the relationship between sustainability of the daily routine and family propensity to seek out-of-home placement for their child with disabilities. A second objective was to investigate child-specific, within-family and social-ecological factors influencing sustainability of the daily routine.

### **Methods**

- I. The sampling frame for the study consisted of all English-speaking families registered with the Government of Alberta, Family Supports for Children with Disabilities (FSCD) program, and in receipt of child-focussed services. A stratified (by child age group: early childhood, middle childhood and adolescence), random sample of 1300 families were invited, and 538 (41%) agreed to take part.
- II. There were three annual waves of data collection. The Family Life Survey (FLS) was administered in each wave. The FLS incorporated pre-existing scales and new items to obtain data on child and family characteristics, family resources and constraints, family accommodations (adjustments & adaptations), the sustainability of the daily routine and out-of-home placement propensity.
- III. In addition to the survey, a total of 267 in-depth, face to face interviews were conducted with 202 families. The interviews were conducted by graduate occupational therapy students trained in responsive interviewing. Families were invited to share their stories of family life. Most of the interviews took place in the family home, and were digitally recorded and later transcribed for analysis.

### **Participants**

- IV. The participating families were diverse. The sample included single-parent, traditional, blended, dual-income, skip-generation and multi-generation households. A number of the families were new immigrants, and others had moved to Alberta from other provinces. There were biological and adoptive families, inner-city families, farming families, mining town families, aboriginal families living on reserve, families living in commune, and others (see Table 1).
- V. The participating families were also diverse with respect to child 'conditions'. The majority however were raising children with intellectual disability and/or an autism spectrum disorder. *We asked parents to tell us what the most important thing was for us to understand about their child. One father expressed the thoughts of many when he said that the most important things for us to understand were that "he is loved" and "his condition does not define him".*

**Table 1.** *Child, parent-carer and family characteristics (n=538)*

			Mean (SD) or %
Child	Age	0-5 years	30
		6-12 years	35
		13-18 years	35
	Sex	Male	65
		Female	35
	*Impairment Type	Intellectual disability	48
		Autism spectrum disorder	36
		Cerebral Palsy	15
		Downs Syndrome	11
	Disability (activity limitations)	A little	15
		Fair amount	23
Quite a lot		23	
A great deal		39	
Parent	Age		41.08 (8.26)
	Sex	Male	12
		Female	88
	Language spoken at home	English	96
	Highest educational attainment	Did not complete high school	9
		High school graduate	18
		Diploma/trade certificate	40
		University undergraduate	25
	University postgraduate	9	
Family	Residence	Major urban	56
		Minor urban	19
		Rural	25
	Family type	Couple, single-earner	28
		Couple, dual-earner	48
		Couple, no-earner	3
		Lone parent, earner	15
		Lone parent, non-earner	6
	Total household income	< \$40,000	27
		\$40,000 - \$69,000	20
		\$70,000 - \$89,000	20
\$90,000 +		33	
Total number of Children (<18 years)			2.23 (1.18)

\*not mutually exclusive categories

## SELECTED FINDINGS

The findings presented in this report are based primarily on data collected in year one (2009) of this three year study.

### 1.0. Out-of-home placement propensity (see Section 2)

- 1.1. Approximately one in six families reported having at least thought about out-of-home placement as an option for their child with disabilities. A total of 34 families (6.4%) were at the time seriously considering or taking steps to place their disabled son or daughter out-of-home.
- 1.2. Out-of-home placement propensity is positively associated with child age, behaviour problems and complex medical needs. No association was found between placement propensity and diagnosed condition (e.g., ASD) or disability severity (i.e. child functioning).
- 1.3. Child behaviour problems and/or complex medical needs may give families cause to first think about out-of-home placement. However,

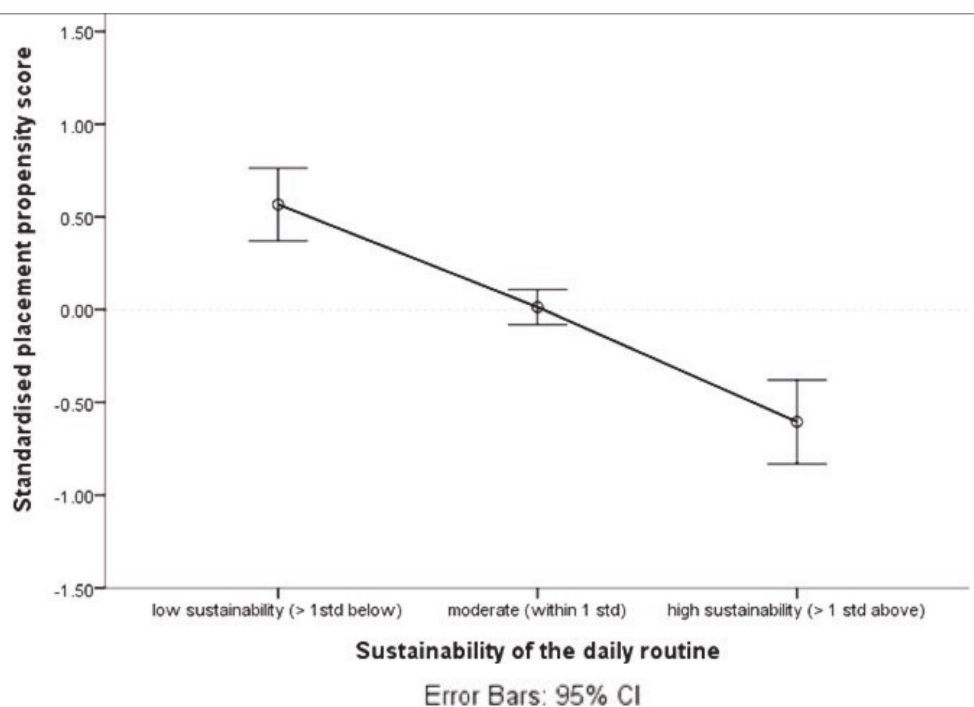
it is usually only when families are struggling to sustain a daily routine that they give this more serious consideration.

- 1.4. Sustainability of the daily routine is the single strongest 'predictor' of placement propensity (see Figure 1). Families with the least sustainable daily routines (> one standard deviation below the mean) are approximately *seventeen times* more likely than families with the most sustainable daily routines (> one standard deviation above the mean) to be seriously considering out-of-home placement.

### 2.0. Sustainability of the daily routine (see Sections 1-3 & 5-6)

- 2.1. All families face the same central adaptive challenge: *to weave together varied family interests and activities into a sustainable daily routine.* More sustainable daily routines are viable, that is fitted to the local ecology and family resource-base; and, *congruent* with the family's values and goals, and with the needs, interests and competences of individual family members.

**Figure 1.** Placement propensity by sustainability of the daily routine



- 2.2. Many families struggle with (1) balancing the inevitably competing needs and interests of all their children; (2) reconciling the desire to protect with the goal of integrating their child and family into the community; (3) juggling earning and care giving activities; and (4) accessing and navigating funding and services (*see Section 1*).
- 2.3. Families with the least sustainable daily routines report high levels of accommodation activity (i.e., actions taken, avoided or delayed to sustain a daily routine). These parents are more likely to have quit work, reduced their level of contact with professionals and/or time spent implementing home programs, and/or cut back on family activities and time together (*see Figures 2-4*).
- 2.4. There is a relationship between sustainability of the daily routine and child characteristics, including disability severity (i.e., functional limitations) and behaviour problems. Specifically, families raising children with more severe disabilities and/or a greater number or intensity of behaviour problems tend to have somewhat less sustainable daily routines. *However,*
- 2.5. The sustainability of the daily routine depends more on social-ecological factors than child characteristics. Key factors include **parent control-over-work** (i.e., work flexibility), **adequacy of child care** options/arrangements, perceived **responsiveness of services** to the family's needs and priorities, and **shared family responsibility** for the child care and domestic workload.
- 2.6. The practice of recruiting parents as interventionists may have unintended, adverse effects. To free up time in their daily routine to implement home programs many parents will sacrifice personal leisure time, participation in paid work, and time spent with other family mem-

bers. This can create or exacerbate imbalance, thereby reducing the sustainability of the daily routine. (*see Section 6*).

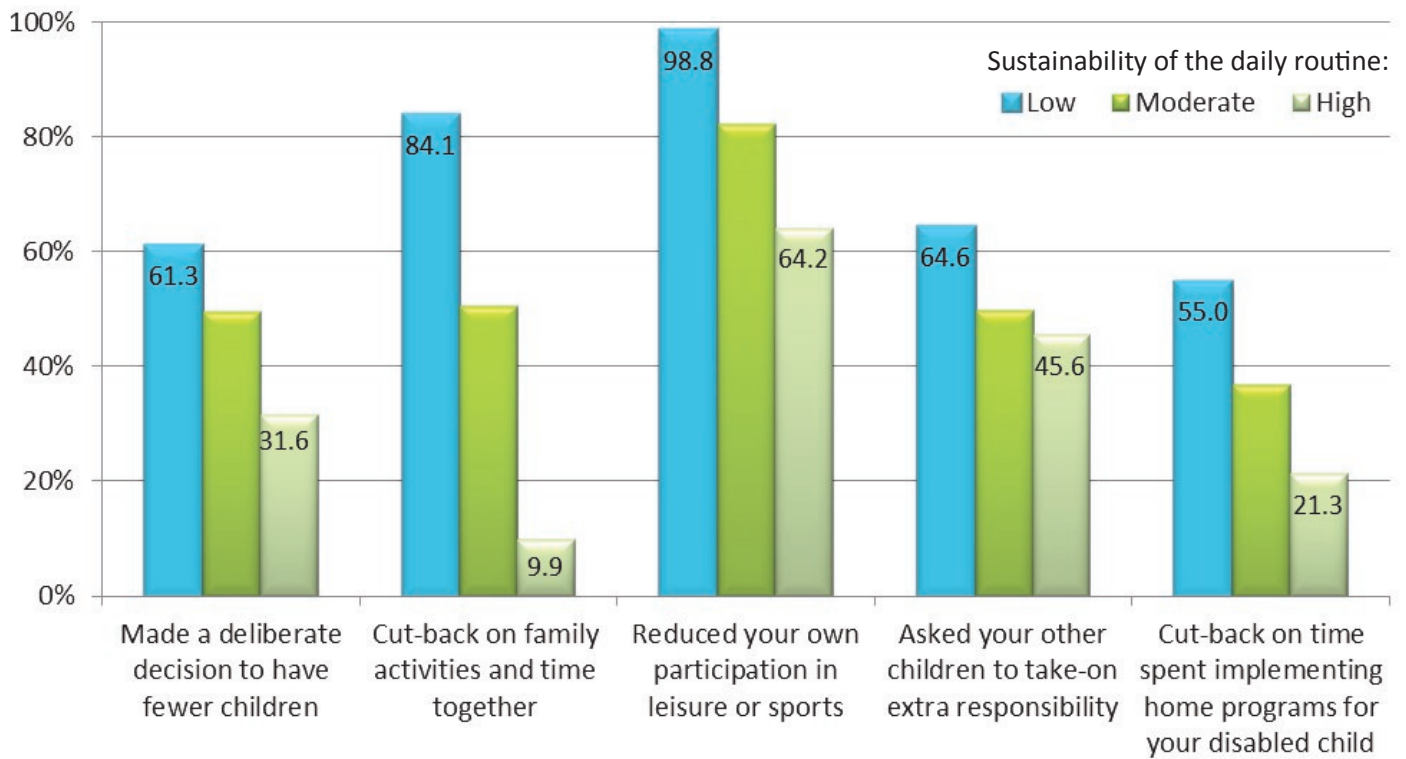
### **3.0. Child behaviour problems and family-level resilience (*see Sections 3 and 5*)**

- 3.1. There is an inverse relationship between the number and intensity of child behaviour problems and *family life congruence* (i.e., meaningfulness of the daily routine, and balance with respect to the needs and interests of family members). *However,*
- 3.2. Families raising children with disabilities and behaviour problems generally 'do well' (i.e., have higher than average family life congruence) under conditions of high social support and low financial hardship. One in three families raising disabled children with high behaviour problems reported above average family life congruence, and might therefore be described as resilient. Almost all of these families had high social support and low financial hardship.
- 3.3. Families with low levels of social support and high levels of financial hardship typically struggle—with lower than average family life congruence—even when the number or intensity of behaviour problems is low.

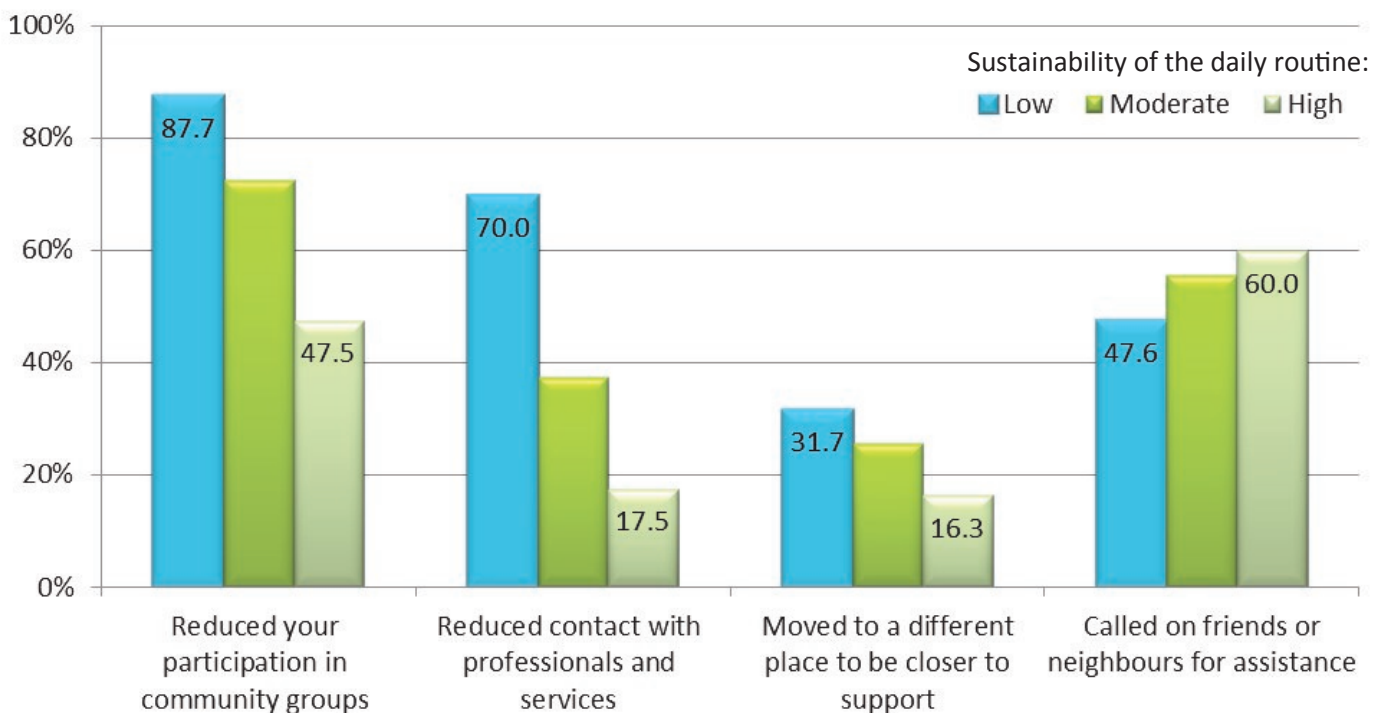
### **4.0. Positive impact of children with disabilities (*see Section 4*)**

- 4.1. Most parents report benefits as a result of having a child with disability, such as strengthened emotional bonds between family members, personal growth and perspective transformation, and social relationships. These reported benefits reflect deep, lasting, and transformational changes rather than artifacts of stress, coping, and "sense-making" of an adverse situation (i.e. having a child with disability).

**Figure 2. Family related accommodations by sustainability group**

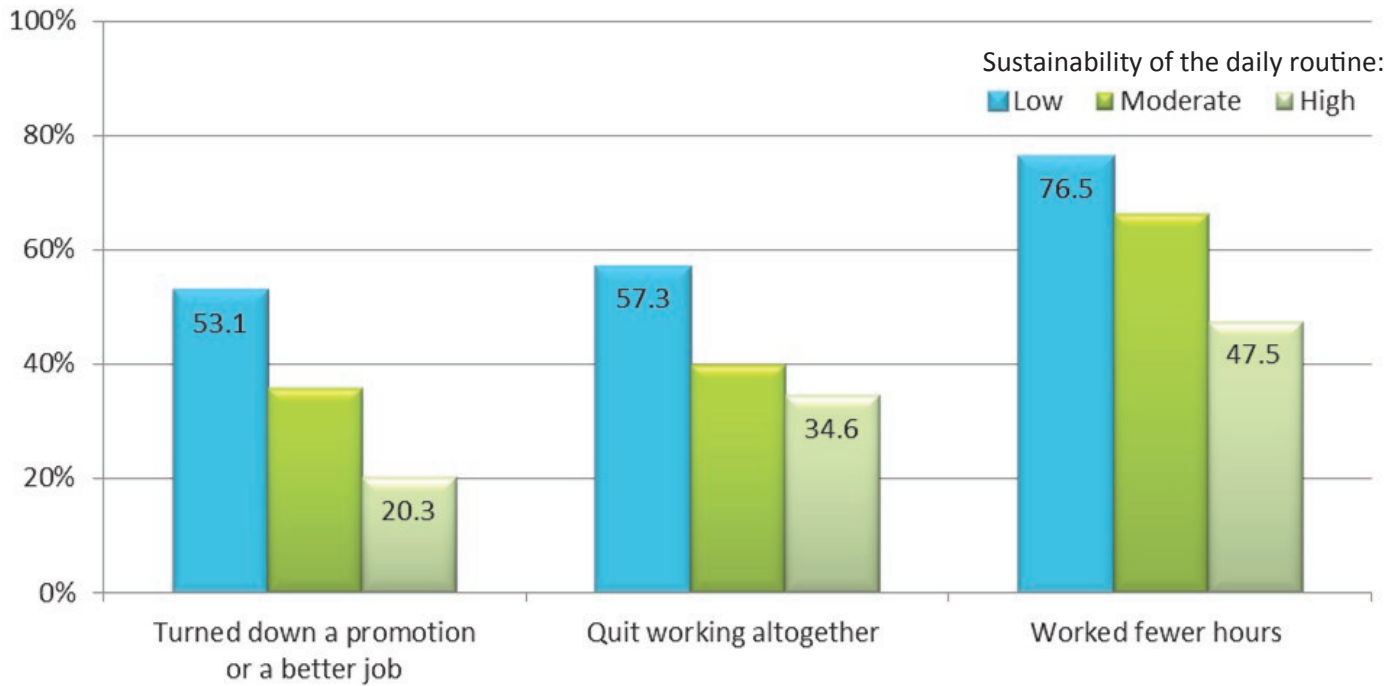


**Figure 3. Community related accommodations by sustainability group**





**Figure 4.** Work related accommodations by sustainability group



## 5.0. Conclusions

- 5.1. Parents are unlikely ever to consider placement as an option for their disabled child if their daily routine is fitted to the local ecology and family resource-base, and *congruent* with their values and goals, and with the needs, interests and competences of individual family members.
- 5.2. Sustainability of the daily routine is more dependent on the availability and accessibility of culturally relevant resources (e.g., social support, responsive services, work flexibility, inclusive child care) than child-specific *or within-family* factors.
- 5.3. When a family has reasonably good resources (e.g., social support, disposable income, work flexibility and suitable/inclusive child), outcomes are likely to be good (i.e., the daily routine is likely to be high in sustainability) *even in the context of severe stressors*.
- 5.4. A major concern for parents is balancing the inevitably competing needs and interests of all their children. Many worry that their other, non-disabled children are ‘missing out’. Consequently, many parents are living with a haunting sense of guilt and a permanent sense of inadequacy.
- 5.5. Many families raising children with disabilities are struggling ‘to make ends meet’. In the absence of suitable supports (i.e., formal & informal), many parents are cutting back their work hours or having to quit work altogether in order to care for their disabled child, resulting in financial hardship.
- 5.6 Parents value the funding and services they receive. However, the challenge involved in accessing and navigating funding and services is a threat to the sustainability of the daily routine. To many parents it seems as though the system is designed to discourage families from accessing support (see Section 1).

## *Parents say...*

### **Raising a child with disabilities can be rewarding.**

Two out of three parents said that, overall, having a child with disabilities has been positive for their family. Further, “as a result of having a child with disabilities”

- Over 70% of parent-carers said that their family unit had emerged stronger.
- Almost 90% said that wonderful people had come into their lives.
- Almost 90% said that they had learned what was really important in life. And,
- Over 50% said that they now laugh more and are less bothered by trivial things.

### **At the same time, raising a child with disabilities can be immensely challenging.**

- Approximately one-half of the participating families said that all they seemed to be doing was reacting to one crisis after another, and were always on edge wondering ‘what next?’
- Almost two-thirds of parent-carers said that their family life revolved around their child with disabilities, and were concerned that their other children were ‘missing out’.
- Over three-quarters of parent-carers said that they have had to give up more of their life than they had ever expected.
- More than one-half of the participating parent-carers reported feeling trapped by their daily routine, and almost one-third said that any dreams they had now seemed out-of-reach.

### **Keeping your family life running is particularly challenging when you experience financial hardship and/or have little support from others outside of the family.**

- Over 50% of parent-carers reported having at least some difficulty paying their bills over the past three months. 20% expected that they would have to do without basic things over the coming three months.
- 60% of parent-carers said that, in general, professionals and service providers respond to their family’s needs and priorities. 40% were either uncertain or said that professionals and service providers were not responsive.
- Approximately 40% of parent-carers indicated that they would like more hours of child care. The cost of their preferred childcare arrangement was the most common reason parent-carers gave for not using more childcare.
- 70% of parent-carers said that people showed at least some concern or interest in how they and their family were doing: 30% of parent-carers said that people showed little interest or concern.

### **It is really difficult to juggle work and family responsibilities.**

- 27% of working parent-carers say that they very often or always find it difficult to fulfill family responsibilities because of their work responsibilities.
- 47% of parent-carers report that, most or all of the time, they are coming home from work too tired to do the chores that need to be done.
- 19% of working parent-carers report that they very often or always find it difficult to concentrate or fulfill work responsibilities because of their family responsibilities.
- 22% of working parent-carers find that they almost always arrive at work too tired to function well because of the household or childcare work they have done.

# 1

## The Family Life Project

The face of the Canadian family is changing. Over the last half century the number of lone-parent, same-sex, common-law and blended families have risen dramatically, and the dual-income family has long overtaken the 'traditional' family (i.e., male breadwinner/ female care giver) as the most common family type (Statistic Canada, 2011). Yet the central adaptive challenge for families remains the same. That is, to weave together varied family interests and activities into a sustainable daily routine. The daily routine is a family's 'way of life' and answer to the question, *how are we to reconcile what we want for our children, ourselves and our family with what is possible given our present circumstances?* The answer may be more or less sustainable. A more sustainable daily routine is viable (i.e., fitted to the local ecology and family resource base), and congruent with the family's values and goals, and with the needs, interests and competencies of family members (Gallimore & Lopez, 2002; Gallimore, Weisner, Bernheimer, Guthrie & Nihira, 1993; Gallimore, Weisner, Kaufman & Bernheimer, 1989; Gallimore, Bernheimer & Weisner, 1999; Weisner, 2007 & 2008; Weisner, Matheson, Coots & Bernheimer, 1997).

Constructing and maintaining a viable and congruent daily routine is a struggle for many families today. Many parents are reporting high levels of role conflict and overload: They are struggling to eke out the time and energy they need to successfully juggle earning and caring activities (Duxbury & Higgins, 2012). The struggle is such that it has been described as "*the* topic of the 21st century for families, employers and governments" (Human Rights and Equal Opportunity Commission, 2007, p. ix,

emphasis added). There are potentially many contributing factors. The rise in the household debt-to-income ratio is one. Another is the dramatic increase in work demands: Canadians are working longer hours, on average, and may have less work flexibility (Duxbury & Higgins, 2012). A third factor is persistent gender inequality, as the participation of women in paid work has increased at a faster rate than men's participation in care work (Statistics Canada, 2011).

**Sustaining a daily routine that meaningfully integrates earning and caring activities may be particularly challenging for families raising children with disabilities.** These families face many out-of-the-ordinary demands. Some of these are directly related to their child's disability and care needs. Other out-of-the-ordinary demands and hardships have little or nothing to do with the child's disability *per se*, but are rather caused by negative social responses and social arrangements that do not take their needs, interests and circumstances into account (Dowling & Dolan, 2001; Green, 2007). For example, many parents feel the sting of social stigma attached to disability (Farrugia, 2009; Francis, 2012; Gill & Liamputtong, 2011; Green, 2007); some struggle to maintain meaningful employment and an adequate standard of living due to a lack of reasonable workplace accommodations and a dearth of inclusive and affordable childcare options (Freedman, Litchfield, & Warfield, 1995; Gordon, Rosenman, & Cuskelly, 2007); and, many are overwhelmed by the challenges involved in accessing and navigating fragmented and inflexible service systems (Browne, Rokeach, Wiener, Hoch, Meunier & Thurston, 2013; Hodgetts, Nicholas, Zwaigenbaum & McConnell, 2013).

Difficulty constructing and maintaining a viable and congruent daily routine has been linked to adverse outcomes for families raising children with

disabilities, including but not limited to 'voluntary' out-of-home placement (Llewellyn, Dunn, Fante, Turnbull & Grace, 1999; Llewellyn, McConnell, Thompson & Whybrow, 2005). Data from the United States and Australia suggest that as many as one in two families will at some point at least consider placing their disabled child out-of-home (Blacher & Hanneman, 1993; Hanneman & Blacher, 1998; Llewellyn, et al. 1999; Llewellyn, et al. 2005). Consecutive Australian studies found that families with less sustainable daily routines are more likely to consider and actively seek out-of-home placement (Llewellyn, et al. 1999; Llewellyn, et al. 2005). Specifically, these studies found that family propensity to place is greatest when there is a lack of congruence (i.e., 'misfit') between the daily routine and (a) the family's values and goals (e.g., "We are trapped by our daily routine"), and (b) the perceived needs and interests of individual family members (e.g., "I worry that my other children are missing out"). In contrast, these studies found that, when workload and responsibility is shared and the disabled child and his/her family are more fully integrated into the community, parents are less likely to consider out-of-home placement as an option.

**The focus of this study was on the daily routines and out-of-home placement propensity of families bringing up children with disabilities in Alberta, Canada.** One objective was to obtain a robust estimate of how many families are seriously considering out-of-home placement as an option for their child. Another was to investigate factors influencing families to continue caring at home for a disabled son or daughter or seek out-of-home placement. Our primary hypothesis was that out-of-home placement propensity varies as a function of the sustainability of the daily routine.

A third objective was to investigate factors influencing sustainability of the daily routine, including child-specific, within-family and social-ecological factors: *How is it that some families raising children with disabilities, and not others, succeed in constructing a viable and congruent daily routine?* In addition, this study permitted investigation of the perceived benefits of having a disabled child. In Section 4 we address the question of whether the benefits reported by parents are better viewed as artefacts of stress processing and a resource for coping, or as veridical (i.e., corresponding to fact) accounts of positive impact and transformation.

---

### **Research questions:**

What factors influence family attitudes toward out-of-home-placement?

How do families raising children with disabilities keep their family life running?

How is it that some families 'do well' when others, exposed to similar stressors, struggle?

Are the reported benefits of having a child with disabilities real or imagined?

Does parent implementation of home programs for children with disabilities have any adverse effects on family life?

## BROADENING THE RESEARCH AGENDA

*“Now as before, the research addresses the mother’s situation almost exclusively, with very little attention paid to fathers, siblings, or the family system” (Wallander & Varni, 1998, p.37).*

Researchers have focused a great deal of attention on family adjustment and adaptation to children with disabilities. The traditional and still dominant approach to research in this field starts out with the assumption that having a child with disabilities is a ‘disturbance’ or ‘perturbation’, and then focuses on stress and coping processes, and [what are usually presumed to be] ‘outcomes’ for other family members. Many studies have investigated stress and psychopathology among mothers [and to a lesser extent, fathers and siblings] of children with disabilities, the stress-buffering role of social support, and the utility of various coping strategies (e.g. Dabrowska & Pisula, 2010; Plant & Sanders, 2007; Zablotsky, Anderson & Law, 2012). This research has had a number of positive impacts. It has, for instance, helped justify services, including but not limited to early intervention, in-home help, and psycho-educational programs for parents and respite care.

*“The history of research in this field is marked by a longstanding and pervasive belief that having a child with disabilities is a tragedy entraining lifelong hardship for families” (Risdal & Singer, 2004, p.95).*

A concern is that much of the research in the field assumes that having a child with disabilities is not only a disturbance *but also* a tragedy. [Assuming that having a child with disabilities is a disturbance is not the same as assuming that having a child with disabilities is a tragedy. A disturbance is merely an event or situation occasioning change or adaptation: Losing your home to a flood is a disturbance, and so too is winning the state lottery.] Consequently, researchers have, until quite recently, focused almost exclusively on measuring what are usually presumed to be the ill-effects of having a child with disabilities (e.g., heightened maternal stress, marital disruption). Few studies have attempted to rule out plausible alternative explanations for heightened levels of maternal stress and other negative ‘outcomes’; and, few studies have explored the positive impact of having a disabled child.

*“The notion of the disabled family is an inappropriate one. [Families raising children with disabilities] have just as much in common with mainstream families as they do with each other” (Patching & Watson, 1993, p. 130).*

Another, perhaps even more fundamental concern is that by framing ‘the problem’ as one of family adaption to disability, the traditional approach to research has produced limited insight into the adaptation of families *with* disabled children to normative challenges and demands. Moreover, by reducing the experience of raising a child with disabilities to ‘stress and coping’ (i.e., for the purposes of research), the necessary context for understanding why these families may be stressed [and why they do what they do, such as seek out-of-home placement] is lost. There is however growing recognition that families raising children with disabilities are faced with the same tasks and challenges as families with non-disabled children: they are families first (Dowling & Dolan, 2001; Freedman, Litchfield & Warfield, 1995; Gallimore, et al., 1999). All families, for example, have to make a living, balance the inevitably competing needs and interests of family members, and manage interactions with ‘outsiders’ to ensure



that the proper impression of the family is maintained. Yet, comparatively few studies have shed light on how families raising children with disabilities meet such normative challenges. And few studies have investigated what it means to have a child with disabilities in this context, i.e., in light of the everyday challenges and accomplishments of 'normal' family life.

By framing the problem as one of family adaptation to having a child with disabilities *and* by making the dubious assumption that having a child with disabilities is a tragedy entraining lifelong hardships *and* by treating the social and ecological context in which families live as a background given, the traditional approach to research in this field has certain predictable outcomes. To some extent the sorts of problems that are identified and, in turn, the sorts of solutions that are proposed are pre-determined. Specifically, the traditional approach quite naturally leads to proposals for 'special services' aimed at modifying or reforming the individual child, caregiver and/or family. The concern is that the traditional approach potentially precludes consideration of social-ecological constraints and resources that families raising children with disabilities may need in order to meet the normative, everyday adaptive challenges they face. For example, families raising children with disabilities no doubt need, but may have unequal access to, the same kinds of resources that most other families need in order to successfully juggle work and family demands, such as meaningful and flexible employment, comprehensive health insurance, and affordable childcare options.



## THE ECOCULTURAL PROJECT OF FAMILY LIFE

All families construct daily routines. Some routines may be chaotic, others more orderly, but all serve to maintain family life (Bernheimer & Keogh, 1995; Bernheimer & Weisner, 2007). Daily routines are made up of ordinary, mundane activities [i.e., ‘the stuff of life’] such as preparing meals, travelling to and from work, housekeeping, reading to children, soccer practice, homework, watching TV, play-dates, visiting grandma, and so on. The activities that a family weaves into a daily routine (i.e., what is included and excluded), and the way in which these are organised – including who does what, how, when, where, with whom and for what purposes – varies over time: *“Daily routines evolve ... and are neither static, rigid, arbitrary, optimised, nor entirely voluntary”* (Gallimore, Bernheimer & Weisner, 1999, p. 56).

*The family project of sustaining a daily routine “must always be understood as a project somewhere, in some particular community with its constellation of goals and local constraints and opportunities”* (Weisner, 2009, p. 229).

Cross-cultural studies have long documented variation between communities with respect to patterns of everyday family life (Gallimore & Lopez, 2002). Less variation is found within any given community. One reason for this is that, within any given community, families start out with the same basic ‘cultural toolkit’ with which to construct their daily routine. This includes, for example, shared beliefs about what children need (e.g., in order to become respectable members of *their* community), ‘scripts’ for the performance of roles such as ‘mother’ and ‘father’, and strategies or models for reconciling work and family demands. Another reason is that, within any given community, families face similar ecological constraints including, for example, constraints imposed by the local climate and topography, subsistence patterns (i.e., the way in which families make a living), modes of transportation,

school hours, threats to safety, and child care resources.

*Families have some degree of freedom to shape their daily life as they wish it to be, however not all routines are possible, and not all possible routines are acceptable* (Gallimore, Bernheimer & Weisner, 1999).

Within any given community however, there is some degree of variation in how families organise, adapt and sustain their daily routines. This is because the daily routine is, simultaneously, culturally patterned and constrained by the local ecology, and “a fulcrum of human agency” (Gallimore & Lopez, 2002, p.74S). Idiosyncrasies are created through the process of accommodation. Accommodations are intentional adjustments that families make (i.e., actions taken, avoided or delayed), sometimes in response to ‘stressors’, to juggle the many changing and competing demands they face and to accomplish longer term goals. In turn, the accommodations made by families and the resulting daily routine vary as a function of (a) *the family schema*, (b) the particular needs, interests and competences of individual family members, and (c) the family resource base (Gallimore & Lopez, 2002; Gallimore, Bernheimer & Weisner, 1999; Weisner, 2007 & 2008).

(a) *The family schema* is the product of culture and experience: Culture may equip families with a basic ‘toolkit’, but families adapt this in response to their particular experience/s and circumstances. The daily routine can be viewed as, more or less, an observable instantiation [or *working out*] of the family schema, which includes beliefs about who they are (e.g., in relation to their family-of-origin, and a generalised other), ideas or ‘theories’ about what children need and how these needs are best met; their goals and expectations for their children and family as a whole; and, their disposition toward and approach to solving any problems they may encounter. The family schema provides direction and moti-



vational force, although families are not always conscious of the assumptions or beliefs influencing their actions.

(b) The activities of everyday family life, and the way in which these are woven into a daily routine also vary as a function of *the needs, interests and competencies of individual family members*. For example, the daily routine that accommodates the needs of very young children will be different from the daily routine that accommodates the needs and wants of teenage children. In addition, the way in which families organise their daily routine may vary depending on the competencies of individual family members including, for example, a parent's problem-solving skills or coping repertoire. A major challenge for parents is sustaining a daily routine that balances (*in a way that seems 'right' to them*) the inevitably competing needs and interests of individual family members (Weisner, 2007).

(c) The accommodations made by families and the resulting daily routine also hinge upon their social and economic resources. Families with more resources have more power or freedom to shape their daily life as they wish it to be. For example, families who rely on two incomes to 'make ends meet' must organise their daily routine accordingly. Similarly, the availability of support from grandparents and/or significant others has a bearing on what routines are possible (e.g., whether parents are able to have 'date nights'). With respect to the 'sustainability of the daily routine' however, the question is not how much the family has but rather, whether what the family has is *sufficient* to support the activities that they have woven into a daily routine (Gallimore, et al., 1999; Weisner, 2008; Weisner, et al., 1997).

## **THE FAMILY LIFE PROJECT**

The Family Life Project was a three year, multi-method (survey + interview) study of the daily routines and out-of-home placement propensity of families bringing up children with disabilities in Alberta,

Canada. This report (section 2-6) is based on data collected in Year one (2009). The sampling frame for the study consisted of all English-speaking families registered with the Family Supports for Children with Disabilities (FSCD) program (i.e., a provincial government funding body), and in receipt of child-focussed services. Following University of Alberta ethics approval (File#B-060808), and with the assistance of FSCD personnel, a stratified (by child age group: early childhood, middle childhood, adolescence) random sample of families were invited to take part.

The recruitment procedure followed the Dillman (1978) method, which is widely regarded as best practice in survey administration in the social sciences. Firstly, families received a letter informing them about the forthcoming survey. Within two weeks, each family received a copy of the survey package, including the "Family Life Survey", cover letter, consent form, pencil, and a return postage paid envelope. Approximately two weeks later, a follow-up reminder postcard was mailed out. Then approximately two weeks after this, another copy of the survey package was dispatched to families who had not yet responded. All respondents received an honorarium of CAN\$30.00.

The Family Life Survey which was completed by the family nominated primary parent-carer, incorporated previously validated items and scales, and new items created for the purpose of this study. Prior to administration, the Family Life Survey was reviewed (i.e., pilot tested) by a parent-carer advisory group. Members of the advisory group completed the survey individually and then critiqued the survey together as a group. Based on the feedback received, changes were made to the layout of the survey, and some potentially confusing routing instructions (i.e., If X, go to Z) were revised.

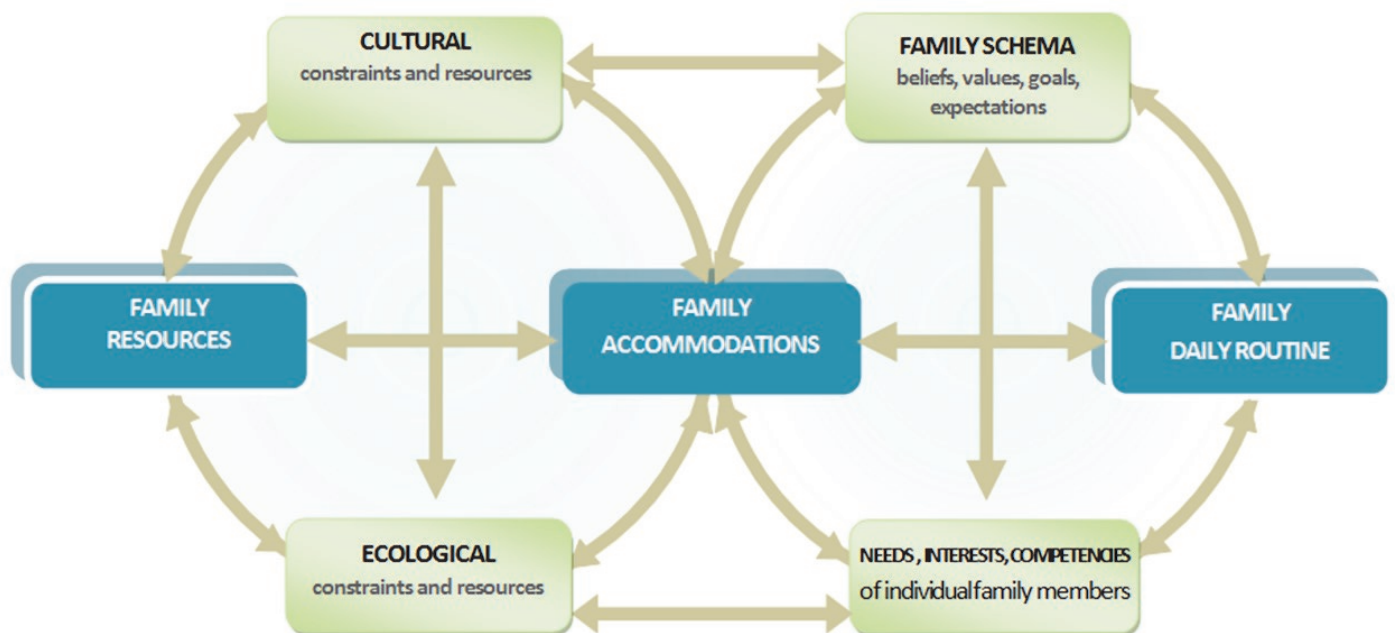
The survey incorporated items to collect demographic data, including but not limited to data on household composition; primary parent-carer sex,

age, ethnicity, educational attainment and employment status; and, the sex, age, impairment type and activity limitations of the (*nominated if greater than one*) disabled child. In addition, the survey incorporated items to gather data on behaviour problems in children 4-18 years (Taffe, Gray, Einfeld, et al., 2007); financial hardship (Barrera, Caples & Tein, 2001); social support/integration (Brevik & Dalgard, 1996); perceived stress (Cohen & Williamson, 1988); control-over-work (Marmot, Smith, Stansfeld et al., 1991); work-family conflict (Livingstone & Scholtz, 2006); parent adherence with prescribed home programs; child integration into groups for children with and without disabilities; parent preferences for and utilisation of child care services; family life congruence (Llewellyn, Bundy, McConnell, Emerson & Brentnall, 2010); family functioning (Epstein, Baldwin & Bishop, 1983); family accommodations; parent reported benefits (Scorgie, Wilgosh, Sobsey & McDonald, 2001); and, out-of-home placement propensity (Blacher, 1990).

In addition to completing the survey, a sub-sample of parent-carers were interviewed. Interview partic-

ipants were purposefully sampled to ensure representation of families living in urban and rural areas; multiple family types (e.g., single parent, dual income, traditional); low, middle and high income families; and, a variety of child 'conditions' (e.g., autism, cerebral palsy, intellectual disability). One to three interviews were conducted with each of these parent-carers. The interviews were conducted by graduate occupational therapy students who were trained in responsive interviewing (Rubin & Rubin, 2011). The interviewers utilised a basic interview guide, consisting of questions and probes, to promote consistency and adequate coverage. However, the interview format remained open, flexible and adaptable to encourage in-depth, responsive descriptions of participants' daily routines, including but not limited to the adaptations they had made to accommodate their disabled child. Analysis of earlier interviews informed later ones, and new questions and probes were developed to 'fill-in' gaps in our emerging understanding. Most of the interviews were conducted in the family home, and with participant consent the interviews were audio-taped and later transcribed for analysis. The specific methods of data analysis are described in Sections 2 -6.

**Figure 1.** *The Ecocultural Project of Family Life*



## Study participants

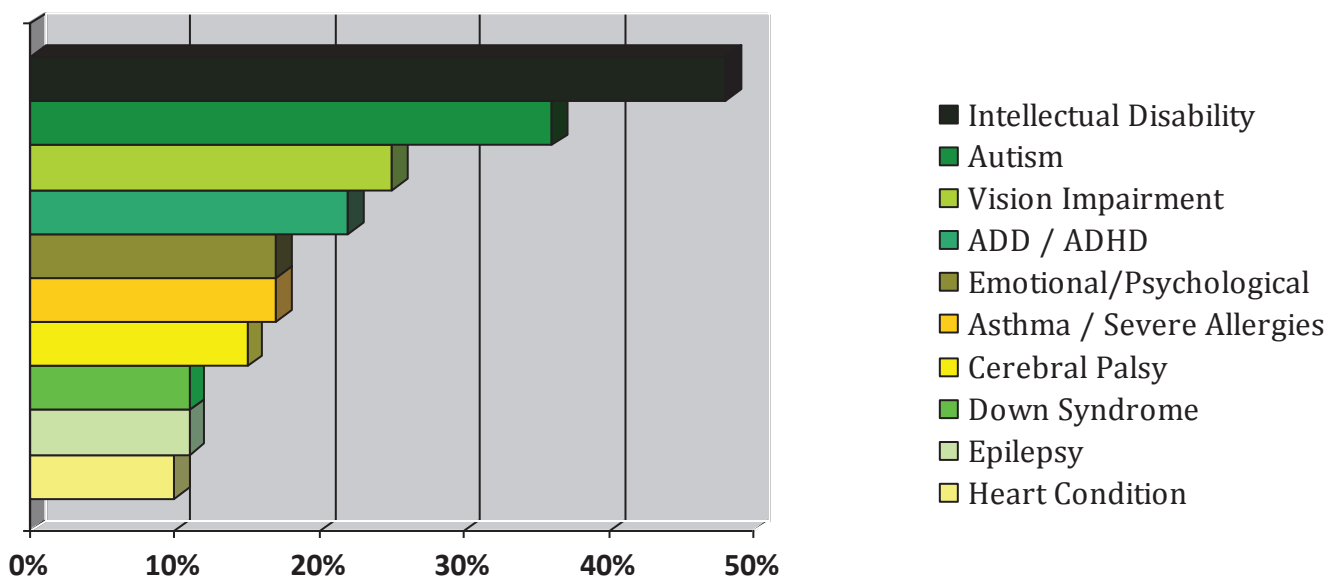
A total of 1300 families were invited to take part in this study. Of these, 538 (41%) completed the Family Life Survey in Year one (2009), including 98 families who were later interviewed. The sample included a roughly equal number of families with disabled children in each age group: 0-5, 6-12 and 13-18 years. The children had a variety of 'conditions'. However, more than one half of the families were raising a child with intellectual disability (48%) and/or an autism spectrum disorder (36%). Other common conditions are shown in Figure 2.

The families who participated in this study were diverse. The sample included single-parent, traditional, blended, dual-income, skip-generation and multi-generation households. *Most of the primary parent-carers were mothers, although fathers performed this role in 12% of the families.* A number of the families were new immigrants to Canada, and others had moved to Alberta from other provinces. There were inner-city families, farming families,

mining town families, biological and adoptive families, aboriginal families living on reserve, families living in commune, and others.

A demographic profile of study participants can be found in Section 2. However these data convey little about the families – who they are and what their lives are like. The following narratives offer greater insight. These narratives were selected from the many that were crafted by the graduate students who interviewed the families: a narrative was written for every family who was interviewed. Selected narratives were chosen on the basis that they were 'typical' in many respects; the challenges faced by these families were faced by many others. Narratives were selected from across all three waves of the study (2009-2011). As far as possible the students used the parent's own words 'in the telling'. Most but not all of the narratives are written taking the perspective of the primary parent-carer (i.e., the parent is telling their story). Additional consent was sought from all parents depicted in narrative. Parents were also given the opportunity to edit their story. Pseudonyms are used throughout.

**Figure 2.** Families caring for children with a diverse range of conditions



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## Can you help us?

graduate student interviewer: Calista Cai

We are Muslim. We come from a country in South Asia. I worked as an engineer there. We have been in Canada for 9 years. I have no job because the economy is bad right now. My wife is working part-time at a restaurant. We are living off a line of credit. We try to send money back to Pakistan for our family because they are going through hard times. My wife's mother lost her house in a flood.


We do not know what our child is diagnosed with. We know she has a delay but that is it. The doctors should have given us documents at the beginning. They told us what she has initially but we do not remember.

Do you know what is wrong with our child?

We have not seen our FSCD [Family Support for Children with Disabilities] worker in 2 years. I keep calling her but she does not return our phone calls. I went down to the office physically but people just directed me to call the worker again and leave a message. Our contract is almost up with FSCD. We would like to have it renewed. We're not sure how to get a hold of her.

We were promised a physical therapist for our child. But our child is 3 years old now and no physical therapist has ever come to our house. This is upsetting because physical therapy is so crucial for our child now, in her younger years. It is important for her to develop and strengthen her muscles.

What should we do? Can you help us?



*Do you know what's  
wrong with our  
child?*

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## An empty shell

Graduate student interviewer: Lindsay Sloane

I was in a relationship with a successful lawyer and living the high life in Florida. It was all about cars, diamonds, and dinners out. When I had my son Benjamin, life slowed down and became about so much more. Within the first year of my son's life I realized that my relationship wasn't going to last; I left shortly after the fighting and hitting began. With no money of my own, a baby and multiple resentments I moved back to Alberta.

I found myself a single mom waiting for a dismal cheque in order to pay my rent in a basement suite. I'm not sure how I didn't see, or was so distracted by my own pain I chose not to see, how my son wasn't developing typically. I didn't know what typical looked like. He was my first child. I was told that boys develop slower. I figured he was independent and creative. I guess I was in denial, I just didn't want him to be different. Then he started to line up pictures, stack cans, place toys in a row across our floor. Eventually he would scream, bang his head onto walls and the floor - even concrete floor. He would take off all his clothes and go outside into the snow and scream. He rocked. His hands would twist and flap. He would cry and cry, nothing I did

*... it felt as though all of my dreams for him had been taken away...*

would console him. I felt like a failure. I would force his head towards me and beg him to "look at mommy", and his eyes would still painfully pull away. My own child would not look at me. Neighbours complained of noise. They wondered about his care. They would avoid us. He was there but not 'there'; like a living form but without any presence. He was diagnosed with autism soon after. When my son received his diagnosis of autism it not only felt like I had lost him, but it also felt as though all of my dreams for him had been taken away along with that diagnosis. I felt like all I had left was Benjamin's empty shell.

It's like his life had just been brutally rewritten and the story was no longer ours. I guess I always assumed that I would raise a normal child. I was so angry. I tried bargaining. I prayed to a God I didn't know or understand. I pleaded to whatever had done this to take it away.

I don't talk about that time in my life very often. I am emotional now because I remember how intense that anger and hopelessness was. I also felt guilty for wishing part of my own son away. I hated autism. It took me a few years and a lot of hurt to finally arrive at the conclusion that 'there's nothing wrong with Benjamin, Colleen - but there IS something wrong with you'. I realized my perspective needed to change. Until I was able to accept my son for who he was, for EXACTLY who he was, my whole life was going to be a battle. My only choice was to accept his autism and to heal.

It was hard to watch typically developing kids. I would sit on the wooden benches at parks and hold back tears. I was angry at the other mother's who didn't even pay attention to the things their kids did with complete ease. I wanted so badly to relate to them. People would ask 'what's wrong with him', 'can he hear me?' and the most hurtful was a cruel 'I certainly don't envy you!' Normally I received sympathetic looks towards my feet or people would say 'awwww' 'poor boy' like he wasn't there. There's ignorance towards disabilities. I don't want him to hear me say 'he's autistic' over and over again trying to 'explain' him away. I don't want him to be seen by the world as 'an autistic'. Benjamin has Autism. Benjamin isn't Autism.



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As a single parent of a special needs child daycare is a catch 22. I wasn't able to work as a nursing assistant because the hours were too long. In order to afford any kind of care where he interacted socially I had to work a minimum wage job that fit within daycare hours. I worried every minute of my shift that he was going to escape. The daycare staff had no special needs training. My son needed one-on-one care for safety reasons. After only a few months I received a call that my son had escaped onto a busy roadway. I opened a small day home in my house and we squeaked by financially until preschool.

Benjamin took his first school bus a few months before his 3rd birthday. FSCD has an amazing program that pays for 3 years of various therapies as well as 3 years of school. It was an intense schedule with his morning bus, day home kids arriving, his return mid day, day home kids leaving, therapists piling in or worse us rushing across the city to their offices. Facilitating and attending the therapy appointments was a full time job. I worried constantly about what would happen when our FSCD PUF school portion ran out, the time when he was suppose to be 'caught up' and 'reintegrated' into a public system. I remember speaking with the CBE area specialist about where he would potentially fit into the public system. After I strongly expressed my concern of him running out of school into traffic, she bluntly assured me 'don't worry, we haven't lost one yet'. I wasn't willing to be the first.

Fortunately I found a preschool for his third/last year of funding where he was able to transition into their grade one. After the funding stopped I was left with a 4,600\$ annual school fee. Today I am married with two more little girls. We pay 14,000\$ annually for Benjamin's school. Shouldn't my child be understood, treated with compassion AND educated....the same as any other child? Why does it cost me 5,000\$-15,000\$ annually for my child to receive this same level of education? I did not ask for his autism. Neither did he. The burden not only of raising and fighting for a special needs child is the parents to carry, and then so are the education costs? Funding of private schools for special needs children is an absolutely necessity in my opinion. There is a misconception that 'private' schools somehow are elite, that parents choose them with many other options. I don't feel I had options for Benjamin, the only facility that had appropriately trained staff was private facilities. Alberta has better funding than any other provinces but still these fee's for a single parent are terrifying. But then again so was the thought of him being hit by a car outside of a public school.

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## I used to be so mousy and shy

graduate student interviewer: Erin Duebel

Jen and I are a family. She always knows when I'm feeling sad and I need a hug or a cuddle. To me she is my whole world! I live every day with Jen likes it's her last. Jen had four different diagnoses including some that were basically death sentences. But, when she got stronger instead of weaker, I said enough is enough. I don't want to know. I just know she is my Jen and I want as much quality time with her as possible. She uses a wheelchair and is basically non-verbal. But, she loves camping, trashy magazines, her TV shows, and football. We're season ticket holders. We're there every year in the same seats. The whole crowd around us knows Jen and always expect her to cheer the loudest! Football is something I've always loved and I used to go all the time before Jen was born. A few years ago I went a little nutty. Jens pediatrician put me on a stress leave for 4 months. In that time I started to do things for myself again including going to some football games. Now, Jen and I love going to the games together.

When Jen was born I didn't want her. I went through post-partum depression right away. I have suffered from depression throughout my adult life. But, as soon as I had Jen in my arms, she was mine and I was her mother. I never wanted to let her go. I had to go through a grieving process at the time to be healthy... mentally. I grieved the death of the child I had lost. I had a wonderful psychologist who helped me through that. Her dad has nothing to do with her. He thinks she's damaged goods, but I know he's the one who's damaged goods. He's missed out on the happiest, most loving child. His parents are amazing though; they've stayed in my life and they do all my babysitting and respite. Whenever I'm at work, or travelling, or need a break, they take care of Jen. I work part-time at a grocery store. I've worked there 18 years and they've been good to me. It feels like my real job is Jen, but with the store on top, I couldn't do it without my ex-in-laws. My parents are supportive in that I talk to them on the phone every day. They live in another town but half the year they live in the states. I take Jen to the states for two weeks a year. Recently I got to try a cruise with my parents and now I'm hooked. Cruises are perfect for people in wheelchairs! Holidaying is my number one thing. I know how important it is to do stuff for myself now.

When my life crashed a few years ago, and I almost lost Jen twice, I stopped work. I started seeing a psychologist and started taking anti-depressants. Medication is a wonderful thing. It was hard to feel judged by people. The day I knew I needed help was when a pharmacist told me I needed to come back Monday to pick up a prescription but I was leaving for the weekend. The pharmacist told me "if you don't pick up the prescription your kid will die, your kid needs to live". All I said was "if I don't get out of this city this weekend I am going to put a bullet in my head or put me and Jen in the car with no seatbelts and drive into a wall at 100km an hour". What the pharmacist said was so insensitive but I knew then I'd gone a little nutty. That's when the doctor put me on stress leave. I've had similar battles in the past with healthcare providers but I've really learned to stand up for myself. I used to be so mousy and shy, but not anymore. Sometimes I feel like my job is yelling. I know I'm the expert on Jens care and I know who the best doctors, dieticians, and OTs are. When I'm in the hospital I make sure I get the people I trust. Even in school, I had to fight to get to the care she needed and after trying three schools I found the one that was the best for her - they just got her. I love her school.



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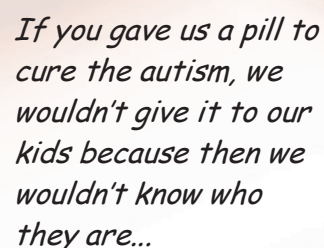
## If you gave us a pill to cure the Autism...

graduate student interviewer: Jarett Stastny

Tyler's a fantastic kid, he's a lot of fun and he is so smart! The IQ is there but if you tested for it you wouldn't get it. There are just too many things - it's the autism, it's the ADHD - there are just too many things blocking it for you to really see how much that boy knows. He doesn't do well with negative statements. He does really well if you're just like "oh good sitting" and "good breathing" and "good whatever"! I have cameras in the house so I can watch everything from my computer, that's helpful. We've got signs on the doors - "STOP you need to ask" - and they're working. But when his impulsivity goes over the top he could just disappear. From morning to night it's constant. You can't relax for a moment, you're always on guard.

My husband loves and needs his work. I work as little as I can to be with the kids. I don't think people really know their kids if they send them off to daycare all day. Being home means I can be involved in everything, including specialized services, which is just the best. I couldn't do that if I was working so I'm happy spending my days at home. For me, to ever stop teaching them would be like giving up on them. I'd rather keep teaching and teaching and teaching because they are always learning and growing. My husband and I always say if you gave us a pill to cure the autism, we wouldn't give it to our kids because then we wouldn't know who they are.

You need patience and a lot of love. If you don't have patience, you will be angry and negative all the time. You're not going to be able to help your kids that way. Patience is everything! Sometimes I wish that I could work a little bit more on something that I like. But then when it's time to go work it's like "no, I just want to stay home and be with the kids"! It's like a fight within myself: I'd like that break from the kids but then I don't want to take it. We're probably one of the most positive families you'll see. People say it must be so hard - well of course it's hard! But it's too busy to get upset about anything!



*If you gave us a pill to cure the autism, we wouldn't give it to our kids because then we wouldn't know who they are...*

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## A mixed bag of successes and frustrations

graduate student interviewer: Matthew Fong

Looking back at how things have turned out for my sons, Curtis and Nick, it's been a mixed bag in terms of successes and frustrations. Our sons are maturing into wonderful young men. Curtis is now seventeen years old and over six feet! Nick recently finished high school with his special needs diploma. We were able to attend the graduation. It was an emotional experience for me personally... having brought him up all these years and finally getting to see him accomplish this major milestone was a really special moment for everyone in the family.

The boys are in different places on the autism spectrum; they each have their own strengths and challenges. When they were young we were really pushing for funding for a care aide to help us out at home. The government could only provide money for them to go to a daycare. My wife and I couldn't figure out the logic there. You can't expect a four year old autistic child to be able to function properly in a loud daycare with lots of kids around! We felt totally helpless and ignored. We also didn't have any respite in caring for them – we only realized this years later because nobody ever told us about respite services in the first place. We were new parents and just figured that it was our responsibility to take care of them 100%. There were certainly times when we could have used a break.

There were struggles as they got older too. Nick did well in specialized school programming but Curtis had a rougher time in school. Because Curtis's intelligence is rated – and saying this always bothers me – 'higher' than Nick's, Curtis went into the mainstream curriculum. Curtis had a tough time in junior high because he doesn't cope well with competition. In classes like gym he was always breaking down; the teachers never listened to our advice to provide him with a non-competitive physical education curriculum – not once. He was at the point where he'd be talking about killing himself. That was really tough on my wife and I. We felt so helpless. The high school that he is in now is a little better at responding to his needs, but it took a lot of pushing to get them there. Now Curtis is starting to feel better about himself. Seeing him in a better place is really encouraging.

I'm not working right now because of layoffs, but I'm enjoying the extra time I get to spend with my sons. The boys and I do activities around the house together like chores and cooking. I think it's important that they have practical skills like that, as well as skills like taking the bus and managing their own spending. I'm watching our family's spending to help stretch my severance pay. Lately our favourite activity has been sitting down together and watching classic TV shows in our basement. That's what we like to do - be together and do things as a family. Nick is actually really into a show that my wife and I watched when we were dating. He loves it so much he'll even quote it sometimes. Even though he's an adult now, Nick and my wife and I recently made the decision together to retain Nick's legal guardianship. It gives us some peace of mind about his future and gives him some comfort knowing that we're sticking together for a while yet.

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## There are things that you have to sacrifice

graduate student interviewer: Miriam Parakkal

My husband and I moved to Canada from Africa with our boys, Andrew and Caleb. Cara, my youngest, was born here. We're both chartered accountants. We're six people in our home; me, my husband, my cousin Shaina, who has come to Canada as the children's nanny, and my three kids. Canada is very different from my home country. People here keep to themselves. I don't know why. Maybe it's the long winters. It's very, very tough to make friends here. To this day I can go to work and there's no person of whom I can say, "Oh this is my friend". I do have one or two neighbours to whom I say "hi", but people just mind their own lives and don't get involved. People here are polite but I don't think they want to be too friendly because they don't want other people to be involved in their lives. Back home, as much as people are nosey sometimes, and they want to know other people's business, I think "it's a good thing because you get - I mean - to know each other and [for] everyone in the community, everyone is a family." When we were at home, we would never worry about the babies. We have lots of aunties and cousins who'd take care of them. So babies are not a stress when you're at home. It's really tough in this place that way.

Andrew incurred a brain injury when he was around two and a half years of age. He wasn't born with a disability. It happened when we were back in Africa. He got very sick one day and we took him to the hospital. There was a time when the oxygen didn't reach his brain. He was never the same after that. Because of our extremely hectic routine when we first arrived in Canada nothing really happened for Andrew. We were still trying to get him signed up for programs, trying to get ahold of a social worker, trying to find funding for any intervention program. There's always a waiting list; for intervention programs, for camps, for daycares, for everything. You just have to keep trying things out. I just feel that there isn't enough information out there and it's difficult to find resources. I found the Paralympic Sports Society swimming classes by accident. If you don't search for, or bump into things by accident, there's no way anyone will tell you. The social workers try but I don't think they have enough information to spread around. There are very limited resources. I know because I tried to phone the hotline for disabled kids. Even for a daycare that takes special needs kids they have a waiting list and they tell you that they'll call you when his turn comes. Imagine, to this day he's still on that waiting list. And this is a year later.

There are definitely things that you have to give up sometimes or sacrifice. Family time is one. "There's no family time". I normally drive Andrew to all his programs and things. It's just the two of us that go because it

*People here keep to themselves. I don't know why. Maybe it's the long winters. It's very, very tough to make friends here...*

just makes things easier. Everyone else stays at home. That's time we all could have spent, together at home, catching up with your day. By the time we get back from an activity, everyone is so exhausted, they just want to sleep. And obviously the relationship is a big thing. "You do worry about those things because you do need time to be a woman and a man, you know, without having to worry about other things and unfortunately there's always something to worry about". Sometimes people are not happy with the way things are going, you know, it's just things that come and go. You just do your best to keep things moving and pray that things work out, to keep our family

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together, because we need each other. Here in the middle of nowhere, where there is no one else, you need to stick by each other because if the bond breaks then everything changes.

Another big thing is that you limit the time you've got to play with and get to know the other babies. I think the biggest sacrifice I've had to make is Caleb. "It's so tough to sign Caleb up for lessons on his own without having to consider what is going to happen to Andrew." You can't do that because then Andrew gets frustrated and disappointed. So in the end, it is actually Caleb that is most disappointed. So by all means possible, we try and sign Andrew up for an activity to which Caleb can also go. But a lot of the time, these programs concentrate on physiotherapy, gross motor skills, fine motor skills, and you're thinking, "Why would I sign Caleb up for that?" So in the end Andrew ends up going to those by himself. Caleb should have been signed up somewhere for soccer, and beginning to play soccer, but we always end up thinking "When are we going to do that? How will that work?", because Andrew is still too weak to be playing soccer.

Even when I'm trying to focus attention on everybody, Caleb will always be the last on the line. At the dining table Andrew or Cara will be the ones who sit next to me because they need help. It's definitely not going to Caleb, which is frustrating because I know he feels it. "What makes it worse is that he's still a baby and needs the attention, but sometimes I feel he just has to live with it." As much as he won't say it, I do think he feels left out. It's tough but the reality is that Andrew will have the first hand at help or anything. It's either Andrew or Cara. I think that's the biggest sacrifice we've had to make. Sometimes I fear that as the other kids get older they might end up drifting away because they don't always get the attention that Andrew gets. You wonder: "How will the other babies react? What are they going to do with their lives?"


There are smaller sacrifices too. Sometimes I just want to relax and do nothing! You tend to lose out on sleep, because either we're studying, or working, or trying to catch up on pending household chores. We end up doing stuff late night. But because my husband and I are late night people we can finish all this work even at one or two in the morning. It's not normal, but what is abnormal has become normal in this house. But you know, besides missing out on family time, which I feel is important, I don't feel like it's a job that I'm doing, doing things for Andrew that is. I like doing it because I know that it's good for him. We don't try and make it feel like we're missing out on so much. We would rather not be doing anything else. We love doing it because we know it's for him. We know that when Andrew is fine, everyone else is happy. We know that there are wonderful things in store for us and in store for him. We just keep working towards him getting better and doing as much as we can do. "He doesn't have to be perfect because he is perfect the way he is now for us anyway. We could never have asked for more."

*Here in the middle of nowhere, where there is no one else, you need to stick by each other because if the bond breaks then everything changes...*

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## You give me hope


graduate student interviewer: Ashley Thomson

 *If you're beside me in this fight, I know I'll make it through the night...*


I met Carol in her daughter Lisa's hospital room. The family didn't think Lisa would survive this recent medical emergency, but she had made it through the darkest night and was now stable and sleeping soundly. Carol and I went to the cafeteria for a cup of coffee, and as we walked down the halls she sang out "hello!" to nurses and aides, calling them all by name. Although Carol is no taller than five feet I had to jog to keep up with her, and throughout our conversation, the brilliant smile that lit up her face did not fade. If you could somehow "plug-in" to this woman, I imagine that she could provide enough energy to power a small town.

 *I get all my strength from you...*


Carol often refers to herself as though she is a machine, capable of running in different "modes." These modes correlate with Lisa's health. When Lisa's health or behaviour changes, Carol "keeps everything running" by going into what she calls "chaos mode...you try this and it doesn't work and you try that and it doesn't work, and you try and figure out anything that works because, that's what you do! You choose to survive."

 *And there's nothing I can't do...*

When Carol talks about "figuring out what works," she is referring to far more than finding a solution to Lisa's health problem. Going into chaos mode means that Carol is going to be at the hospital with her daughter for days or weeks at a time. She must figure out how to maintain her employment as a nurse, work with her husband to keep the household running, stay connected to her three other children, and alter Lisa's care plan to accommodate her changing needs upon discharge. Altering Lisa's care plan can include finding and securing new respite services, care-aides, and school programs, making revisions to Carol's work schedule, reconsidering family responsibilities, and re-negotiating funding and fund allocation with her social worker.

 *But whatever this life brings...*


Carol's daughter Lisa was born with a disease that causes developmental delays, extreme sensory issues, central pain syndrome, and up to 250 seizures a day. She is also "a screamer," says Carol. "My grandmother was an opera singer, and I think Lisa got her voice. She can scream for eight hours a day straight, so loud it rattles the windowpanes. You think it's humanly impossible, but that's what she does." Carol didn't think her daughter would live past the age of two, but the family recently celebrated Lisa's 18th birthday.

 *Just when I thought nobody cared...*

When Lisa was growing up, Carol didn't receive much support from Family Support for Children with Disabilities (FSCD.) "They didn't believe me that Lisa required as much care as she did. They said they didn't have the data to say that I was telling the truth." At around 5 years old, Lisa was sent to a hospital in another city. Her screaming continued as per usual, and staff and patients could hear her three units away. At this point, Carol was sent what she describes with a laugh as "the biggest social worker they could find! The social worker basically told me that the reason I'd never got what I asked for is that nobody believed me how bad I said it was."


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I didn't phone for help in the middle of the night, I didn't hound the physician, I didn't abandon my child, I did not hurt my child. Basically, because I'd kept everything running, I did not qualify for more care."

 *You reached out and with your hand, took mine...*

Carol's family moved from a rural town to a bigger city center so that Lisa could have better access to services. It was a difficult move. All members of the family left behind close friends and a very supportive community. "At the grocery store they'd open a till especially for me and carry my bags out to the car, because everybody knew she'd start screaming soon. Our pharmacist lived right around the corner so he would drop prescriptions off on his way home." The family couldn't survive on one income in the bigger city, so Carol went back to school to renew her nursing registration. She would study between 10pm and 2am or in the bathroom, as it was often the quietest room in the house.

Carol currently works part-time as a nurse. The family health benefits she receives are essential, because Lisa's medications are not covered and cost several thousand dollars every few months. When Lisa's health or behavioural status changes, Carol uses up her sick time, holiday time, and as many leaves-of-absence as she can. She has to be home to take care of Lisa, because there is nobody else to do it. The policies of respite facilities and schools are such that, "respite will say 'forget it, she is sick pick her up.' The school will call, 'she is vomiting come and get her'. And so then you are in the middle of the work and you go 'Oh no, here we go again.' So you have to be really good with your boss so you can have that flexibility so it just makes a lot of extra stress that you are always waiting for the next crisis to happen."


 *All it takes is love and faith...*

Lisa's health and behavioural status have never stabilized, so the next crisis is never far away, but Carol tries to find "flexibility in the chaos." When chaos hits, Carol may stay at the hospital with Lisa for weeks at a time, turning the responsibilities of the household over to her husband and her three other children. Even though her kids were raised to be self-sufficient and independent, Carol's husband becomes very stressed during these times because he is suddenly responsible for cooking and cleaning for the kids and helping them with their schoolwork, in addition to his full-time job.

It's been hard for Carol and her husband to keep their relationship going. Carol often feels exhausted from looking after Lisa, and doesn't have the emotional energy to deal with problems that may arise in their relationship, so the problems "get buried." When Lisa was born, Carol's husband said that he would not assume any caregiver responsibilities. Carol was the full-time caregiver for all four of the children. "He would always say he had so much stress with his job and so therefore I took on even more work load. I was getting three hours of sleep, then he would still say he had so much stress that he needed to go golfing. If I asked for one thing he would always say 'why do I have to, my stress level is worse.' So I couldn't ask for help because I wouldn't get it anyhow, and it would hurt more to ask and be rejected than to just do it myself." Two weeks ago, Carol and her husband had to decide if they would put a chest tube into Lisa or not. If they didn't, Lisa would have died within hours. The decision to keep Lisa alive was the catalyst for them to start mending the tears in their relationship.




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 *Saying you will stand by me...*


Carol has three other children, two daughters in their early twenties and a son who is in his mid-teens. When the kids were growing up, Carol had to limit the activities they were involved in for financial reasons, and also because Lisa's screaming and unstable health meant that Carol could rarely drive the kids to practice or sit and watch a game. Limited funding from FSCD restricted her from hiring a respite worker. Carol tried to compensate for the lack of time spent with her kids by sending them to summer camps and for weekends at their grandparent's farm whenever she could. Still, Carol would often see the kids taking out their frustration and exhaustion on her and her husband, on each other, or by acting-out at school. Her son was recently diagnosed with Attention Deficit Disorder, and Carol worries that it is a learned behaviour from all the years of seeing his sister Lisa get the attention she needs when she screams and acts-out.

Now that the kids are older, Carol sends quick texts and messages on Facebook to keep in touch with them when she's at the hospital. Home has always been a very stressful place to be, and Carol feels that her family is "not as tight" as they would be. "I don't meet everyone's needs, but I do the best I can. I would like to be able to do things, to play with my kids and not just parent my kids. But that seems to be where my time gets cut."

 *It might be dark, and I might be scared...*

When Carol decided to place her daughter the first time, her family was on the brink of burnout. Her son was one year old and Carol existed on three hours of sleep a night. With Lisa placed out-of-home, the day-to-day calmness around the house improved, but Carol suspected that Lisa was being abused and neglected during both of the out-of-home placements. Although the house was calmer, Carol had zero peace-of-mind. In both cases, Lisa went into medical emergencies that required her admission to hospital, and her needs were so high upon discharge that the out-of-home placement sites would not take her back. Carol was always grateful to have Lisa back home so that she could provide her daughter with the highest quality of care, but burnout was always right around the corner. Carol repeatedly requested additional support, but because she is trained as a nurse, she does not qualify for homecare support. Upon urging from her family doctor and therapist, Carol recently tried to take a short-term disability leave for stress, but her insurance company denied her request.

Carol has been preparing for the past year to make the transition with Lisa from the youth service system to the adult service system. She has been told that her adult service social worker is "a tough one," and Carol often feels like her social worker provides her with vague information and little support, making her life more difficult instead of easier; "sometimes I feel like she's messing with me on purpose."

 *You give me hope...*

Carol cherishes coffee dates with friends, where she can vent her frustration and recharge her batteries. She is getting geared up for her daughter's wedding two weeks from now. "I've missed so much of their lives, the past few weeks have been chaos, but I've just got to be at this wedding and have an amazing time." Carol finds the silver lining and cherishes the opportunity to spend time with her husband. She also has faith that they will be able to work through their problems, driven by the work ethic and stubbornness that usually powers her through her days.



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Carol doesn't speak much about her own well-being, but when I asked her how she maintains her mental and physical health, she told me to listen to this song...

## Hope

*I can't believe, you found me here  
You saved me in the nick of time  
Just when I thought nobody cared  
You reached out and with your hand, took mine  
You know just how to pull me through  
That's what I love about you  
You give me hope  
And I can face another day  
All it takes is love and faith  
And the courage to believe  
You give me hope  
And there's nothing I can't do  
I get all my strength from you  
Saying you will stand by me  
You give me hope  
It might be dark, and I might be scared  
But what ever this life brings  
Knowing that you will always be there  
I can take on anything  
If you're beside me in this fight  
I know I'll make it through the night*

- Paul Brandt



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## Normal families go out to Boston Pizza

graduate student interviewer: Erin Duebel

Allison is a happy girl. She's five and basically non-verbal. She and her older brother Kenneth don't get along at all. It's so stressful when they're together. She just screams; she screams when he comes near her and when she started school she'd scream every day. I think some kids may have distanced themselves from Kenneth because of her; he's having trouble making friends. There's a lot less stress in our house when they aren't around together. I wish I could put him in swimming lessons because he's missed out on a lot. So has she; I've always wanted to put her in dance or gymnastics but it's just too expensive. There isn't a lot of money around for extra things; we're kind of drowning in bills. It always comes down to the money around here. There's never enough of it. I sort of wish I could work more so I could help out with the financial situation in our family but we just couldn't find childcare for her. As soon as she was diagnosed with Autism at 2 years old the woman who was taking care of her wouldn't take her anymore. So the decision was made fast. I had to cut my hours and we took the financial hit.

Work used to be my break because I liked my job but now work is stressful. My husband gets a lot more alone time than I do because he works so much. My only alone time is in the morning; I get up before everyone else and I get a few minutes to have coffee, check my e-mail, stuff like that. I could probably use more sleep. I guess maybe when she's in school I'll be able to work more and that will help with money. My husband works construction in his own business. He makes more money than I do. If the weather is bad and he can't work it's stressful. Although, since he started working for himself he's had a more regular schedule and he is home for dinner most nights and he has the weekends off. When he worked for a company he worked 16 hour days sometimes and he would miss seeing the kids at all.

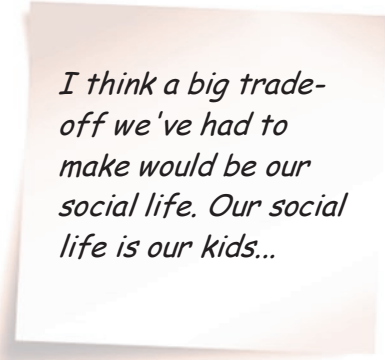
I felt like a single parent. It's easier now because I go to bed early and my husband gets Kenneth into bed. When school starts our schedule will change because Alison will have treatment sessions five times a week after school instead of during the day. It's good and bad because now Kenneth will be home and he doesn't do well with her sessions. He wants attention so he can ruin the sessions by setting her off. We might get to use the time to have him do his homework now. Before we had to wait until she was asleep to do his homework and that's just too late. He was too tired. So, we'll see, I'm nervous about the school year.

I think a big trade-off we've had to make would be our social life. Our social life is our kids. Normal families go out to Boston Pizza. They used to invite us but we haven't been to a restaurant with the kids in about four years. It's hard sometimes to hear other parents talk about their kids doing this or doing that and I just think how we couldn't do that with ours. I think that the kids have traded that off too. I have an old friend who has two kids who are their ages and we didn't get invited to their birthday party this summer. We don't know anyone else who has a kid with Autism except maybe the other parents who go on the community outings but we haven't really bonded. One night of respite a week also isn't really enough of a break. If my husband and I wanted to go out on a weekend or something we can't find anyone who will take her. We don't have any family that will help.

*Little things that mean nothing to most parents mean so much...*

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We've been trying to potty train Alison for over two years now and when we finally get it it will be so rewarding. For us, little things that mean nothing to most parents mean so much. When you have a kid like Alison and they say mommy or daddy for the first time it's so great. It seems trivial but when we realize that she understands more than we give her credit for it's a really nice thing to discover. I'm also really glad we've been able to meet some of the people we have through Alison's therapy and things like that. We may never have crossed paths otherwise. Alison is a really happy girl and who knows, maybe when she starts school I'll have time to use my gym membership again. For now, I'll just keep doing whatever I have to do to keep everything going.



*I think a big trade-off we've had to make would be our social life. Our social life is our kids...*

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## Sleeping with one eye open

graduate student interviewer: Camille Dubé

When Cameron was two and a half years old, that's when I really noticed the changes. He was very aggressive. He started pinching and biting his twin and was very, very hyper. By age three he became self-abusive. That's when we started accessing community services. They were excellent for the day-to-day stuff. "We put all kids in different sports and were constantly on the run taking them to their clubs and sports. We felt this would be healthy for them.... It wore us out but it was easier than being at home with all three of them and trying to live in a war zone". It was most difficult to get good, timely support in crisis situations. Cameron didn't respond to medications like other children. Many had very adverse side effects and when something went wrong we would have to wait far too long for help.

When you have a child with a disability, you really need to make sure that the professional help that you're eliciting is helping. You have to advocate for yourself and your child. "Sometimes parents can be labeled as unable to control their children because they cannot be consistent. In our case the problem was a really difficult-to-deal-with child who had so many different issues that it made it difficult for us to cope at times. Consistency does become difficult when you still are trying to have jobs and when you have other children and other health issues". I had an instance where a psychologist wanted me to use specific behaviour principles and when I tried to tell her they weren't working she'd just tell me to keep trying. How far does it have to go? I mean Cameron will pound his fists and take out a whole wall and I'm not talking just a little spot. He will completely demolish our house.

Since Cameron entered puberty, he has become much more oppositional. They have tried him out on different meds to help with that, but he still doesn't even really have a firm diagnosis which has made it difficult to medicate him. His lack of a firm diagnosis has been a huge barrier for us in terms of accessing appropriate supports and services. We've got a new doctor looking at his diagnosis again because within five or ten minutes you can ask him something and you can get the F-word coming at you, and then maybe three minutes later you can say something to him and he's acting very level, very neutral and he will talk to you normally. The doctor has even noticed that in his office.

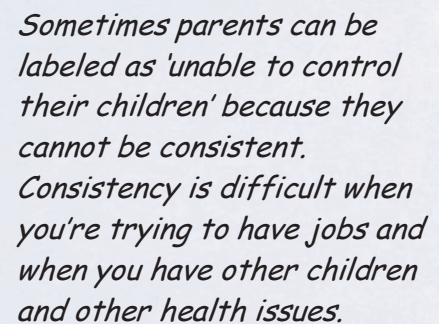
We can't do anything together as a family because my husband and I are constantly having to police between Cameron and our youngest son Brent. We can't even leave the two of them together in the same room unsupervised. Cameron has extreme jealousy of his younger brother. He has tried to suffocate him so at all times we really have to watch. I only work three and a half days per week because my husband works long hours. That way I can get home and protect Brent from Cameron. I work through my breaks and even then it's always a mad rush for me to get home so that the respite worker can take Cameron out. I have my own medical issues too so it becomes difficult to work around my own medical appointments as well.

We are planning a trip to the lake this summer. I am going to fly with Cameron while my husband drives with Cameron's twin brother and our youngest. That way the trip isn't ruined. You'd think I'd be able to figure it out, how to keep my own son in control. After all I do have a graduate degree and I am a special education teacher. I've tried everything with him and nothing works. Cameron is very aggressive, he is narcissistic, oppositional, and engages in self-abusing behaviours often. When he flies into a rage he has hit his head on

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the concrete, has thrown objects at us with such force that they are embedded in the wall, he's grabbed a bar out of his closet and come after us with it; he has no sense of empathy towards others whatsoever. We have locks on our other children's bedroom doors. What I am most afraid of is Cameron flying into a rage and seriously hurting someone, his younger brother in particular. We're afraid that he just might grab a knife and end up stabbing him.

This is not to say that Cameron doesn't have his strengths. He is very high-functioning for an Autistic child and does quite well academically, which makes him very difficult to place in the school system. He also responds really well to structure, so I think potentially he could be productive one day; maybe even attend college or university. On the other hand he could also realistically end up on the streets. I am really looking forward to finally purchasing some new coffee tables sometime in the near future; it seems as though Cameron is at the point now where he shouldn't destroy them like he did everything else in our home. We're really hoping that he matures or I don't know how much longer we can handle everything that he is demolishing. He is literally tearing our family apart. We've considered placing him out of home because there is just no letup; we never get any time out for the rest of the family or for our marriage. We really just take things a day at a time, step by step and you just wake up and you start over again and you hope it will be a good day.



*Sometimes parents can be labeled as 'unable to control their children' because they cannot be consistent. Consistency is difficult when you're trying to have jobs and when you have other children and other health issues.*



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## I am going to tell you about the celebrations

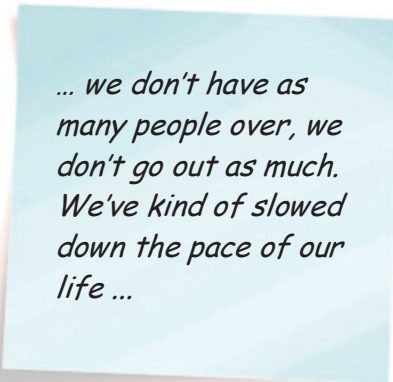
graduate student interviewer: Miriam Parakkal

Things had changed a little bit over the last year for Lydia, her husband Matthew and their sons Shawn, and Evan. The year before, they had so much going on. They had gone overseas to explore treatment options for Evan's condition. They were also running a support group for parents of children with disabilities. Lydia had decided a change of pace was needed for their family: "We've slowed down some of the outside activities and done more as a family because I think we were trying to do too much... So, we don't have as many people over, we don't go out as much. We've kind of slowed down the pace of our life more than that we did before".

Lydia and her husband Matthew and the boys love spending time together biking, camping or just staying at home. Lydia has a systematic routine going in order to manage the household and childcare. She works four days a week from home and finds "blocks of time" in the day to implement Evan's therapies while multi-tasking. She made the decision to take on fewer hours of work in order to spend time with Evan and work on his therapy instead of having what she calls, "a revolving door" of different people coming for inconsistent periods of time to work with him through early intervention.

Working with the interventionists is a team effort for Lydia and she considers herself an important member of the team. "I tend to be a very involved person and so I want to know what's happening. I sit in on the majority of the meetings where the consultants come out. I want to know what they're hearing and what they think the issues are and what we should be working on next so that we can incorporate that into what we're doing. I also have the most knowledge of him and what he can do and so there is often times, where spending an hour with him, you don't get a full picture of what he is able to do. And so there's a lot of input that I have and then feedback that I get from them because I don't have a background in OT, PT, speech-language, all of that education... So we bounce ideas back and forth then we come up with programs."

Lydia and her husband implement therapies for Evan outside of and in addition to what the consultants have recommended: "we have the best reasons to be able to help him. And so sometimes there are things

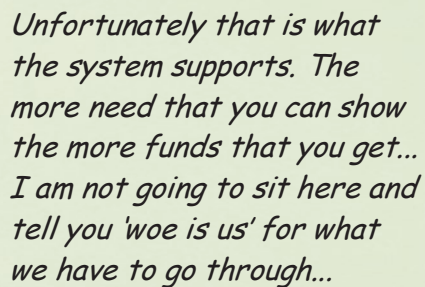


*... we don't have as many people over, we don't go out as much. We've kind of slowed down the pace of our life ...*

that are missed or things that are not necessarily a priority for other people that are priority for us. It's important for us right now for him to strengthen his legs and build muscles. We have an exercise machine that we bought two years ago and he does that an hour a day and that's not really a priority in their mind but it is in our mind because he's developing so much better by using that exercise machine, both physically and cognitively. So yeah that's something that we do outside of the programming because we believe that it's important for him."

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Other families of special needs children have advised Lydia to give the appearance of struggling when the case worker would come to their home in order to assess their need for funding. “So, unfortunately that is what the system supports. The more need that you can show the more funds you get. . . I’m not going to come down - my hair in curlers and sit here and tell you ‘woe is us’ for what we have to go through.” Instead Lydia chooses to focus on the positive. “I am going to tell you the celebrations of things that we’ve achieved and accomplished. And that’s what I am going to focus on. He [Evan] does not need to hear what he cannot do. He needs to hear what he’s done and that’s what we need to work on and build on. We are not going to grow if we keep talking about what we are not and what we can’t do. The only way we can grow is if we were saying, ‘Look at what we’ve changed and let’s look at what we can move towards’. It’s not in me to focus on what can’t be done and I don’t want to be like that and if that means that I lose some funding, then I guess I lose some funding.”



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## Our tilt table

graduate student interviewer: Erica Kronstal

I see myself as being the manager in charge of a tilt table, with a huge pile of marbles on it. I have one job, and that's to try to keep all the marbles from falling off the table! So I tilt it a little bit this way, and a little bit that way, and I spend all my time and energy trying to find the perfect balance so that none of the marbles fall.

My little girl Beth is now nineteen years old. When she was born there were a lot of old school doctors and the entire medical system was not as advanced as it is now. Beth was born screaming and pale, the same way she looks now following a seizure. But she was discharged from the NICU with no explanation and we were sent home. I knew something was different about this baby, she never made eye contact, she wasn't meeting any of her developmental milestones, and she seemed to be always either screaming and agitated, or perfectly still. At 5 ½ months she was diagnosed with a rare condition. That's all I was told, the name of the disease, and that it was awful. Being a nurse, I pulled out the nurse's medical dictionary and looked up the word, and all I found was one sentence. And all I could gather from that one sentence was that our lives were going to change, and that my daughter would never be normal.

I cried a lot during that one week we were at the hospital. But once we went home I knew I had to be strong again. I had a husband who was working full time, and two other children, all of them under the age of 3 ½. We lived in Saskatchewan, and had little to no supports, no family close by, and no access to any therapy. A few months later our family moved from Saskatchewan to Alberta. The government support that was offered to us was ten days of respite a year, and three dollars and fifty cents towards a babysitter for a few hours each week. But it was hard to find a respite worker who was able to care for Beth. During those days Beth screamed a lot, at the top of her lungs, you could hear her down the block. Beth was sleeping three hours a night but only in fifteen minute intervals. I asked the doctor to give Beth a sleeping pill, which I thought was a reasonable request, but they just said 'no'. The screaming would get to you, and you never knew when it was going to start. But I felt like I had to make a choice that I was going to deal with it and that I was going to survive it. I made a choice to drink a lot of coffee and tea to cope with the stress and exhaustion. When life got rough I'd make myself a hot cup of tea and I would make myself sit and sip. For even ten minutes. I would tell myself to put things back into perspective. Or sometimes I would lock myself in the bathroom and take a shower, between the sound of the running water and the fan sometimes you could drown out the screaming. Even going for groceries was a pleasant break, or reading a book when I could imagine that I was escaping into another world. And sometimes, when all the children seemed to be crying, I would just join them. And I know it wasn't just me, it affected the entire family. Once I found my other daughter hiding in a closet and she said 'I'm just trying to find some quiet Mom'.

As she got older the school district insisted on integrating Beth into a regular classroom. She was integrated on paper, but she was really segregated. I was often phoned to come pick her up, or she'd be placed in the hallway or an empty office, when everyone was tired of the screaming. I felt like I had no school, no respite, no help. But I was surviving, even if only barely. And so placing my child in a group home was never something that crossed my mind. Until one day a therapist gave me some mom to mom advice based on her own personal experience. She could tell that I was nearing burn out and she recommended that I look at out of

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home placements before it was too late and I landed up in the hospital and then the government was in control over where Beth would live. I was at the end of my rope, I didn't imagine I could live like that much longer. I needed a break, I needed to recharge. So I took a good look in the mirror and realized that I was tired, and unless I did something it wasn't going to go away.

It was hard to find a group home that would take a child who screamed the way Beth did. We had no choice, only one option, so although my gut was screaming it's the wrong home, I felt it was the right choice. It was the hardest thing. You know placing my child in a group home was harder than having her die. I couldn't entrust my child, who was non-verbal and couldn't defend herself, into someone else's care. A mother doesn't even send her 5 ½ year old to camp, let alone a group home to live. My heart broke like crazy. I second guessed everything I was doing. But I knew that without supports I could not survive at home with her any longer. I also worried a lot about what my other children would think; would they think that I was going to give them away too?

Beth had monopolized my life. My life revolved around keeping her healthy and happy. When I placed her in a group home I started to wonder who I was now, what was I supposed to do in my day? But soon I learnt to live life more 'normally'. I could devote time to my other children and do things that were important. But soon I realized that I had only exchanged one type of stress for another. I began making frequent trips to the city to check up on Beth. I worried about her there, nobody was clipping her toe nails, she didn't seem to be bathed properly, and the staff couldn't figure out the difference between Tylenol plain and Tylenol cold. My gut was still telling me something wasn't right. Once when I went to visit I couldn't get into the house because the staff said they weren't able to prepare the kids for a visitor and that it was their policy that I should have given them at least 4 hours notice to visit. When I was allowed in I often found that the doorknobs to the bedrooms, closets and the bathroom were missing. The doors were basically all locked because they couldn't be opened without a device to turn the mechanism. Sometimes a mother of another child at the school would phone me and say 'it's a gorgeous day out here, I think it's a really good day for a drive', hinting that maybe something wasn't quite right that I should check in. There were other things that rubbed me wrong, like the staff smoking in the house, or how they made all the children drink from one glass because they were too lazy to do dishes. Despite the red flags Beth lived there for three and a half years. And then the final straw came, Beth had black and blue buttocks, black raccoon eyes, and most likely a broken nose. And when I started delving into it I realized that the school was covering for the group home, and the doctor's office seemed to be covering for both of them. My worst nightmare had come true.

I had to get my child out of there. But at the same time I remembered what it was like to have her at home. I couldn't have her suffer because I was burnt out. And sometimes you do what you have to do, even if you don't like it, right? So we moved to a larger city to find care. Our daughter lived at home with us for a few years while we had access to a wonderful respite home. Then we were told that our respite home was to be shut down and not replaced so we felt we had no option but to place Beth in a second group home. Placing my child a second time was no easier than the first, but at least this time she was closer to keep an eye on now. I tried to spend as much time at the home as I could, and to help educate the staff, who were all very young. Because we now lived in a city Beth was able

*We moved to a larger city to find care... Placing my child a second time was no easier than the first...*

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to attend a school for children with disabilities. This school was a dream come true. They were properly set up to handle a child like Beth, they had a phenomenal facility, a place to change a diaper, multiple staff per room, a swing and a pool and they understood her sensory sensitivity. Some people would say we segregated her, but in actuality placing Beth in a segregated school made her more integrated! The staff was trained to deal with children with medical issues and severe disabilities, and they respected me and treated me like a member of their team.

Things seemed to be going fairly smoothly, although the home still seemed less than ideal, it was working. Beth lived at this home for a year and a half. Then one day I received a phone call that Beth had sustained a head injury. Injuries with Beth were common since she had so many seizures a day. I went to pick her up, took her to the hospital, got her stitched up, took her back to the group home and went over the signs of a concussion with the staff. That night she started vomiting in the middle of the night. I only found this out when I phoned them at 2:30 pm the following day. Beth ended up three weeks in the hospital, and they didn't think she'd make it. At that time they gave her an NG tube, and as a result the group home wouldn't take her back because of her increased medical needs.

No facility would take Beth so she came to live with us at home. We were able to resume using our previous respite home which never did get shut down for after school, which allowed me to work part time during the week. But Beth's body continues to fail her, last July her lung collapsed, she had pneumonia, and then another lung collapsed. During a stay at the hospital we found out that she contracted MRSA, which then eliminated her from the respite home, and a lot of care facilities. Although Beth continues to fight, she is now palliative, and her health is failing more each week. They didn't expect her to live until Christmas. But she's surpassed that, and she continues to fight. She is living at home full time and we finally have the support we need at home. I had to take a crash course in how to run my own business! We have care workers through funding from both PDD and Alberta Health Services, but I have to do all the T4 slips, CPP, EI, you name it. I've had to learn a lot over the last year! It took a while to find good caregivers, but now I am blessed with two wonderful ladies. Also PDD made an exception that I can be paid with some of the hours. This has made a huge difference for our family since my husband is currently unemployed. I feel this should be an option for more families, because for our family it allowed us the option for me to stay home more with Beth, and only work part time. Having this flexibility has kept us coping longer. Especially since I couldn't get short-term disability leave through work - they deemed me competent since I wasn't on a psych unit yet!

So these days we're still surviving. You have to. You have no choice. I'm not denying that I need a break. But each day I choose to count my blessings. Even in the midst of a really tough day, there's always something to celebrate. Maybe today I get a chance to go for a half hour coffee with a friend. And maybe today the coffee is really, really good! There are so many things I look forward to when my turn comes. My brother has access to a cabin in Saskatchewan, and it's one of my favourite places to go. This year my other children went, but I had to stay home with Beth. I told them, "wiggle your toes in the sand for me, have a cup of coffee on the deck and enjoy the peace and quiet, and hear the loons"! That's what a break is for me, the absence of chaos. When life settles down, I want to go wiggle my toes in the sand for a whole week, in Hawaii! These are my dreams, but they're realistic dreams, they are going to happen for me one day! And my dream for Beth, for the rest of the time she's with us, is to aim for the most amount of smiles per day!



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## We are your neighbour, your sister, your friend, your daughter

graduate student interviewer: Michelle McIndoe

It's a typical quiet Tuesday morning. The kids seem to be in good spirits so I decide to try my luck and take them clothes shopping. Having three children under the age of five means that they grow quick and there is a never ending need for clothes that fit. So, I pack up all three kids and we head off to shop. With my two youngest in the cart and my eldest by my side helping me navigate my way through the crowded store we set out. All seems well until I hold up a shoe to my daughters foot and suddenly out of nowhere she freaks out. High pitched screams pierce through the otherwise silent store. She starts banging her head, yelling louder and louder, creating a bigger scene every minute. People take notice and work their way over to watch the spectacle that is my daughter. It doesn't take long before the un-approving glances come my way and the comments about my lack of parenting abilities are voiced. The scene continues for another forty five minutes, during which my daughter is too agitated and upset to move her out of the situation to somewhere more private. In the end we leave without any new clothes and head home. All of us tired, disappointed and upset. We will have to leave the shopping for another day.

This trip to the store is a typical day for me. In the following pages, I am going to try to paint a picture of my life for you. Why? Because I think we all need to walk a day in someone else's shoes. I am not about to delude myself into thinking that by reading the following you will understand my experience. I do, however hope that the following causes you to pause and think before you judge the mother whose kids are going crazy in the line beside you the next time you are at a store. Because that lady is me and there is more to me than the frantic mother you see.

Having my family has been a journey with many twists. Life raising three kids is tough. Children come with their own set of unique gifts and challenging traits. This is even more true when two of these children have significant cognitive disabilities. Having my family has changed every aspect of who I am. Through my family I have become a stronger, tenacious and resourceful mother and wife.

Having our children in our life has put us at odds with the world around us. I have a friend, her son was diagnosed with cancer a few years ago. Through their battle with cancer, she and her family got messages on Facebook, people gave them gifts, baked them meals, prayed for them, called them, gave them money, visited them and offered support in any way they could. Cancer is a devastating and frightening experience that no family should go through alone. My daughter Jade was diagnosed with autism around the same time as my friend's son. It was devastating for me to go through the diagnosis, no parent ever wants to hear that their child has an illness that will follow them for the rest of their life. Despite the devastation that took hold of my life, I got no support. Family and friends disagreed with the diagnosis and thought I was going crazy. Unlike my friend, in my time of distress nobody baked anything for me. Nobody called to see how I was. All they did was ask why my kid was spinning and why were they acting so weird. From this time on, we have felt judged and alone.

*Pause and think before you judge the mother whose kids are going crazy in the line beside you... Because that lady is me and there is more to me than the frantic mother you see...*



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My eldest Bradley is a beautiful and smart boy. Bradley didn't start talking until he was three, now you can't get him to be quiet. His excited chatter manages to shatter the quiet and often lonely solitude of my house and is music to my ears. He has his share of difficulties. A sensory processing delay means that every day things like going up and down stairs are more difficult. Having further difficulties with processing means he also experiences a lot of anxiety and gets overwhelmed easily.

My second oldest is my daughter Jade. She is a busy little girl who loves those around her. Despite being delayed in so many areas she is smart and continues to learn and develop every day. She has severe speech, motor and cognitive delay. This means everything we do with her has a purpose as we try to take advantage of a small window in time where she can develop and learn to her full potential.

My day is consumed by my three children and their various needs. Given the challenges that my two eldest present, this means that my day is filled with programming from various therapists that come into our home. I am continually watching out for trouble from all three kids. I spend my day trying to avoid major accidents and use all our time to meet some specific learning or developmental purpose. My daughter is still unable to use a toilet on her own, my son is unable to play or make friends his own age, and my third son is continually finding trouble. There are very specific allergies that I have to work around, a very specific programming schedule to coordinate, and a house to maintain. These things keep me on my feet running all day long.

Despite all this, I do all that is within my physical and mental power to help ensure that my kids are healthy and happy. Like all children mine are very unpredictable. The invisibility of their illness makes us a target for judgment and criticism. To look at my kids in public and say that I am a lazy or poor mother because my kids are out of control would be a serious error in judgment. The nature of Jade's diagnoses results in meltdowns that are both frequent and unpredictable. This means that our trip to the store is never typical and that often times we are openly criticized and judged by those in my community.

My life is often noisy, busy and somewhat stressful. Friends and family have a hard time finding the patience to put up with my children let alone relating to what I go through. Because of this, I have lost a lot of support. This has been a difficult loss for my family to go through. Watching friends and family members withdraw has been painful and made my life more difficult and lonely. This experience has left my husband and I without an outlet or shoulder to cry on. We all have a need and desire to feel heard and understood, I never imagined that I would lose the supports that I have.

*This fight drains me of time and energy that I could be putting into my family. Instead, my time and energy goes to unnecessary assessments, phone calls, paper work and appointments...*

This feeling of loss and the unknown is something that many parents in my situation experience. There is a poem called Welcome to Holland by Emily Perl Kingsley; it was written about parents in situations such as mine. It relays a fitting metaphor of planning a trip to Italy. While onboard you find out that the plane will be landing in Holland instead. You land in this different place where you don't know the language, rules or culture. This is very fitting for the adjustments you make after having a child with a disability. I also find it a fitting metaphor for my social life. All my friends boarded the plane and made it to Italy. They have the perfect families, and are now in their own world, they don't seem

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to understand why I am still stuck in Holland. But I am here none the less trying to navigate the challenges and find the beauty of this place that I am in alone.

Despite feeling overwhelmed and alone, I have had to adapt to my circumstances. As a result I have become very proactive. Many have told me that I am a tenacious person, I suppose to someone looking in on my life this is true. I wasn't always this way. Having two children who need extra support and help has meant that I have had to become an advocate for them. I am not looking for a hand out, but in this case I need one. Services and supports can be hard to get. I equate it to a game where you have to beg for help and for time that your family needs. This is a belittling and demeaning game to play, but I have learnt to put what pride I have aside and play their game so that I can get what little support they have to offer me. Perhaps the most frustrating part of this is the state fighting leaves me in. This fight drains me of time and energy that I could be putting into my family. Instead, my time and energy goes to unnecessary assessments, phone calls, paper work and appointments.

What does this all mean for me as a person and as a mother? That frantic mother you see in the grocery store is a woman who has had to adapt. What you see in front of you is a result of that adaptation. She looks tired because she is. She doesn't do her hair or put on makeup in the morning like most women because, there isn't time for that anymore. Her life looks slightly out of control because it is. I used to be in control, I had time for myself, I had time to invest in my marriage, I had a life filled with friends. I have had to accommodate to allow my children to receive the supports that they have today. This has meant that I need to get up at five in the morning to get an hour to myself before the day begins. It also means I have little time alone with my husband and our relationship is strained and stretched at times. The busyness of our routine means that each kid misses out on one-on-one time with their parents. What gets me through these hard times is the hope that down the road they can be a productive part of society, that they can be good people. Seeing this one day in the future will make all the pain, loneliness and challenges worth it.

While you may have a small taste for my life and an even smaller understanding of why I do what I do, my situation is not hopeless. There are many things that can be done for people in situations such as my own that would make our burdens a little lighter. Perhaps the simplest being that we don't need to hear that we are bad parents or feel that you are judging us. We don't want your sympathy, if you want to be a friend be one but if not, move on. Creating a means of support and time for parents to process what they are going through together would be of great benefit to my family's overall well-being and the mental health of all parents who are in situations such as mine.

There are many more things that I could tell you and many more things I could suggest that may make the lives of myself and people in situations such as mine a little easier. It is my hope that you are able to identify with some part of my life. That you can get a small taste of what I go through so that you can appreciate and better support the great diversity that surrounds you next time you see a family like mine. No family fits into a perfect mold, mine certainly does not. But despite our unique needs and challenges we do exist. We grow up around you, we are your neighbour, your sister, your friend, your daughter. There are more of us than you may realize and, we all could use your support.

## THE BALANCING ACT AT THE HEART OF FAMILY LIFE

The families who participated in this study were diverse. Yet these families struggled with many of the same questions and challenges with respect to organising, adapting and sustaining a daily routine. Four over-arching and somewhat inter-related challenges emerged from our analysis of survey and interview data. These are (1) difficulty balancing the competing needs and wants of their children; (2) tension between wanting to protect *and* wanting to integrate their child and family into the community; (3) conflict between earning and care giving activities; and, (4) trouble accessing and navigating supports and services.

**Figure 3.** *The BIG four challenges*



### 1) *Difficulty balancing the competing needs and wants of our children*

*“... how are parents of the disabled to fulfill their responsibilities to the disabled child’s siblings when emotional resources are drained with the disabled child, when parents want the “normal” child to make up for what the child with disabilities cannot, when parents want something not to be difficult? Many answers are offered here: try to find some “special” time to be with the “normal” sibling; explain to them*

*what’s going on; give them space to express their feelings; generate resources from extended family, friends, community; remember that love is all that matters. All these are true. But they do not eliminate the haunting sense of guilt, confusion, and self-doubt that arises – bit by bit or all at once – as you see the effects on the other sibling(s) of what you’ve given to the disabled one. There is a permanent sense of inadequacy ...”* (Gottlieb, 2002, pp. 229-230)

When the daily routine is unsustainable and sacrifices or trade-offs have to be made, it is usually the mother’s needs and interests that are ‘sacrificed’ first. Yet uppermost in the minds of many of the mothers and fathers who participated in this study was the concern that their other, non-disabled child was, in one way or another, ‘missing out’. These parents are caught in a moral bind. On the one hand, they feel morally compelled to do anything they can to help their disabled child. On the other, the official morality of ‘normal parenting’ requires them to ‘pour themselves out’ equally among their children. Consequently, many parents live with a ‘haunting sense of guilt’ and ‘permanent sense of inadequacy’.

One mother wept as she explained that “it’s just that he always gets put to the side. You know, because Alex’s needs are so much huger than his”. Similarly, another mother observed that “she [sibling] got the brunt of it... Jacob [child with a disability] was so sick all the time... so she didn’t get the attention that she needed. But I mean, there’s a lot of guilt... we haven’t always been as patient dealing with her issues, because, from dealing with Jacob”. Some offered moral justification for prioritising the needs of the disabled child. One argued, “fair is not equal, fair is what you need... It’s fair that Timothy gets 65% of our time and Emily [sibling] gets 35% because that’s what they need.” Notably, this mother later reported that “I’m volunteering to be a Sparks leader specifically so I can spend time with her. I mean, we still try, she’s still our daughter, it’s not just Timothy, so you have to divvy it up”.

In an effort to balance the need and interests of their children, some parents endeavoured to normalize family life by including all their children in family activities. As one mother told us “there is three of them, we’re a family, we’re a team”. Other parents cut back on their child’s treatment programs to carve out space for family time: “You are going to have so many therapists in your lifetime which is great... but you are only going to have one family time... You know, therapists will go, family memories won’t”. Likewise, another mother stated “I started to become a little more protective of our time, our family time, and on days when we have a revolving door to our house to say ‘okay, in the evenings we’re not doing anything, and we’re just going to be together over the weekends, we’re just going to be together’”.

## **2) Integrating the child and family into the community**

Many parents in this study were ambivalent about integrating their child and family into the community. On the one hand, parents want to avoid social situations in which their identity as a ‘good parent’ or ‘normal family’ might be questioned; and, they want to protect their child from the cruelty of ignorant people. On the other, many parents expressed a desire for fellowship, and want their disabled child to participate more fully in (community) life. As one father stated, *“my goal is to make [our child’s] life bigger than just her parents, so we try to do lots in the community; shopping, play groups, swim lessons, visiting the library.”* Different families may reconcile these two potentially conflicting goals [to protect and to integrate] in different ways, and any one family may lean one way (e.g., toward protection) and then the other at different times.

The parents who participated in this study described positive as well as negative social encounters. On the positive side, many parents talked about the wonderful people who had come into their life as a result of having a child with disability. Further, many parents described positive responses from

complete strangers: respect, patience and understanding. One mother shared her family’s experience: *“We just find going to the library or going to the pool or going to the grocery store, people are familiar with us now and people are very approachable, very respectful and we’ve had just really positive reactions from complete strangers. You know even just going to Costco and people are more or less very friendly, you know we’ve never had issues that I can think of with parking spaces or, people are just, I don’t know, she just brings out the best in people maybe, or they just have these little moments of compassion.”*

However, negative and hurtful experiences had made some families quite wary. A number of parents were hurt when once close friends and family members ‘dropped out’ of their lives or excluded them from social occasions. Many had experienced the sting of judgement when, for example, their child had behaved badly in the store and strangers had brazenly questioned their competence. And (perhaps worst of all), many parents literally ‘felt for’ their disabled son or daughter when he or she was marginalised by his/her peers (e.g., was not invited to a birthday party), or was subject to name calling and/or other forms of victimizing. In response to such negative social experiences, families may pull tight together and ‘bunker down’, shutting out the world, at least for a time.

Families raising disabled children with challenging behaviours (e.g., disruptive or aggressive behaviours) may be particularly vulnerable to social isolation. As one mother shared, *“Especially when she was younger, people were quite scared of her cause she’d bite at random and so a lot of kids got bit by her, and if she had a complete meltdown at somebody’s house we’d have to leave and it’s not easy to have people here either, so it’s hard to reciprocate in a relationship. So our social life definitely lacks and you know we have one or two good friends that understand but you still don’t... So you’re kind of in prison... but that’s okay.”*



### **3) Making a living and caring for a disabled child**

All families have to solve the problem of how to make a living *and* care for dependents. The 'traditional' (usually gender-based) division of earning and care giving responsibilities works for some, particularly if the single earner has a sufficiently high income. However, most families do not have this option. To solve the problem they have to rely upon some combination of flexible work scheduling and child care, formal and informal. However, flexible employment conditions and suitable child care options are hard to come by. Consequently, many are struggling to *make ends meet*: they are uncertain whether they can pay their bills, and are doing without some of the basic things their family needs.

Many parent-carers in this study had to quit work or work less in order to care for their child with disabilities. One parent explained, *"I can't be somewhere for too long, so [working part-time] works for me. I mean I could do with more money which would go with the full time work, but then again I have to strike a balance. [My children] need me too so I do what I can and I come back"*. Another parent reported that, *"I went back down to part time work again, because the school couldn't handle him, nobody could handle him, ... so then we didn't have as much money coming in. Luckily we're frugal, ... we didn't go on any trips or anything for years, but at least we didn't have a lot of debt and things, so that was a relief, but it just, all that time of not travelling, not ..., it takes its toll, like, on a relationship, like it's still a struggle, you know, we lost a lot of years that we didn't do stuff together as a couple..."*

Some parents have a strong support network which enables them to return to work on a part-time or full-time basis. One mother reported: *"next year I'm going back to work full time so she'll be [at a day home] every day for half the day that she's not in pre-school, and then both my parents and my in-laws [live here] so she spends a lot of time, she's very attached to my mom, so she spends quite a bit of time with*

*grandparents, so we've got a great support system."* However, many parents had difficulty finding suitable child care, and/or had deep reservations about entrusting others with the care of their child. One mother reflected, *"I feel like I can't work a full time job because I don't think I could put [my child] in day-care, because I think they'd ignore him all day, because he's quite happy to sit and rock all day long and my fear would be that they would let him do that ... so I worry that he wouldn't do well in a daycare setting, so I feel I need to be here for him before and after school, so I'm trying to figure out a way to do that and work..."*

Some parents also had a supportive work environment and flexible work hours, which helped them to juggle work and care giving demands (e.g., to keep appointments, respond to crises, and so on). For example, one father reported, *"I have a real good work ... especially when [my child] was in the hospital there, it was 'I get a phone call I'm out of here. I'll see you, I'll let you know when I'm coming back. Maybe I'll be back tomorrow, I'll let you know.' Or, you know, 'I'll be in early, or I'll be in on Saturday'. They're really understanding for my needs."* However, other parents reported that their workplace could not accommodate the needed flexibility within their day, which led them to quit work or change work environments. One mother explained that *"the work I do I basically create my own schedule. I have to. ... I went to college and I was working in a doctor's office and I had to leave because I could not do the completely structured setting"*.

### **4) Trouble accessing and navigating supports and services**

*"The day that your child is diagnosed you are like 'what do we do next?' And then when you are first introduced to the world of funding or whatever you want to call it is mind-blowing. It's very, very confusing. You don't know where to start, who to call, what to do. There is no book that's placed in your hand saying that your child is Autistic, here you go, here are*

*the people you call. It's nothing like that... You're going through the yellow pages. You are on the internet. So you talk to probably twenty people who don't give you one piece of information that you want before you get to the person who says 'oh yeah this is what you got to do'... This is a maze."*

The families in this study valued the supports and services they received, and spoke highly of individuals who worked with them. However, the families consistently reported difficulty with accessing and navigating the service system. The system creates uncertainty and burden: To many it seems as though the system is designed to discourage families from accessing support. Periods of transition, such as the transition from child to adult services, were particularly unsettling. However, accessing and maintaining needed supports could be challenging at any time. Parents described the process as overly bureaucratic, onerous and demeaning. Some suggested that the work involved in accessing and managing services was tantamount to running a small business.

Obtaining useful information about the available funding and services is one challenge. Many parents said that they did not know where to begin looking and had received little or no guidance. One concern was that there was no central place they could go to for information: Parents often learned about services by 'word of mouth'. Another concern was a perceived lack of transparency. Many parents felt as though there was an inherent level of secretiveness associated with obtaining supports: they were concerned that the information they needed was withheld from them. One parent stated, "But [the agencies are] not telling you about [the funding that is available], and when they do tell you about it, they say they shouldn't be telling you about it."

The process of qualifying for and retaining funding and services is another challenge. Many parents said that they had to 'fight for' services, and this was exhausting. The parents' stories also revealed what

seems to be an internal contradiction. On the one hand, the complex processes, procedures, rules and regulations made some parents feel like they were always under suspicion, as if they were trying to perpetrate some kind of fraud. On the other, many parents were instructed by 'system insiders' on how to 'play the game', which involved downplaying their strengths and accentuating their struggles in order to get the funding and services they needed. One parent explained, "*well there is the challenge of understanding what the funding is for and how to word the requests so that they understand what you want in a way that they are willing to provide it.*" Some parents but not others learned how to play this game.

*"You know what I'd like more of, is for them to not be so difficult with funding issues and you know, the whole politics and the inconsistency and the secretiveness of things... It's just not a transparent program... It depends on who your worker is, it's kind of like a lottery, like I've had some terrible workers that... Like when you're doing your annual contract and in the home where I had to break down crying for them to understand the depth of what their services did and why I needed things. Sometimes it feels like you're committing fraud by doing a contract... Others—[laughs] it felt like it was their money they were giving to you and you had to prove your case to them, you know, and it shouldn't be that way."*

A third set of challenge relates to accessing supports and services. Obtaining funding for services is one challenge, obtaining the services the family actually needs is another. Two barriers were identified. One is the lack of suitable workers and appropriate services. The waiting lists for some services, such as respite care, can be long. The other problem is the lack of flexibility in the system with respect to how families can use the funding they receive. A number of parents could readily identify individuals or agencies who could provide the services they needed, but the rules and regulations were such that they



could not use the funding they received to obtain those services. For instance, one parent wanted to continue using the same trusted respite home, but when her child turned 18 she was required to use a different service. This parent explained, “*what we’ve been doing is maintaining that agency that we had previous, and just paying them through her AISH money, so basically using her whole AISH cheque to pay for her services.*”

Finally, parents spoke at length about the discontinuity of services and the uncertainty this creates. Many parents observed that the different workers and agencies involved in their lives didn’t seem to ‘communicate’. Consequently, many families had to

repeat their story and fill out mounds of paper work requesting information that other agencies already had. Service discontinuity, as they moved from child to adult systems, was a particular concern. Parents described this time period as a rocky and tumultuous one. Due to such discontinuity, several parents suggested that there is a need for an individual or “go-between” to help families navigate the system/s. One mother expressed the view of many when she said, “*In my opinion, there should be liaisons, I don’t even know if that’s the right word, the person to help you through the system, and make it widely available.*”

### ***Parents want...***

- |                     |   |
|---------------------|---|
| <i>Transparency</i> | Information about funding and services should be easy to access. Some families may need assistance to help them through the application process.    |
| <i>Ease</i>         | Parents should not have ‘to fight’ for funding and services, or be required to spend an inordinate amount of time dealing with ‘red-tape’.          |
| <i>Flexibility</i>  | Greater flexibility with respect to how funding can be used would enhance family capacity to access the supports their child and family needs.      |
| <i>Continuity</i>   | Enhanced continuity of care, across agencies (e.g., better communication) and through normative transitions would greatly reduce stress and burden. |

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## 2

### **Sustainable family care for children with disabilities**

**Purpose:** The purpose of this study was to investigate factors influencing families to continue caring for their children with disabilities at home or seek out-of-home placement.

**Method:** A stratified (by child age group) random sample of 538 families raising children with disabilities in Alberta, Canada took part. Participants completed the Family Life Survey, which incorporated measures of child and family characteristics, sustainability of daily routine, and out-of-home placement propensity.

**Results:** Family placement propensity is inversely associated with the sustainability of the daily routine. Sustainability of the daily routine is, in turn, more strongly associated with social-ecological resources, including parental control-over-work and the adequacy of child care options, than with child characteristics, including disability severity and behaviour problems.

**Conclusion:** If families have the social-ecological resources they need to create and maintain a daily routine that is congruent with their values and goals, and with the needs, interests and competences of family members, then they are unlikely to give out-of-home placement any serious consideration.

The majority of parents want to continue caring for their sons and daughters with disabilities at home, and they are expected and actively encouraged to do so. Notwithstanding, and for reasons that are not well understood, a substantial number of parents will 'voluntarily' place their disabled son or daughter out-of-home. The aim of this study was to investigate the attitudes of parent-carers in Alberta, Canada, toward out-of-home placement. The primary objective was to identify factors that may explain why some families, and not others, seriously consider out-of-home placement as an option for their child. This knowledge is vital for developing social care policies and programs that support parents and promote sustainable family care for children with disabilities.

## **BACKGROUND**

Since the 1960s, public policy and professional practice in high income countries have by and large endorsed family and community care for children with disabilities. However, the voluntary out-of-home placement of children with disabilities remains an option that many families will seriously consider and some will actively pursue. In the United States, for example, Blacher and colleagues tracked an initial sample of one hundred families of young children with severe to profound intellectual disability over a period of ten years and found that over half of the families seriously considered out-of-home placement at some point, and more than one in five followed through (Blacher & Hanneman, 1993; Hanneman & Blacher, 1998). Similarly, in a multi-year study involving 81 families of school-age children with severe disabilities and high support needs in Australia, Llewellyn, McConnell, Thompson and Whybrow (2005) found that over 40% of the families had at least considered placement as an option, and by study end, 18% had either placed or had taken steps to place their child out-of-home.

A small but not insubstantial number of studies have investigated factors influencing parent decisions to continue caring at home for a son or daughter with disabilities or seek out-of-home placement. However, much of the extant research is now dated and/or is based on small, non-probability samples. Further, most of the available data emanates from just three countries: the United States, Australia and Israel. Notwithstanding, the extant data supports at least three firm conclusions. The first is that the decision to seek out-of-home placement is not one that parents take lightly (Blacher & Baker, 1994; Hostyn & Maes, 2007). For example, Mirfin-Veitch, Bray and Ross (2003) found that, for parents in their study, the decision to place was "the hardest and most painful decision of their lives" (p. 105). The second is that out-of-home placement is usually an act of last resort (Blacher & Hatton, 2001). Llewellyn, et al. (1999), for instance, found that parents did not want out-of-home placement for their child but this became "the only means by which the family could 'survive'" (p.229). The third conclusion supported by extant research is that the decision to place is rarely spur-of-the-moment, although the final decision may be triggered by a crisis. Typically, the decision is long in the making—a process rather than a discrete act—driven by snowballing stressors and delayed by guilt feelings (Blacher, 1990; Bromley & Blacher, 1989; Bruns, 2000; Llewellyn et al., 1999).

The question is how can the observed variation among families with respect to their attitudes toward and actual placement of disabled sons and daughters be explained? To date, family attitudes and decisions related to placement have proven hard to predict (Blacher & Hanneman, 1993; Llewellyn et al., 1999; Rimmerman & Duvdevani, 1996). 'Low risk' families may be identified with a higher degree of confidence. The problem appears to be a lack of specificity, which is a common problem when it comes to the prediction of rare conditions or events. Notwithstanding, the limited available



data suggest that family propensity to place is positively associated with child age, care need (i.e., dependency) and behaviour problems; and, inversely related to family resources, including but not limited to family cohesion and adaptability, and the availability of support from extended family and significant others (Bromley & Blacher, 1991; King, King, Rosenbaum, & Goffin, 1999; Kobe, Rojahn, & Schroeder, 1991; Llewellyn et al., 1999; Raif & Rimmerman, 1993; Rousey, Blacher, & Hanneman, 1990; Tausig, 1985).

Several studies have also found that family attitudes toward out-of-home placement and placement rates vary with ethnicity and socioeconomic position (Bruns, 2000; Hill, 2011; Hostyn & Maes, 2007; Rimmerman & Duvdevani, 1996). In the United States, Blacher, Hanneman and Rousey (1992) found that European-American families tend to have more favorable attitudes toward out-of-home placement than African-American and Latino families. Similarly in Israel, Azaiza, Rimmerman, Araten-Bergman and Naon (2006) found that Jewish families were more likely to seek out-of-home placement than Arab families despite reporting lower levels of personal and family burden.

Data on the relationship between service use and placement propensity is more equivocal. Some studies have found a positive association between placement propensity and family utilisation of support services such as respite care (Blacher, 1990; Blacher & Hanneman, 1993; Bottuck & Winsberg, 1991; Cohen & Warren, 1985; Perry & Black, 2006). Of course this at-first-glance counter-intuitive finding could simply be due to greater service utilisation by families with greater need. However, difficulty with services (i.e., accessing, navigating, negotiating, and so on) is a major source of stress for many families, and it has been implicated in the decision to seek out-of-home placement (Bruns, 2000; Hostyn & Maes, 2007; Mirfin-Veitch et al., 2003). Moreover, some formal services may inadvertently

add to the overall 'burden of care'. Many parents are, for example, asked and expected to implement onerous, time consuming home therapy protocols which may tax family resources (Llewellyn et al., 2005; Mirfin-Veitch et al., 2003). Cole and Meyer's (1989) survey of 103 parents of children with severe intellectual disability offers some insight into what resources parents think may be useful in maintaining the child in the home. From a set list, parents were asked to identify the five potentially most important resources. In rank order from most to least frequently cited, these were (i) assistance from one's spouse, (ii) coverage for medical and dental expenses, (iii) evening/weekend childcare in the home, (iv) funds for extra help around the house, and (v) professional consultation for behaviour problems.

Family propensity to place may be the most reliable predictor of actual future placement. Blacher and colleagues developed a simple ordinal scale to measure placement propensity, called the Placement Tendency Index (PTI) (Blacher, 1990). This scale consists of stages a family may go through in the process of deciding to place their child. Possible scores range from 1 ("we have never thought about it") through to 6 ("we have placed our child"). In a longitudinal study, Blacher and colleagues have found that the PTI has excellent predictive validity: there appears to be a monotonic relationship between placement tendency score and the probability of future placement. The data suggests that, although still undecided, once a family starts making inquiries (i.e., a score of 4 on the PTI), out-of-home placement becomes highly likely. Blacher and Hanneman (1993) however emphasise that families can back away from, as well as move toward placement, at any stage. Other studies, including one study involving families of children with an autism spectrum disorder in Canada, have provided additional support for the predictive validity of the PTI (Perry & Black, 2006).

## ***Theoretical approaches***

One of the more pressing challenges for research is the specification of causal mechanisms or pathways linking child-specific, within-family and social-ecological factors to placement propensity: Identifying families-at-risk is one task, but understanding why these families are 'at-risk' is necessary for the development of prevention focused policies and programs. Stress and coping theory, applied to the family system, comprises one potentially useful conceptual framework. For example, applying Patterson's (1988) Family Adjustment and Adaptation Response model (the FAAR model), certain child characteristics may be conceptualised as demands, and continuing family care for children with disabilities may constitute evidence of positive family adaptation or 'resilience' (*i.e., a demonstration of competency with respect to the performance of vital 'family functions' despite significant hardships*). The model anticipates variation with respect to how families respond to the demands they face. This is because families vary with respect to their capabilities (*i.e., within-family and community-level resources and coping behaviours*), and the meanings they ascribe to their situation (*i.e., demand and resource appraisals*). Family outcomes (*bonadaptation or maladaptation*) are then a function of continuous interaction over time between demands, capabilities and family meanings.

Ecocultural theory offers an alternative theoretical approach for understanding placement propensity and actual out-of-home placement of children with disabilities. This theory is not inimical to stress and coping theory. Rather, it encompasses and contextualises stress and coping processes. At the heart of both ecocultural theory *and* the FAAR model, for instance, is the agentic family that is at once *acted on* (*i.e., shaped and constrained by*), and *acting upon* (*i.e., shaping*) the immediate circumstances of their lives. Furthermore, ecocultural theory and the FAAR model are somewhat compatible with respect to

factors thought to influence family adaptive processes and outcomes. For example, ecological constraints and resources (ecocultural theory) are compatible with family and community-level demands and resources (FAAR model).

However, there are fundamental differences between these theories. Drawing on Aristotle's discussion of the four causes, stress and coping theory (including the FAAR model) may be classified as an 'efficient cause' theory. This theory begins with some disruption or potential threat, and then focuses on how individuals or families respond. Ecocultural theory on the other hand may be classified as a 'final cause' theory. This theory posits that the central adaptive challenge for all families everywhere, and the final cause of family accommodations (ecocultural theory), adjustments or adaptations (FAAR model), is *sustaining a daily routine*. This involves *but cannot be reduced to* family responses to disturbances or stressors. Gallimore, Bernheimer and Weisner (1999, p.58) elaborate

*"All families must construct and maintain a daily routine, but not all daily routines are possible. A sustainable family routine is a compromise among the constraints we must live with, the values we hold, and the characteristics of individual family members. We do not arbitrarily choose when to go to work or shop or cook dinner; it is not irrelevant to deeply held values that families schedule meals so that parents and children are usually present; we do not participate in carpools to get children to special activities or services because we like the incidental social interactions involved in organising them. Sustaining routines to reconcile many competing factors is an enduring family project, not just an occasional mobilisation of coping strategies in response to stress".*

The process of sustaining a daily routine involves fitting the routine to the local ecology and family resource base. Resource-fit *-when family resources*

*roughly match and support the activities the family weaves into a daily routine* - is thought to be a necessary condition for sustainability. In turn, resource-fit is understood to be a function of ecological constraints and resources, and the family's values, goals and expectations. The assertion is that although *having more* (education, wealth, status and so on) is advantageous, the determining factor is *having enough*. However, ecocultural theory also asserts that resource-fit is not a sufficient condition for sustainability. In addition to fitting the routine to family resources, parents try to organise their daily routine in a personally meaningful and morally right way. This involves fitting the daily routine to the family's values and goals, and effectively juggling the varied and inevitably competing needs and interests of family members. Ecocultural theory posits that a daily routine that holds little meaning, and/or revolves around the needs of any one family member is a less sustainable daily routine (Bernheimer, Weisner & Lowe, 2003; Weisner, Matheson, Coots, & Bernheimer, 2005; Weisner, 2009). Sustainability of the daily routine is therefore a function of resource-fit and *family life congruence* (i.e., meaning and balance).

A second important difference between ecocultural theory and stress and coping theory has to do with the emphasis placed on structure *vis a vis* agency. Applications of stress-coping theory tend to treat structure—the ecological and cultural context in which individuals and families live—as a *background given*. Stress and coping research then quite *'naturally'* leads to recommendations and interventions focused on modifying or re-forming the individual child, caregiver and/or family. By contrast, ecocultural theory, as the name suggests, problematizes the ecological and cultural context in which the family lives. The enduring family project of sustaining a daily routine, Weisner (2009) asserts, “must always be understood as a project somewhere, in some particular community with its constellation of

goals and local constraints and opportunities” (p. 229). As such, not all routines are possible, and not all possible routines are acceptable, either to the family and/or their cultural community (Gallimore, Bernheimer & Weisner, 1999). Moreover, in any given ‘somewhere’, some families may be more constrained, with respect to what is possible and acceptable, than others. For example, families of children with disabilities may be more constrained by inflexible employment conditions (i.e., due to a greater need for flexibility) and/or a lack of child-care options (i.e., because inclusive childcare options are in short supply) (Booth-LaForce, & Kelly, 2004; Freedman, Litchfield, & Warfield, 1995; Grace et al, 2008; Gordon, Rosenman, & Cuskelly, 2007; Owen, Gordon, Frederico, & Cooper, 2002; Seltzer et al. 2001; Warfield, 2001).

The concept of culture is more or less absent from stress and coping theories. In ecocultural theory however, culture is a key to understanding family adaptation, including the adaptation of families *with* children with disabilities, and the adaptation of families *to* children with disabilities. In ecocultural theory, culture is ubiquitous, existing in the minds of actors and the social institutions that members of a cultural community together create. We can think of culture as an enabling resource; Skinner and Weisner (2007) explain that we *use* ‘cultural models’ (i.e., *schema*) to make sense of experience, to plan and take action in different situations and, to evaluate and anticipate the behaviours of others. Cultural models then enable us to fluently interact and coordinate our actions with one another on the basis of taken-for-granted, shared understandings. However, culture also constrains. Enculturation instills within us dispositions toward some ends but not others (e.g., continuing to care for a disabled child at home rather than placing them out-of-home); and, equips us with some but not other scripts and strategies for action (Bargh, 2007; Estany, 2011).

The moral conflict experienced by parents who are struggling to balance the needs and interests of their children (e.g., “I worry that my other children are missing out”), and the guilt feelings experienced by those contemplating or actively seeking out-of-home placement are examples of how culture can shape experience. To experience such moral conflict and guilt feelings parents must first have some moral intuition or belief that what they are doing is not ‘right’, and such moral intuitions are culturally transmitted (Vaisey, 2008). In a now classic work, first published in 1975 and re-produced in 2006, Voysey Paun (2006) observed that mothers of children with disabilities are more than normally held accountable, and indeed hold themselves accountable to a cultural model of ‘normal parenthood’: the official morality of childrearing. Among other things, this official morality requires parents to effectively balance the needs and interests of their children (i.e., the cultural ideal of equal treatment), and to continue caring at home for them: normal parents do not place their children out-of-home (Voysey Paun, 2006). Notably, Llewellyn et al. (1999) found that parents offered moral justifications for their decision to place their disabled son or daughter out-of-home (i.e., “it was the right thing to do”), and Bruns (2000) found that moral support (i.e., “you are doing the right thing”) was an essential ingredient for actively pursuing out-of-home placement.

Two quite recent Australian studies have applied ecocultural theory to investigate factors influencing families to continue caring at home for a disabled son or daughter or seek out-of-home placement. The first of these studies involved a sample of 171 families of preschool age children with severe disabilities, and the second, 81 families of school-age children with severe disabilities (Llewellyn et al., 1999; 2005). Utilising the Ecocultural Family Interview to gather data on family routines and accommodations (including actions taken, avoided and delayed), these studies found that families who were

seriously considering or actively seeking placement tended to have less sustainable daily routines. More specifically, family propensity to place was greatest when there was ‘misfit’ or a lack of congruence between the daily routine and the family’s values and goals, and the needs and interests of other family members, particularly non-disabled siblings. In contrast, when workload and responsibility was shared, and the disabled child was more fully integrated into the community, parents were less likely to be considering out-of-home placement as an option for their child. Other interview based studies have also found that difficulty striking a balance between the needs of disabled and non-disabled siblings - and more broadly, between work *and* family *and* caregiving demands - is a primary influence on the decision to seek out-of-home placement (e.g., Bruns, 2000; Hostyn & Maes, 2007; Mirfin-Veitch, Bray & Ross, 2003).

The purpose of this study was to investigate placement propensity among families of children with disabilities in Alberta, Canada. Guided by ecocultural theory, and building on the research conducted by Llewellyn and colleagues in Australia, we hypothesised that sustainability of the daily routine (resource-fit and family life congruence) at least partially mediates the effect of child-related stressors (e.g., disability severity, behaviour problems, complex health care needs) and general family functioning (i.e., cohesion, expressiveness, problem-solving) on family attitudes toward placement. In turn, we investigated the relative contribution or weight of child-related stressors *vis a vis* selected indicators of ecological resource-fit in predicting sustainability of the daily routine. Our ‘hunch’ was that shared responsibility (for keeping family life running), services that are responsive to the family’s needs and priorities, flexible employment conditions (i.e., control-over-work), and satisfactory childcare options may contribute more to sustaining a daily routine than child-related stressors.



## METHOD

This study was nested within a three year, multi-method study of work-family-care integration in families bringing up children with disabilities in Alberta, Canada. The sampling frame consisted of all English-speaking families listed in the Alberta Department of Children and Youth Services, Family Supports for Children with Disabilities (FSCD), Child-Focused Services registry. Following Ethics Board approval (File#B-060808), and with the assistance of FSCD personnel, a stratified (by child age group: early childhood, middle childhood, adolescence) random sample of families were invited to take part. Data collection included annual surveys and in-depth interviews with a purposively selected sub-sample of primary parent-carers. The present study is based on survey data collected in Year one (2009).

Calculation of the sample size required for the study was based on four parameters. These were (1) an estimated population of 5000 families in Alberta with one or more children with disabilities and high support needs; (2) a predicted response distribution of 25% of families who are seriously considering or have taken steps to place their disabled child out-of-home (Llewellyn et al., 2005); (3) an acceptable margin of error of 5%; and, (4) a confidence level of 95%. With a predicted participation rate of approximately 25% and a projected attrition rate of 15% over the three years of the study a total of 1300 families were invited to take part with the goal of recruiting and retaining a sample of 273.

The recruitment procedure followed the Dillman (1978) method. Firstly, families received a letter informing them about the forthcoming survey. Within two weeks, each family received a copy of the survey package, including the “Family Life Survey”, cover letter, consent form, pencil, and a return postage paid envelope. Approximately two weeks later, a follow-up reminder postcard was mailed out. Then approximately two weeks after this, another copy of the survey package was dispatched to families who had not yet responded. All respondents received an honorarium of CAN\$30.00.

The Family Life Survey, completed by the primary parent-carer, incorporated items to collect demographic data, including but not limited to data on household composition; primary parent-carer sex, age, ethnicity, educational attainment and employment status; and, the sex, age and diagnosed condition of the (*nominated if > 1*) disabled child. In addition, the survey incorporated items derived from previously validated scales and researcher-generated items to collect data on child and parent-carer characteristics, ecological resource-fit, general family functioning, family life congruence and placement propensity.

### ***Child and parent-carer characteristics***

Disability was measured by a single item, “*To what extent does a long-term physical condition, mental condition, learning or health problem reduce the amount or kind of (age appropriate) activities this*

#### **Definition of key terms**

*Ecological resource-fit*: refers to the perceived fit between the daily routine and the family’s local ecology and resource-base. The question is whether the family has the resources it needs to meet demands and achieve longer term goals.

*Family Life Congruence*: refers to the perceived fit between the daily routine and the family’s values and goals, and the needs, interests and competences of all family members. The question is whether the daily routine is meaningful and balanced.

*child can do?"* with five response options ranging from 'not at all' to 'a great deal'. General health was measured by a single item, *"How would you describe this child's general health?"* with five response options from poor through to excellent. A similar question, with the same response options, was used to obtain a measure of parent-carer general health, *"How would you describe your general health?"* Complex medical care needs, along with diagnosed condition, was also assessed by a single item which asked parents to identify, from a list, *"any... long-term conditions which have been diagnosed by a health professional"*. Number and intensity of child behaviour problems (in children 4-18 years of age) was assessed using the 24 item short form of the Developmental Behaviour Checklist (DBC-24) (Taffe, Gray, Einfeld, et al., 2007)

### ***Ecological resource-fit (see Appendix A)***

A measure of ecological resource-fit was derived from items tapping social support and integration (Brevik & Dalgard, 1996), financial hardship (Barrera, Caples & Tein, 2001) and perceived stress (Cohen & Williamson, 1988). In addition, control-over-work was measured by five items with four response options ranging from never through to often: *"I have a say in what I do at work"*, *"I can work from home if I wish"*, *"I have a say in how I do my job"*, *"I have a say in my own work speed"*, and *"My scheduled work hours are flexible"* (Marmot, Smith, Stansfeld et al., 1991). Shared responsibility (i.e., shared with spouse and/or other family members) was measured by a single item, *"Responsibility for keeping our family life running is shared"*, with four response options ranging from strongly disagree to strongly agree. Adequacy of formal child care arrangements was measured by the item, *"Given the choice, would you like to use less, the same number or more hours of child care?"* And responsiveness of services was measured by the item, *"In general, professionals/services respond to our family's needs and*

*priorities"*, with five response options ranging from strongly disagree to strongly agree.

### ***Family level variables (see Appendix A)***

A measure of general family functioning (cohesion, expressiveness and problem-solving) was obtained using items derived from the General Family Functioning scale of the McMaster Family Assessment Device (Epstein, Baldwin & Bishop, 1983). Items tapping Family life Congruence (i.e., meaningfulness and balance in the daily routine) were adapted from the Family Life Interview (Llewellyn, Bundy, McConnell, Emerson & Brentnall, 2010), and placement propensity was measured using the Placement Tendency Index (PTI), described above (Blacher, 1990).

### ***Data analysis***

The data were analysed using PASW (SPSS) v.18 and AMOS v.20. Data were entered and then re-entered into SPSS. Discrepancies were identified and data-entry errors were corrected. After cleaning the data, a demographic profile of study participants was generated. Excluding items tapping child behaviour problems (for which there were just three response options) and control-over-work (for which data was not missing-at-random), Bayesian estimation (i.e. utilising the Markov chain Monte Carlo algorithm and a saturated model) was employed to replace missing values with predicted values, and transform the ordered-categorical (i.e., partially missing) data into numeric data. This approach has a number of advantages over traditional approaches to the treatment of missing data, such as listwise or pairwise deletion or mean substitution, which can result in a significant loss of data and/or biased estimates. In essence, this approach solves the problem of incomplete data through an iterative and progressive process, utilising what is known (i.e., prior probabilities) and what is learned, to replace missing values with the most likely values (Shafer & Graham, 2002; Arbuckle, 2010).



**Table 1.** *Child, parent-carer and family characteristics (n=538)*

			Mean (SD) or %
Child	Age		9.49 (4.77)
		0-5 years	30
		6-12 years	35
		13-18 years	35
	Sex	Male	65
		Female	35
	*Impairment Type	Intellectual disability	48
		Autism spectrum disorder	36
		Cerebral Palsy	15
		Downs Syndrome	11
	Disability (activity limitations)	A little	15
		Fair amount	23
		Quite a lot	23
A great deal		39	
Parent	Age		41.08 (8.26)
	Sex	Male	12
		Female	88
	Language spoken at home	English	96
	Highest educational attainment	Did not complete high school	9
		High school graduate	18
		Diploma/trade certificate	40
		University undergraduate	25
		University postgraduate	9
Family	Residence	Major urban	56
		Minor urban	19
		Rural	25
	Family type	Couple, single-earner	28
		Couple, dual-earner	48
		Couple, no-earner	3
		Lone parent, earner	15
		Lone parent, non-earner	6
	Total household income	< \$40,000	27
		\$40,000 - \$69,000	20
		\$70,000 - \$89,000	20
		\$90,000 +	33
	Total number of Children (<18 years)		

\*not mutually exclusive categories

A composite measure of child behaviour problems was obtained by calculating the mean of all available DBC-24 raw item scores. The internal consistency reliability of the DBC-24 in this study was  $\alpha = .83$ . To create a composite measure of control-over-work we computed the mean of the primary parent-carer and (when applicable their) partner responses on each item, and then we computed the mean of the integrated item scores. The internal consistency reliability of the integrated control-over-work scale

was also  $\alpha = .83$ . Confirmatory factor analysis (CFA) was then employed to develop and validate measures (i.e., demonstrating convergent and discriminant validity) of other latent constructs: ecological resource-fit (financial hardship, social support/integration, and perceived stress), general family functioning and family life congruence. Using the CFA model regression-based composite scores (i.e., factor scores) were derived for each of these latent variables.

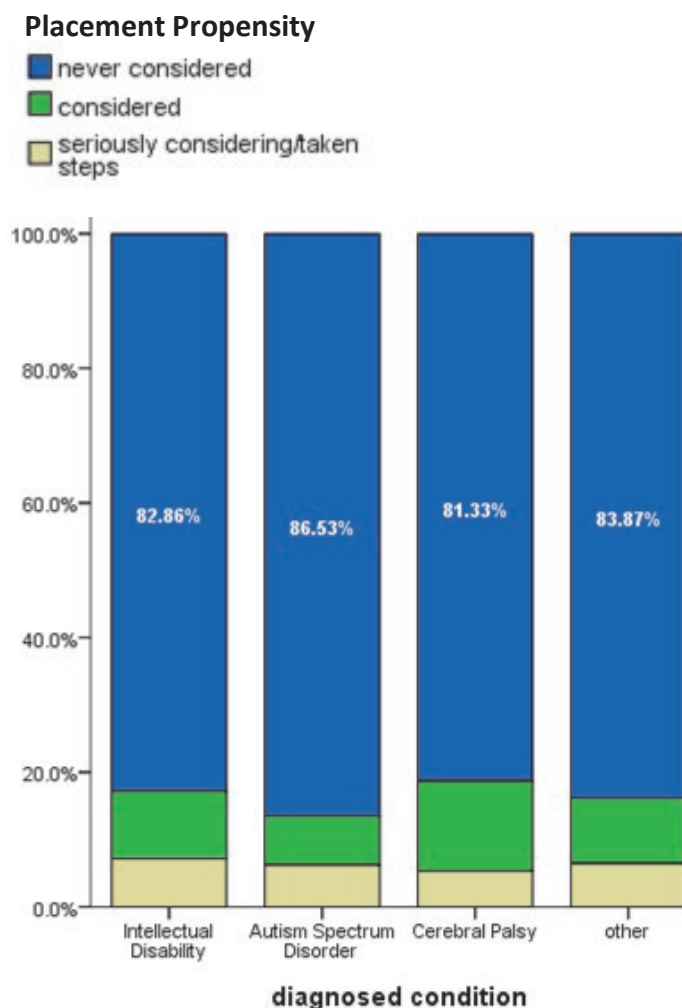
Bayesian transformation of the placement propensity scale, based on a saturated model, resulted in a more normal distribution (mean = 0; std = 1; min=-2.76, max= 3.02; skewness=-.101, kurtosis=-.06). Path analysis (i.e., structural equation modeling with observed or composite variables) was therefore performed to investigate direct and indirect effects of child characteristics, general family functioning, ecological resource-fit and family life congruence on the placement propensity of families with disabled children 4-18 years of age. Due to the skewed distribution of raw placement propensity scores we also created a three point ordered-categorical scale (1=never considered, 2=have thought about placement, and 3=seriously considering or have taken steps to place) and performed a multinomial logistic regression analysis. Finally, path analysis was employed to investigate the contribution of child-related stressors and selected indicators of ecological resource-fit to sustaining a daily routine.

Absolute fit of the CFA and path models was assessed using the  $\chi^2$  goodness-of-fit test. The  $\chi^2$  value is the traditional measure for evaluating overall model fit: a non-statistically significant  $\chi^2$  value indicates close fit between the proposed model and the data. However, the  $\chi^2$  goodness-of-fit test has several limitations including but not limited to sample size sensitivity (Schermelleh-Engel, Moosbrugger & Müller, 2003). Therefore we report multiple supplementary indices, including but not limited to the  $\chi^2$  value divided by its degrees of freedom (*CMIN/DF < 3 is good*); the Comparative Fit Index, which compares the specified model to an independence model (*CFI >.95 is good*); and, the 90% confidence interval around the root mean square error of approximation (*RMSEA90*), which should contain a value that is less than 0.06 to indicate the possibility of close model fit (Schreiber, Nora, Stage, Barlow & King, 2006).

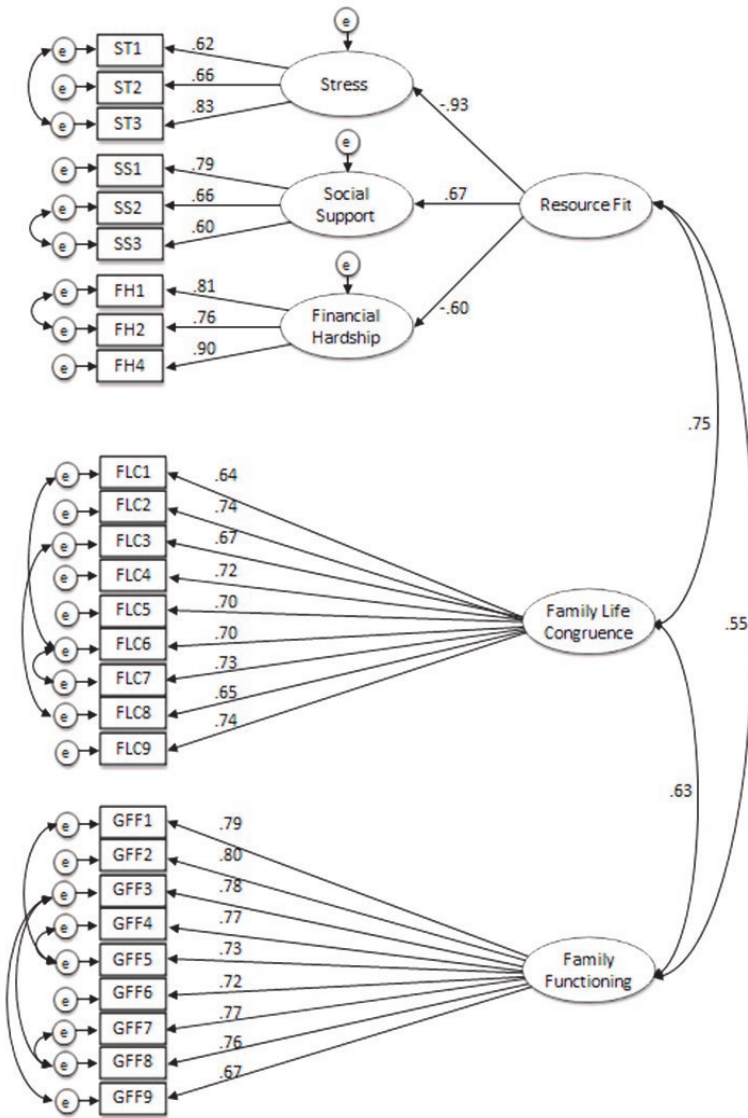
## RESULTS

A total of 1300 parent-carers were invited to take part in this study. Of these, 538 primary parent-carers (41%) completed the Family Life Survey. A demographic profile of study participants is presented in Table 1. The majority of the participating families (84%) indicated that they had never considered out-of-home-placement as an option for their child, although this number decreased as child age increased (See Table 2). At the high end of the propensity spectrum, one in ten families with a disabled child 13 – 18 years of age were seriously considering or actively pursuing out-of-home placement. No significant association was found between placement propensity and diagnosed condition (see Figure 1).

**Figure 1.** Placement propensity by diagnosed condition



**Figure 2.** CFA with bootstrap, standardised path coefficients (n=538)



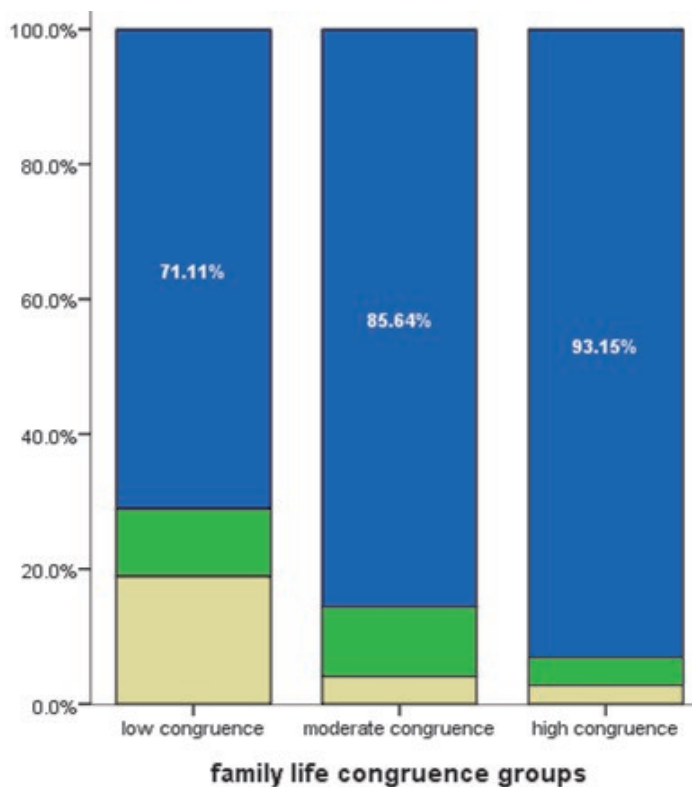
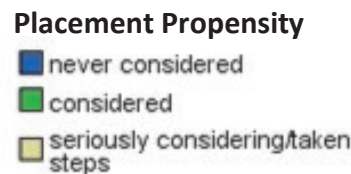
Model Fit Indices:  $\chi^2 = 699.57$ ,  $DF = 307$ ,  $p < .05$ ,  $CMIN/DF = 2.28$ ,  $CFI = .95$ ,  $TLI = .95$ ,  $RMSEA90 = .044 - .054$

**Confirmatory factor analysis: construct validation**

The three factor CFA model displayed in Figure 2 fit the data reasonably well, as evidenced by the supplementary fit indices. However, to obtain this model a small number of items were dropped due to correlations between error terms. Discriminant validity was assessed in two steps. Firstly, the fit of the three factor model shown was compared to the fit of a two factor model by constraining the

variance of family life congruence and general family functioning and the covariance between them to be equal to one. The three factor model provided a significantly better fit to the data ( $\chi^2$  difference = 150.48,  $p < .001$ ). Second, the fit of the three factor model was compared to the fit of a two factor model in which the variance of family life congruence and resource-fit and the covariance between them were constrained to be equal to one. Again, the three factor model provided a better fit ( $\chi^2$  difference = 122.23,  $p < .001$ ). Overall, these results provide good evidence of convergent and discriminant validity; family life congruence, general family functioning and resource-fit, as measured in this study, appear to be discrete albeit inter-related constructs.

**Figure 3.** Placement propensity by family life congruence (n=538)



**Table 2.** Placement propensity by child age group (n=532)

	Never considered % [95%CI]	At least thought about it* % [95%CI]	Seriously considering / taking steps % [95%CI]
Child < 6 years (n=162)	93.2% [89-97]	6.8% [3-11]	0.6% [0-2]
Child 6-12 years (n=183)	82.5% [77-88]	17.5% [12-23]	7.1% [3-11]
Child 13-18 years (n=187)	78.1% [72-84]	21.9% [16-28]	10.7% [6-15]
Total	84.2% [81-87]	15.8% [13-19]	6.4% [4-8]

\*including those families who report seriously considering or taking steps to place

### **Correlations between study variables**

Table 3 presents a zero-order correlation matrix of study variables. Modest, but statistically significant correlations were found between placement propensity and all study variables with the exception of total number of children < 18 years of age. Placement propensity was most strongly correlated with Family Life Congruence and this, in turn, was most strongly associated with Resource-fit. Child age did not correlate strongly with any variable. However, child age is positively correlated with placement propensity and negatively correlated with the perceived responsiveness of professionals/services to the family's needs and priorities. In other words, the parent-carers of older children tend to be less positive about the formal support they receive.

Significant correlations were found between parent educational attainment, control-over-work and household income. And each of these three indicators of socioeconomic position were significantly correlated, in the direction one would expect, with financial hardship, social support, perceived stress and general parent health. The correlation between household income and financial hardship was, as expected, particularly strong ( $r = -.61$ ).

Figure 3 shows the distribution of placement propensity categories (i.e., never considered, thought about it, and seriously considering/taking steps) within family life congruence groups (i.e., one stand-

ard deviation or more below the mean, within one standard deviation of the mean, and one standard deviation or more above the mean).

This figure clearly shows that families with low congruence are more likely to have at least thought about placement as an option for their child. Indeed, using binary logistic regression analysis we found that the unadjusted odds of at least having thought about placement are more than five times greater in the low family life congruence group than in the high family life congruence group [ $B = 1.71$ ,  $S.E = .52$ ,  $OR = 5.53$ ,  $p = .001$ ].

### **Predictors of placement propensity**

To investigate the direct and indirect effects of child characteristics, general family functioning, resource-fit and family life congruence on placement propensity we tested the path model displayed in Figure 4. Direct, indirect and total effects are presented in Table 4. The model fit the data well and accounted for a modest but statistically significant 18% of the variance in placement propensity ( $r^2 = .18$ ,  $p < .05$ ). Overall, the findings confirm our hypothesis: the effects of child-related stressors are partially mediated by sustainability of the daily routine (including resource-fit and family life congruence). However, child age, number and/or intensity of behaviour problems, and complex medical care needs each had statistically significant direct (unmediated) effects on placement propensity.

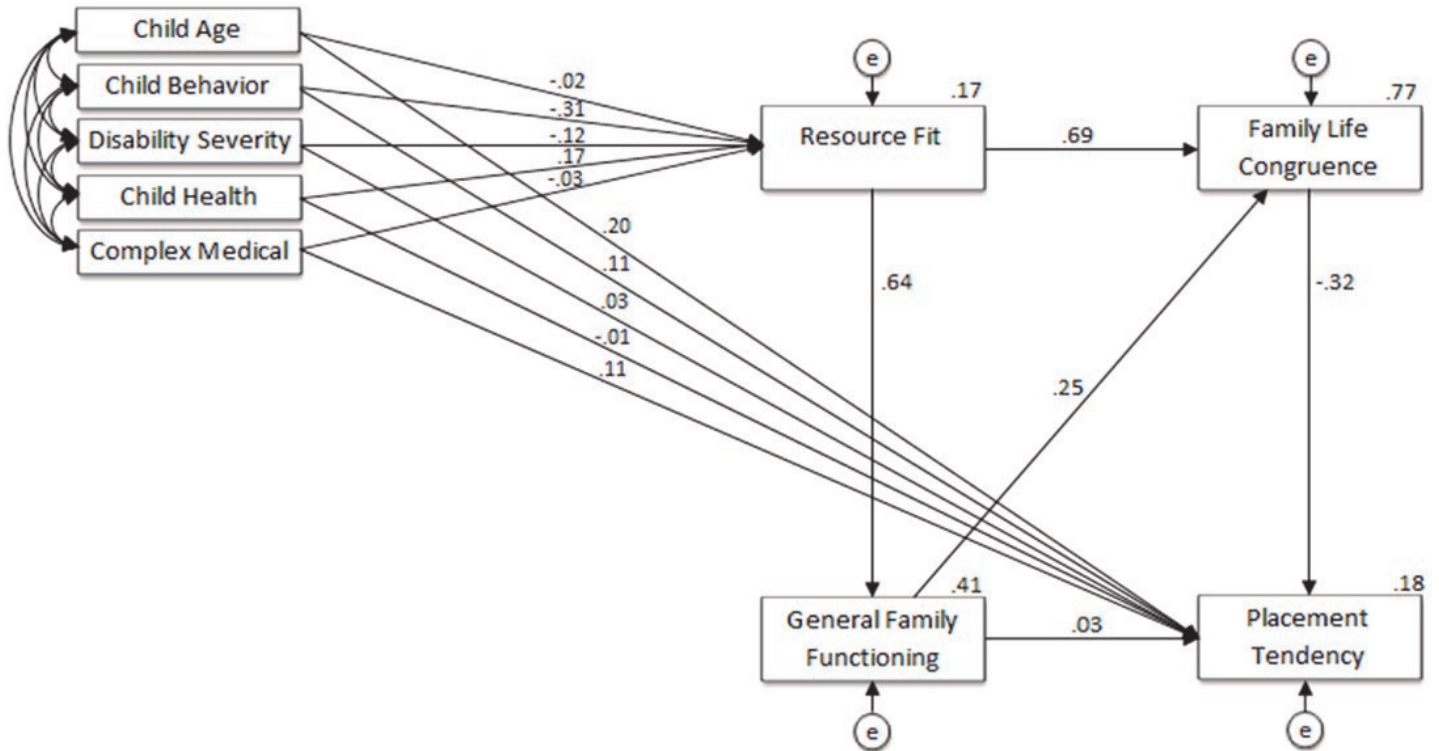
**Table 3. Zero-order correlation matrix**

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21
1. Placement propensity																					
2. Family Life Congruence	-.36*																				
3. Resource Fit	-.32*	.89*																			
4. Social support	-.25*	.64*	.79*																		
5. Financial hardship	.15*	-.44*	-.69*	-.49*																	
6. Perceived stress	.31*	-.79*	-.99*	-.73*	.66*																
7. GF Functioning	-.24*	.69*	.64*	.48*	-.34*	-.58*															
8. Child age	.18*	-.01	-.00	-.05	-.07	.00	-.03														
9. Disability Severity	.12*	-.22*	-.12*	-.07	.03	.11*	-.06	-.00													
10. DBC behaviour problems	.18*	-.32*	-.34*	.29*	.27*	.33*	-.26*	-.16*	.03												
11. Child general health	-.14*	.19*	.22*	-.15*	-.22*	-.21*	.15*	.01	-.19*	-.08											
12. Complex medical needs#	.14*	-.10*	-.10*	-.07	.07	.11*	-.01	-.07	.21*	.04	-.31*										
13. Control-over-work	-.15*	.27*	.27*	.28*	-.22*	-.24*	-.21*	-.11*	.00	-.08	.04	-.01									
14. Shared responsibility	-.13*	.45*	.46*	.37*	-.24*	-.44*	.43*	-.06	-.12*	-.13*	.12*	-.01	.07								
15. Wants more childcare#	.10*	-.22*	-.21*	-.18*	.14*	.19*	-.14*	-.05	.12*	.22*	-.05	.08	-.10*	-.08							
16. Responsive services	-.18*	.32*	.36*	.41*	-.21*	-.33*	.27*	-.14*	.02	-.14*	.18*	-.02	.22*	.20*	-.11*						
17. Parent-carer age	.15*	.02	.07	.01	-.20*	-.07	-.06	.56	-.11*	-.14*	.08	-.11*	.03	.04	.01	-.07					
18. Parent education	-.09*	.08	.17*	.14*	-.38*	-.14*	.12*	-.03	.11*	-.19*	.08	-.00	.20*	.01	-.04	.08	.15*				
19. Household income	-.10*	.16*	.30*	.19*	-.61*	-.27*	.18*	.05	.08	-.18*	.12*	-.01	.11*	.07	-.05	.07	.14*	.46*			
20. Married/common law#	-.10*	.08	.17*	.09*	-.34*	-.16*	.13*	-.07	.03	-.08	.02	-.03	-.02	.19*	.03	-.04	.04	.17*	.40*		
21. Total children	.04	.03	-.02	.03	.08	.03	.04	-.15*	.03	.14*	-.01	-.00	-.07	.03	.01	-.06	-.19*	-.08	-.08	.17*	
22. Parent general health	-.14*	.34*	.39*	.31*	-.31*	-.38*	.33*	-.09*	-.00	-.26*	.25*	-.10*	.21*	.17*	-.10*	.19*	-.10*	.17*	.30*	.15*	.02

#point-biserial correlation; \*p<.05



**Figure 4.** Path model predicting placement propensity (n=475)



Model Fit Indices:  $\chi^2 = 24.63$ ,  $DF = 11$ ,  $p = .010$ ,  $CMIN/DF = 2.24$ ,  $CFI = .99$ ,  $RMSEA90 = .024 - .078$

That is, the results suggest that there is a relationship between these child characteristics and placement propensity that cannot be fully explained by their effect on the sustainability of the daily routine or general family functioning. In addition, the results suggest that the effects of resource-fit and general family functioning on placement propensity are fully mediated by Family Life Congruence.

To further investigate the relationship between placement propensity, child characteristics and family life congruence, we employed multinomial logistic regression with placement propensity group as the dependent variable. The results are presented in Table 5. The overall model was statistically significant (Likelihood ratio test  $\chi^2 = 71.79$ ,  $df = 12$ ,  $p < .001$ ). The parameter estimates suggest that what may cause families to at first consider placement as option for their child may be different from the factors that cause them to give placement

more serious consideration. Specifically, the results suggest that increasing child age and behaviour problems may lead families to consider placement, but it may only be when families are struggling to sustain a daily routine (specifically, when there is low family life congruence) that they may give this more serious consideration.

***Sustainability of the daily routine: child vs. ecological predictors***

To investigate predictors of sustainability, two path models were tested. The first included child characteristics and the second included selected indicators of ecological resource-fit. The first path model (Figure 5) shows that child characteristics, including age, behaviour problems, disability severity, general health status and complex medical care needs, together accounted for 19% of the variance ( $r^2 = 0.19$ ,  $p = .006$ ) in sustainability of the daily routine.

**Table 4.** Standardized direct, indirect and total effects with bootstrap standard errors (n=475)

Measures		Effects Decomposition		
Predictor ->	Criterion	Direct (SE)	Indirect (SE)	Total (SE)
FL Congruence	Placement propensity	-.32* (.06)		-.32* (.06)
Family functioning	Placement propensity	.03 (.06)	-.08* (.02)	-.05 (.05)
	FL Congruence	.25* (.04)		.25* (.04)
Resource fit	Placement propensity		-.25* (.04)	-.25* (.04)
	FL Congruence	.69* (.03)	.16* (.02)	.85* (.01)
	Family functioning	.64* (.03)		.64* (.03)
Child age	Placement propensity	.20* (.04)	.01 (.01)	.20* (.04)
	FL Congruence		-.02 (.04)	-.02 (.04)
	Family functioning		-.01 (.03)	-.01 (.03)
	Resource fit	-.02 (.04)		-.02 (.04)
Child behaviour	Placement propensity	.11* (.04)	.08*	.18* (.04)
	FL Congruence		-.27* (.04)	-.27* (.04)
	Family functioning		-.20* (.03)	-.20* (.03)
	Resource fit	-.31* (.04)		-.31* (.04)
Disability severity	Placement propensity	.04 (.04)	.03* (.01)	.06 (.04)
	FL Congruence		-.09* (.04)	-.09* (.04)
	Family functioning		-.07* (.03)	-.07* (.03)
	Resource fit	-.11* (.05)		-.11* (.05)
Child health	Placement propensity	-.01 (.04)	-.04* (.01)	-.06 (.05)
	FL Congruence		.15* (.04)	.15* (.04)
	Family functioning		.11* (.03)	.11* (.03)
	Resource fit	.17* (.05)		.17* (.05)
Complex medical	Placement propensity	.11* (.05)	.01 (.01)	.11* (.05)
	FL Congruence		-.02 (.04)	-.02 (.04)
	Family functioning		-.02 (.03)	-.02 (.03)
	Resource fit	-.03 (.04)		.03 (.04)

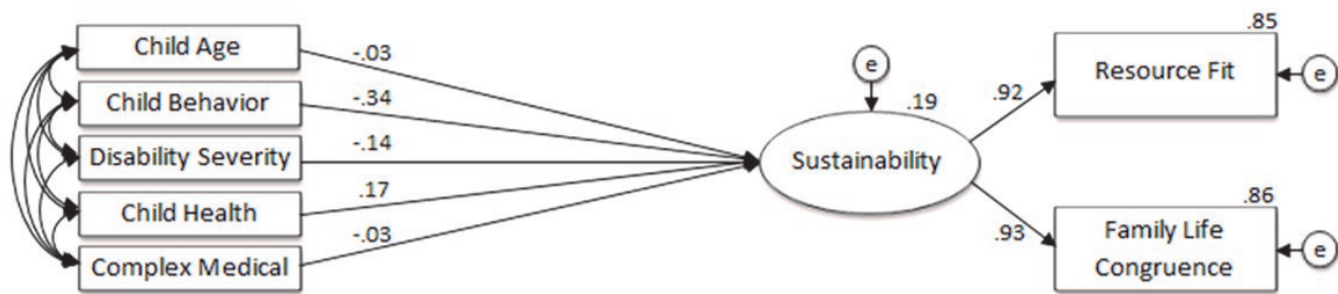
\*p < .05.

**Table 5.** Multinomial logistic regression: parameter estimates (n=475)

	Criterion			
	Considered/taken no action		Seriously considering/ have taken steps	
	B (S.E)	Exp(B)	B (S.E)	Exp(B)
<i>Intercept</i>	-4.50 (.68)		-6.30 (.96)	
Child age	0.09 (.04)	1.09*	0.22 (.06)	1.24*
Child behaviour	1.77 (.53)	5.86*	1.11 (.63)	3.05
Disability severity	0.04 (.17)	1.04	0.20 (.21)	1.22
Child health	-0.01 (.17)	0.99	-0.22 (.21)	0.80
Complex medical	0.99 (.49)	2.71*	0.95 (.56)	2.58
Family life congruence	-0.33 (.28)	0.72	-1.30 (.36)	0.27*

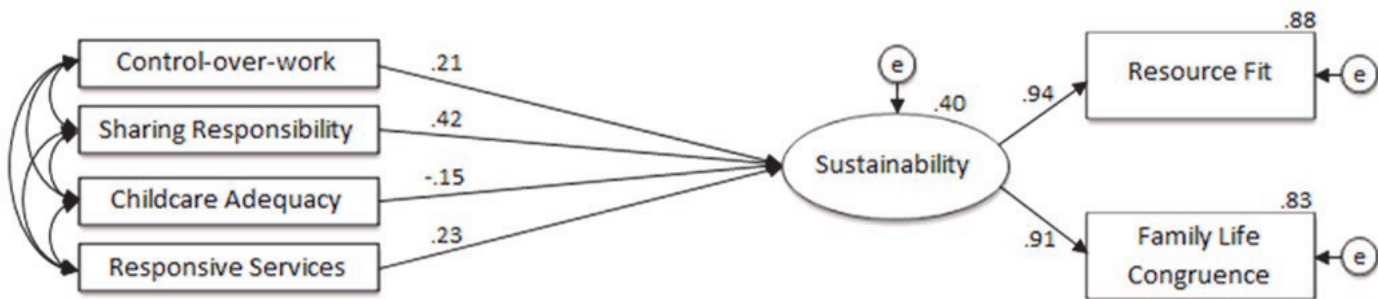
\*p < .05

**Figure 5.** Child characteristics as predictors of sustainability (n=475)



Model Fit Indices:  $\chi^2 = 19.61$ ,  $DF = 4$ ,  $p = .001$ ,  $CMIN/DF = 4.90$ ,  $CFI = .98$ ,  $RMSEA = .90$ ,  $RMSEA90 = .05 - .13$

**Figure 6.** Selected indicators of resource-fit as predictors of sustainability (n=475)



Model Fit Indices:  $\chi^2 = 3.77$ ,  $DF = 3$ ,  $p = .29$ ,  $CMIN/DF = 1.26$ ,  $CFI = .99$ ,  $RMSEA = .02$ ,  $RMSEA90 = .00 - .08$

No statistically significant association was found between sustainability and either child age or complex medical care needs, controlling for other child characteristics.

The second path model (Figure 6) demonstrated excellent fit, as evidenced by the statistically non-significant  $\chi^2$  test. Furthermore, control-over-work, shared responsibility for keeping family life running, the sufficiency of formal child care arrangements and responsiveness of professionals/services to the families needs and priorities together accounted for a substantial 40% of the variance ( $r^2 = .40$ ,  $p < .001$ ) in sustainability of the daily routine. The path coefficients of all four predictors were statistically significant: each contributed to the model.

Over one-half (61%) of the respondents agreed or strongly agreed with each of the following statements: “responsibility for keeping our family life running is shared” and “In general, professionals/ services are responsive to our family’s needs and priorities”. However, over one half of the respondents (51%) reported wanting more child care. The most common reasons these parents gave for not using more child care were the prohibitive cost (35%) and lack of availability (21%). Notably, 30% of all families, and 64% of those families who wanted more childcare reported that a childcare provider had refused to care for their disabled child.

## DISCUSSION

Family life in Canada has been radically transformed by changing social norms, economic imperatives and demographic trends (Duxbury & Higgins, 2001). For example, the dual-income family has displaced the prototypical male breadwinner/female homemaker as the typical Canadian family type (Ross & Roberts, 1999); and, the participation of mothers in the Canadian labor market has grown more than two-fold over the last three decades (Sauvé, 2000). Such radical societal changes have brought with them new challenges for families, and an increasing number of parents are reporting high levels of role-conflict and overload. Put simply, many families today, particularly lower income families who may depend on two full-time incomes to survive, are struggling to eke out the time and energy they need to juggle both work and family demands.

Sustaining a daily routine that effectively reconciles work and family demands may be particularly challenging for families bringing up children with disabilities (Booth-Laforce & Kelly, 2004; Gordon, Rosenman, & Cuskelly, 2007; Grace, Llewellyn, Wedgwood, Fenech & McConnell, 2008; Reichman, Corman, & Noonan, 2008; Statistics Canada, 2008). These families have to juggle work and family and the out-of-the-ordinary time and strain based demands associated with caring for a disabled child. In this study we found that those families who are 'doing best' tend to have more of the kinds of resources that most families today (i.e., whether they have a disabled child or not) need in order to create and maintain a daily routine that is high in 'congruence', that is a routine that is meaningful to them, and which balances the needs and interests of all family members. Such resources include shared responsibility for keeping family life running, control-over-work (e.g., more flexible work hours), sufficient/ satisfactory childcare arrangements, and services that are responsive to their family's needs and priorities.

Approximately one in six families who took part in this study had at least thought about out-of-home placement as an option for their child. Consistent with past research we found that child age and child-related stressors, including number/intensity of behaviour problems and complex medical care needs, heighten family propensity to place a disabled child out-of-home. However, in this study, as predicted, we found that the most potent and proximal predictor of placement propensity was family life congruence: parents are more likely to seriously consider placement as an option for their child when, for example, they feel trapped by their daily routine and/or family life revolves around the needs of their disabled child. These findings are consistent with those previously reported by Llewellyn and colleagues in Australia (Llewellyn et al., 1999; 2005). Notwithstanding, and as previous studies have found (Blacher, 1990; Blacher & Hanneman, 1993; Rimmerman & Duvdevani, 1996), placement propensity proved hard to predict. Clearly other factors influence placement propensity. In this study for example, we found statistically significant correlations between placement propensity and parent-carer characteristics including age, marital status and general health. Another potentially highly influential factor that was not included in this study is whether the idea or option of out-of-home placement had ever been presented to the family by a professional or significant other (Llewellyn et al., 1999).

Families bringing up children with more extensive functional limitations (disability), a greater number of behaviour problems, and/or poorer general health tended to report lower resource-fit, including greater financial hardship and low social support. These parents may have a harder time finding a suitable childcare provider willing or able to take care of their child which could result in reduced workforce participation and a loss of income; and/or, they may be more exposed to stigma (*and have a harder time managing interactions with others and*



*maintaining the 'proper impression' of the family*), and as a result they may become more socially isolated (Freedman, Litchfield, & Warfield, 1995; Seltzer et al. 2001; Grace et al, 2008; McManus et al., 2011, Owen et al., 2002; Warfield, 2001). However, child characteristics explained little more than 15% of the variance in resource-fit (see Figure 4). Parent and possibly sibling characteristics may contribute more to resource-fit. We did not include parent or sibling characteristics in our path model; however, we did find significant correlations between resource-fit and parent-carer education, income, general health and marital status (see Table 3.)

### **Limitations**

The recruitment of a robust sample of families raising children with disabilities in Alberta, Canada, is a strength of this study, and the participation rate of 41% is reasonable *vis-a-vis* other survey studies. However, we do not know if the participants were different from non-participants in any systematic way/s. Volunteer bias might therefore limit the generalizability of the study findings. Furthermore, government funded support programs differ across countries, states, and provinces. This sample consisted of families receiving supports in Alberta. Therefore these findings may not generalize well to families that do not receive supports or receive supports outside Alberta.

Another significant limitation of this study is that it is based on cross-sectional, point-in-time data. Consequently, the nature of the relationships between the study variables (i.e., directional causality) can only be inferred from theory. For example, the path model presented in Figure 3 infers that resource-fit effects general family functioning when the reverse might well be the case: 'healthier' family functioning may lead to better resource-fit. Similarly the model infers that the relationship between child behaviour problems and resource-fit is uni-directional when this relationship is most likely bi-directional (Hastings & Beck, 2004; Lecavalier,

Leone & Wiltz, 2006; Olsson, 2008): poor resource-fit may result in less than optimal parenting behaviours which may create or exacerbate child behaviour problems, which may tax family adaptive resources resulting in poorer resource-fit, and so on.

Another potential limitation of this study is that it relies on the primary parent-carer for information about the family. Other family members may have different views, and their views warrant further research attention. However, relying on the primary parent-carer, who is usually the mother, for information about family life is defensible. As Voysey Paun (2006) observed, the primary parent-carer is usually at the centre of family life: orchestrating the everyday routine to accommodate the needs, interests and activities of all family members. Therefore, the primary parent-carer has special insight into family life. Furthermore, as the person who is typically most instrumental in weaving activities together into a daily routine, her/his view (e.g., of the needs and interests of family members, etc) may have the greatest influence on the daily routine. The mother's or primary parent-carer's view is therefore, arguably, the most important with respect to predicting what the future may hold for the family and the child.

### **Conclusion**

After reviewing research pertaining to child resilience, Matsen et al. (1999) reached the conclusion that if reasonably good resources are present, outcomes are generally good, even in the context of severe stressors. Likewise, Ungar (2011) has argued that child resilience has more to do with the availability and accessibility of culturally relevant resources than individual or intrinsic factors. The findings of this study support a similar conclusion with respect to families bringing up children with disabilities: If families have the ecological resources they need to create and maintain a daily routine that is meaningful and balanced with respect to the

needs and interests of all family members, then they are unlikely to ever seriously consider placing their disabled child out-of-home, at least not in desperation.

One implication is that disability services or interventions designed to modify or re-form the disabled child or parent-carer in some way may not have a significant or lasting effect on the sustainability of the daily routine, or family placement propensity. Of course there are many other compelling reasons for providing such “special services”, and there may be a sub-group of families for whom these are essential to maintaining the child in the home. However, the results of this study highlight the need for a family-first approach (as opposed to a disability-first approach). That is, to support the adaptation of families *with* children with disabilities, and not merely the adaptation of families *to* children with disabilities. As Patching and Watson (1993) observed, “the notion of the disabled family is an inappropriate one. [Families raising a child with disabilities]... have just as much in common with mainstream families as they do with each other” (1993, p. 130). To this end, many families bringing up children with disabilities will likely benefit from policies and programs designed to promote shared parental responsibility and remove barriers to parent-carer workforce participation. This may include policy supporting reasonable workplace accommodations, including more flexible work hours for both the primary parent-carer and spouse; and, investment to create more affordable, high quality, *inclusive* childcare options.

There are also a number of steps that health and human service providers might take to promote sustainable family care. Difficulty accessing and navigating fragmented, inflexible and/or poorly resourced service systems is a significant stressor, and a barrier to sustaining a daily routine. Initiatives to make the system easier for parents and families to navigate, and to find what they need, will likely have

far reaching impact. This might, for example, include the introduction of parent-held records to eliminate redundancy (i.e., over-assessment): parents should not have to repeat their history over and over and over. In addition, professionals and services may have a more positive impact by taking an ecocultural (holistic) view of the family-in-context, and in turn, planning interventions that promote or support the balancing act that is at the heart of family life: Parents have to care for all of their children. To do otherwise may do harm by ‘tipping the balance’. A daily routine that revolves around the needs and interests of the disabled child is a less sustainable daily routine.



## APPENDIX A *Latent constructs and their manifest variables*

Key		Scale#
	<b>Perceived stress (ST)</b> [1= never, 5 =very often]	
ST1	In the last month, how often have you felt that you were unable to control the important things in your life?	1 - 5
ST2	In the last month, how often have you felt confident about your ability to handle your personal problems? (r)	1 - 5
ST3	In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?	1 - 5
	<b>Social support/integration (SS)</b>	
SS1	How easy is it to get practical help from your neighbours if you or your family should need it? [very difficult = 1, very easy = 5]	1 - 5
SS2	How much concern or interest do people show in how you and your family are doing? [no concern = 1, a lot of concern =5]	1 - 5
SS3	How many people are so close to you that you can count on them if you have a serious personal or family problem? [0 = 0, 4 = 10+]	0 - 4
	<b>Financial hardship (FH)</b>	
FH1	Think back over the last 3 months, how much difficulty have you had paying your bills? [no difficulty = 1, a great deal = 5]	1 - 5
FH2	Think back over the last 3 months, generally, at the end of each month did you end up with ...? [more than enough money left = 1, very short of money = 5]	1 - 5
FH3	In the next 3 months, how often do you think that you and your family will experience bad times, such as poor housing or not having enough food? [almost never = 1, almost always = 5]	1 - 5
	<b>Family life congruence (FLC)</b> [1=strongly disagree , 4=strongly agree]	
FLC1	We are able to do things together that are important to us	1 - 4
FLC2	We exist: any hopes or dreams we had now seem out of reach (r)	1 - 4
FLC3	I am creating the life I want for my children	1 - 4
FLC4	We are trapped by our daily routine (r)	1 - 4
FLC5	I feel trapped by my duties as a parent and caregiver (r)	1 - 4
FLC6	I often worry that I do not spend enough quality time with my other children (r)	1 - 4
FLC7	I often worry that my other children are missing out (r)	1 - 4
FLC8	Our family routine revolves around our child with disabilities (r)	1 - 4
FLC9	Overall, we are able to balance the needs and wants of each family member	1 - 4
	<b>General Family Functioning (GFF)</b> [1=strongly disagree , 4=strongly agree]	
GFF1	We confide in each other.	1 - 4
GFF2	In times of crisis we can turn to each other for support	1 - 4
GFF3	We express feelings to each other	1 - 4
GFF4	There are lots of bad feelings in our family (r)	1 - 4
GFF5	We don't get along well together (r)	1 - 4
GFF6	Planning family activities is difficult because we misunderstand each other (r)	1 - 4
GFF7	We cannot talk to each other about the sadness we feel (r)	1 - 4
GFF8	We avoid discussing our fears or concerns (r)	1 - 4
GFF9	Making decisions is a problem for our family (r)	1 - 4

#before transformation  
(r) = reverse scored

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### 3

## **Rethinking Resilience in Families of Children with Disabilities: A Socio-Ecological Approach**

**Purpose:** The purpose of this study was to investigate resilience among families raising children with disabilities in Alberta, Canada.

**Method:** This study was nested within a three year, multi-method (survey plus interview) study of work-family-care integration. Interpretive description was used to analyse a total of 78 responsive interviews with 63 parent-carers.

**Results:** Families 'do well' when they are able to balance the needs and interests of all family members, and in turn, sustain a sense of 'normal'. Key to this is social support from extended family, friends and neighbours; and, success in navigating the system of support services to get the resources they need.

**Conclusion:** The social-ecological conditions in which families live can be resilience-promoting or resilience-inhibiting. Resilience promoting conditions include services that help families balance the needs and interests of their disabled child with the needs and interests of other family members.



An estimated 3.7% of Canadian children aged 0-14 years have a disability. Of these, forty per cent have a severe to very severe disability to the extent that they require extensive assistance with self-care, mobility, learning and/or communication (Human Resources & Skills Development Canada [HRSDC], 2011). Most of these children will grow up in the care of their families. The majority of parents want to care for their disabled son or daughter at home, and many will continue doing so well into later life. However, these parents typically face challenges and hardships over and above those associated with parenting *per se*. In this study, we explore how parents and families bringing up children with disabilities are able to meet such challenges, and in turn, demonstrate 'resilience'.

### ***Resilience (un)explained***

Families of children with disabilities must contend with numerous out-of-the-ordinary challenges. Some of these challenges may be directly related to the child's disability, stemming from worrying behaviours such as harm to self or others, a tendency to wander, or complex and time-consuming health care needs. Other challenges and hardships have little or nothing to do with the child's condition in itself. Rather, they emerge due to negative social responses to disability or social arrangements that do not take the needs or interests of persons with disabilities or their families into account (Dowling & Dolan, 2001; Green, 2007; Resch, Elliott & Benz 2012; Ryan & Runswick-Cole, 2008). Research has found that some parents and siblings of children with disability experience stigma (Farrugia, 2009; Gill & Liamputtong, 2011; Green, 2007; Voysey, 1972). Other parents struggle to retain meaningful employment, and subsequently are unable to maintain an adequate standard of living due to a lack of reasonable workplace accommodations and/or inclusive childcare arrangements (Freedman et al. 1995; Gordon et al. 2007; Shearn & Todd, 2000; Seltzer et al. 2001; Warfield, 2001). Still others are

frustrated by the challenges involved in accessing and navigating fragmented, inflexible and/or poorly resourced service systems (Browne, Rokeach, Weiner, Hoch, Meunier & Thurston, 2013; McManus, Carle, Acevedo-Garcia, Ganz, Hauser-Cram & McCormick, 2011; Reichman, Corman & Noonan, 2008; Rodger & Mandich, 2005).

Yet despite such challenges and hardships, the majority of parent-carers and families of children with disabilities display positive adaptation in the face of such adversity (Blacher & Baker, 2007; Glidden & Jobe, 2006; Green, 2007; Olsson, Larsman & Hwan, 2008; Ylven, Bjorck-Akesson, & Grandlun, 2006). Although research has consistently found that mothers of children with disabilities are two to three times more likely than mothers of 'typically developing' children to report poor mental health and greater depressive symptoms, the absolute risk of such negative psychological conditions is low (Bailey, Golden, Roberts & Ford, 2007; Montes & Halterman, 2007). Montes and Halterman (2007), for example, conducted secondary analysis of the 2003 US National Survey of Children's Health and found that fewer than 20% of mothers of children with an autism spectrum disorder (ASD) reported poor mental or emotional health.

Furthermore, research suggests that most parents find benefit, and may be positively transformed by the experience of caring for their disabled son or daughter (Scorgie & Sobsey, 2000). And at the family level, researchers have observed that many families 'pull together' to resist stigma and insist on normalcy, establishing new rules, rituals and routines to integrate their disabled child into their family, and their family into the community (Knestricht & Kuchey, 2009; Llewellyn, McConnell, Thompson & Whybrow, 2005; Maul & Singer, 2009; Weisner, Matheson, Coots & Bernheimer, 2005).

The question is: *why do some parents and families, but not others, display such resilience?* To explain resilience, researchers have focused mostly on within-person and within-family factors, including “characteristics, dimensions, and properties of families which help families to be resistant to disruption in the face of change and adaptive in the face of crisis situations” (McCubbin and McCubbin, 1988, p. 247). Rooted in psychological models of stress and coping, many researchers have ‘zoomed in’ on psychological attributes and processes. Collectively, this research suggests that positive maternal outcomes vary, to some extent, depending on levels of family cohesion and adaptability; and, psychological variables such as dispositional optimism, positive affect, internal locus of control, and the utilisation of meaning-focused and problem-focused coping strategies (Baker, Seltzer & Greenberg, 2011; Bourke-Taylor, Pallant, Law & Howie, 2012; Dabrowska & Pisula, 2010; Ekas, Lickenbrock & Whitman, 2010; Greer, Grey & McClean, 2006).

Less research attention has focused on social-ecological factors that may contribute to resilience in families raising children with disabilities. However there is some compelling data linking maternal outcomes to material and social resources (Eisenhower & Blacher, 2006; Emerson, Hatton, Llewellyn, Blacher & Graham, 2006; Emerson & Llewellyn, 2008; Emerson et al., 2010; Hatton & Emerson, 2009; Knestrict & Kuchey, 2009; Olsson & Hwang, 2008; Park, Turnbull & Turnbull, 2002). Emerson and Llewellyn (2008), for instance, analysed data from the Longitudinal Study of Australian Children and found that higher exposure to poverty explained approximately 50% of the elevated risk of distress and psychiatric disorder in mothers of children at risk for disability. Other studies have found a strong association between maternal outcomes and perceived social support (Green, 2007; Pakenham, Samios & Sofronoff, 2005; Pousada, et al., 2013; Resch et al. 2010; Tobing & Glenwick, 2006).

For example, Smith, Greenberg and Seltzer (2012) found that perceived social support predicted changes over an 18 month period in the wellbeing of mothers of young adults with ASD, over and above the impact of behaviour problems.

### ***Social ecology of resilience***

Much of the extant research about families of children with disabilities has been conducted by scholars educated in psychology, and this may explain why the dominant focus of research to date has been on within-person and within-family factors. Another plausible explanation is that researchers have lacked theoretical frameworks or models - equivalent to psychological models of stress and coping - to guide studies of social-ecological factors. However, new models are beginning to emerge. This is in part due to critiques of reductionist approaches suggesting that these approaches lead to “a crisis” of perception because of the separation of phenomenon into component parts (Capra, 2007, p. 365), and in part due to recognition of the importance of social, cultural, and economic environments in understanding the actions, choices, and outcomes of individuals and families (Bronfenbrenner, 1989; Bubolz & Sontag 1993; Ungar, 2011; Winkel et al. 2009). Proponents of ecological frameworks consider multiple contextual factors in their analysis, showing a more complete picture of the phenomenon of interest.

One example is Ungar’s (2011) social-ecology of resilience. Ungar (2011) argues that “resilience is more dependent on the availability and accessibility of culturally relevant resources than individual *or within-family* factors” (Ungar, 2011, p. 6, *our addition*). To help guide both research and theory development, Ungar (2011) proposes four key principles: decentrality, complexity, atypicality, and cultural relativity. Ungar (2011) claims that, collectively, these four principles can resolve the trait-process debate, and potentially explain the phenomenon of resilience.

*Decentrality* refers to the need to shift our focus from individual characteristics to social ecological ones. In this reconceptualization, then, socio-ecological considerations are first, followed by interactions between person and environment, and lastly by individual characteristics. In studying resilience in families with a disability then, the focus is on the environment in which the family lives: access to support, resources, and the extent to which a society embraces inclusivity for persons with disability. *Complexity* refers to the need to resist the temptation “to identify relatively simple relationships between protective processes and predictable outcomes” (Ungar, 2011, p. 6). Rather, we should expect complex processes as well as recognize that resilient individuals (or families) will not do well all the time in all circumstances (Masten & Powell, 2003). *Atypicality* refers to a response to a situation that might be viewed as functional, but culturally non-normative (Ungar, 2011). Seeking alternative living arrangements for a disabled child is one such response.

However, when thinking about the normative ecologies that we live in, built for able-bodied children and families, this might be seen differently. Given the lack of resources available to parents, out of home placement might be viewed as a reasonable response to a social and physical context that does not adequately support families with disability. Ungar (2004) calls this “hidden resilience”. *Cultural relativity* refers to the notion that positive growth is culturally, temporally, and historically embedded (Ungar, 2011). What is normative in one context, may be non-normative in another culture or historical setting. In this light, we might think of disability as something that has been medicalized and problematized in our culture and time, but not in others. With this reconceptualization, the notion of “rethinking and reconstructing” the way that we make sense of disability is made possible.

## AIM AND OBJECTIVES

In this study, Ungar’s (2011) social ecology of resilience provided a framework for the investigation of ‘resilience’—simply defined as ‘doing well’ despite out-of-the-ordinary challenges and hardships—in families bringing up children with disabilities. This of course raises the question: what is ‘doing well’? Consistent with the epistemological underpinnings of qualitative inquiry, we did not define ‘doing well’ *a priori* in this study. Rather, the first objective of our study was to understand what ‘doing well’ meant to the participating families. To accomplish this, we used an inductive method to examine ‘well-doing’ by asking the participants to articulate their everyday experiences of raising a child with a disability. This inductive approach allowed for the possibility that new understanding of ‘well-doing’ could emerge from the data (Glaser and Strauss, 1967). The second objective was to understand the conditions or factors that foster resilience, or enable families to adapt positively and ‘do well’ despite the challenges and hardships they confront.

## METHOD

This study was nested within a three year, multi-method study of work-family-care integration in families raising children with disabilities in Alberta, Canada. The sampling frame for this study consisted of all English-speaking families listed in the Alberta Department of Children and Youth Services, Family Supports for Children with Disabilities (FSCD), Child-Focused Services database. Generally, those who qualify for child-focused services have more severe disabilities. A stratified (by child age group) random sample of 538 families took part. Data collection included annual surveys, and interviews with a subsample of primary parent-carers. Of these interviews, a total of 78 involving 63 parent-carers were included in this analysis. Demographic characteristics of this sample are presented in Table 1.

The interviews were conducted by graduate students trained in responsive interviewing (Rubin & Rubin, 2011). The interviewers utilised a basic interview guide, consisting of questions and probes, to promote consistency and adequate coverage. However, the interview format remained open, flexible, and adaptive to encourage in-depth, responsive descriptions of participants' daily routines, including but not limited to the adaptations they had made to accommodate their disabled child. Analysis of earlier interviews informed later ones, and new questions and probes were developed to 'fill-in' gaps in our emerging understanding. Interviews were audiotaped, with participant consent, and later transcribed for analysis.

We utilized interpretive description (Thorne, 2008) to analyze and interpret the qualitative data. Interpretive description is described as a pragmatic qualitative approach that borrows a variety of methods from other qualitative traditions in order to develop a methodology that is useful for advancing disciplinary knowledge and providing knowledge with practice implications. To do this, interpretive description provides a thick description of the data, but moves beyond this description to answer the "so what" of the data as well (Thorne, 2008). In this study, we wanted to get an in-depth understanding of the participant experiences in order to understand the meaning of resilience for these families within a socio-ecological framework.

The analysis proceeded in several steps. First, the interviewers were trained to conduct a thematic analysis, using the constant comparison method (Strauss and Corbin, 1998). The first step involved coding meaningful "chunks" of data. These were then compared and contrasted to develop appropriate categories. This iterative process involves moving backwards and forwards between the data and the emerging insights/categories/themes. Through a process called axial coding (Strauss and Corbin, 1998), interrelationships between codes were

discovered, and these codes were merged to create comprehensive themes. The graduate students wrote-up their thematic analysis, and also completed a brief vignette that distilled the essence of each participant's story.

The next phase of data analysis began with a review of the thematic analyses completed by the original interviewers. The lead author of this paper and two research assistants reviewed the original thematic analyses conducted by the graduate student interviewers, consolidating and synthesizing the information from these reviews into data charts, organized by themes. We then conducted an in-depth secondary analysis of the interviews, considering resilience as a dichotomous notion: families were either 'doing well' or 'struggling and clearly distressed', and we focused on the "extreme" cases in order to attain initial understanding. We then considered resilience on a spectrum to tease out which families displayed more or less resilience, to begin identifying contributing factors. Consistent with the social ecological perspective on resilience, we considered the ways in which these factors interacted and interconnected to support or undermine positive family adaptation. Analysis continued until saturation was reached; that is, no new themes emerged (Strauss & Corbin, 1998).

## FINDINGS

Parent-carers classified as 'doing well' generally felt connected: the family was close-knit and they generally had a strong sense of belonging to their community. Further, these parent carers reported a high degree of satisfaction reflected in such statements as "I am creating the kind of life I want for my children", "we are able to balance the needs and wants of each family member", and "we are able to do things together that are important to us". As an exemplar of this experience, Lucy<sup>i</sup> and Lee, immigrants to Canada with a 13 year old son with a severe disability, described their lives as meaningful and blessed. They were both employed full time but



**Table 1.** *Child, parent-carer and family characteristics (n=63)*

		Mean (SD) or %	
Child	Age	11.1 (5.3)	
		0-5 years	22
		6-12 years	22
	Sex	13-18 years	56
		Male	67
	Condition	Female	33
		Intellectual disability	25
		Autism spectrum disorder*	41
Cerebral Palsy		13	
	Other	21	
Parent	Age	43.4 (8.8)	
	Sex	Male	13
		Female	87
	Highest educational attainment	Did not complete high school	10
		High school graduate	13
		Diploma/trade certificate	38
		University degree	39
Family	Residence	Urban	87
		Rural	13
	Family type	Lone parent	16
		Couple, single earner	44
		Dual earner family	40
Total number of Children	2.0 (1.0)		

\*low and high functioning

Lucy had some flexibility in her schedule to take their son, Peter, to the many medical appointments he had with different specialists. She was thankful for the healthcare system. In addition, they had supportive friends and were actively involved in their community and church. They described how positive it was to have other children in their community for Peter to play with.

Lucy shared her thoughts:

*"Having [Peter] gives us a different life. It helps us be helpful. Looking at the situation before, first week after the delivery...I can't accept that I have a baby with this. I did not because I was in denial stage, right? And then the community helped me accept that. [Peter] is a gift. And [Peter] was given*

*to you because you can handle the situation....the community helped us accept, that we have a disabled child. Because you know as a parent, you dream big dream for your kids, right? Seems like, it's not that. It's a different plan, so it helped us accept that" (F0955).*

With support from their community and professionals in the healthcare system, Lucy and Lee were able to create a full and meaningful life.

By sharp contrast, parents-carers classified as 'struggling and clearly distressed' used such statements as "we are always on edge wondering 'what next?'" , and "our family routine revolves around ... (child with disability)" to describe their family circumstances. Generally, these parent carers felt



trapped by their duties as parent and carer. For example, Kara, a divorced mother who worked in the service sector with a 17 year old son with a severe disability and behavioural difficulties, indicated that she and her son were isolated because it was difficult to take her son in public and she didn't have a lot of money. Consequently, they stayed home a lot. She described her feelings of entrapment:

*"In general, I just, I don't know, I feel like I was stuck at home and stuck at, like I just felt stuck. And I know that's probably not good to say, and I know that, like we had so many issues and [Billy] was just another one, another issue, and I just felt stuck for so many years, stuck at a dead end job, stuck at...I don't know... I still feel stuck...Money wise, you know I don't have much money...I feel bad because he's not a bad kid it's just the way he is..." (F1135).*

This case is an exemplar of the sentiments described by families who were less resilient: feelings of entrapment, lack of financial resource and social support, and a sense of isolation.

These exemplar cases highlight some of the key factors that contributed to, or diminished resilience in the families we studied. Overall, parents who were doing well reported that they were able to proceed with "business as usual", facilitated by support from family, community, and professionals. In contrast, those who were struggling indicated that their lives revolved around disability. Generally, these families lacked social support, experienced isolation, and reported financial struggle. Overall, our findings point to the critical importance of the social ecology of resilience and are detailed below.

### **MORE RESILIENT FAMILIES**

**"Business as usual".** An important factor that contributed to resilience in families was their ability to maintain what they perceived to be a 'normal' routine of family life that balanced the needs and interests of all family members. In particular, several

participants indicated that they treated their child with disabilities just the same as the other family members. Their lives did not revolve around one child; instead the child with disability fit into their regular family routines. Fiona, for instance, had a 9-year-old son with Down's syndrome. She indicated that as much as possible, he was just another member of the family. She commented:

*"We don't consider anything to be wrong with him, we just treat him like everybody else, I expect anyone who comes here or anywhere we go to treat him like anybody else, to a certain degree I mean of course there are different concessions for him but, all of the kids we know all of our nieces and nephews, they totally accept him they do what they can to interact with him and that's all I expect of them" (F0653).*

Similarly, another participant in our study, Claire (F0901), had two twin boys, one with a disability and one without. She states that it is important to treat the boys equally. As such, she treated her son with disabilities as she would any of the other family members. Claire stated: "If we treat him normally, just like everybody else then he will grow up knowing that he is a normal child" (F0901). She further elaborates:

*"I think the most important thing is not segregating him or treating him differently. If you treat them differently, obviously depending on the severity of the injuries and problems they can't be integrated, but I think the more he can be integrated and be with kids his own age that don't have any type of a disability is only going to help him grow more" (F0901) .*

Related to treating their child with disability similarly, participants exhibiting strong resilience expressed the importance of continuing regular routines and activities. Penny and Brent (F0304), parents of a 13-year-old daughter who has Cerebral Palsy and several other serious health conditions,

indicated that they have maintained their regular activities. For instance, when they found out their daughter had a severe disability they made a decision that they would continue doing activities that they normally would have done, including travel. Consequently, they have travelled with their whole family to five different continents, choosing to adapt their daughter's needs to their family lifestyle.

Denise and Evan (F0691) also had twin boys, one with a disability and one without. Denise felt that even with disability in their family, life "isn't that different," as she and her husband treat each of their children equally and continue to do the things that they love, including camping and cycling. In order to continue family activities they enjoy, they find ways to adapt their environment. For instance, they bring along special equipment so that they can still go camping, and they have a special bicycle attachment for their son with disability so that they can still cycle. In short, they make adaptations so that they can still engage in activities they previously enjoyed. Denise states:

*"It's always been my philosophy that...this is what we like to do, this is our family, there's no reason why [Nathan] can't have as typical and normal a life as possible" (F0691).*

**Social Support.** Social support was a salient theme that came up among many families who seemed to be doing well. Social support came in many forms: through extended family members, friends, neighbours, health care and educational professionals, and community organizations such as churches. Extended family members and close friends and neighbours served as key sources of support for families, contributing to their resilience. Brennan and Jackie (F0245), for example, described their extended family members as their biggest support because they volunteered to care of their daughter for an evening or weekend, enabling them to have time alone. Brennan and Jackie explained that their

daughter is "constantly surrounded by huge numbers of family who have all been wonderful with her". Lauren indicated that her sister and brother-in-law lived next door, and were a huge help in caring for her daughter with disability (F0256).

In addition to support from families, supportive communities and good neighbours made a big difference. Support came in a variety of forms: practical support with needs like child care for the child with disability and/or his or her siblings; emotional support; and, acceptance. Ingrid and John (F0593) found the benefits of living on a colony immense when it came to both familial and friend's support. In this communal living environment, they always had family members and friends close at hand who were willing to help care for their children. This helped enable them to maintain a balanced life. Similarly, Maria (F0247) described living in a very supportive community. Her neighbours worked together and were always willing to provide care for her children. Lucy and Lee (F0955) felt supported by friends who cared for their daughter when they needed to take their son with disability to the hospital. Finally, a few participants indicated that acceptance from others was important in feeling supported. Zoe for example, indicated: "we're lucky to have the people that we have in our life, like all our friends are accepting of our kids" (F0653).

Many parents stated that other parents who had children with disabilities provided emotional support as well as the best source of information about services, funding, and programs available. Danielle explained, for instance, that she had met some supportive friends through the Autism group that she attended. In particular, she found it helpful to have people to talk to that really understood her situation. Some parents were frustrated by not getting the answers they needed from agencies. For them, other parents were an essential source of information. Andrea (F0473), for example, indicated that the agency that provided her funding didn't tell her

much. Instead, she received most of her information through other families. Likewise, Samantha (F0887) indicated that at times it was difficult to know what services were available so she got the most information from talking to other parents of children with disabilities.

Overall, families that were socially involved reported greater family well-doing, indicating that social interaction had positive effects on their family life. Esther and Jake (F0155), for example, had active social lives within their community, their church, and with their extended family. They did not feel isolated, but enjoyed the company of family, friends and neighbours. Danielle (F0262), a stay-at-home mom, made efforts to stay engaged with those around her. Although her extended family lived far away, she found other sources of support: she volunteered at her son's school, attended a support group for parents with children with Autism, and was socially active in her neighbourhood. All of these things helped strengthen her family's life.

### ***Navigating the system of supports and services.***

For those who indicated they were doing well, health care and para-health care professionals were often a key source of support. Numerous participants described the support that was given to them by a range of healthcare professionals including family physicians, pediatricians, speech language, physical and occupational therapists, psychologists, social workers, and respite workers. Danielle described her experience with healthcare professionals as highly supportive:

*"I mean they [professionals] become your first family. (laughs) Um if you don't have a lot of family support in the beginning those people are your rock... right? They are the ones that understand your child where no one else will" (F0262).*

Wendy stated: "we've had a very supportive pediatrician, and lots of OT involvement, and lots of PT involvement, and everybody works so hard, you

know, to get the optimum for him." (F0467). Val likewise indicated support from her family physician: "I just phone, they know about his challenges -- 'come on in' -- they don't even make him wait" (F1141). Tulsa and Pradip (F0072), new to Canada, have also had a positive experience with healthcare professionals. Because English was not their first language, discussing their daughter's medical issues could be very difficult. However, the hospital has provided them with an interpreter which they indicate has relieved a lot of their worries.

Respite workers could also make a significant difference, offering a key source of social support to families with disability. Val, for example, demonstrated this: "My respite has been my saviour. The girl that I have is dedicated strictly to Reed is a blessing; she is wonderful with him. She has taught Reed more than anybody" (F1141). Marcia also had an excellent respite worker for her son. She stated that she was thankful to have someone she can trust.

Unfortunately, the experience of 'normalcy', with meaningful routines, activities, and commitments, social support from family, friends, and neighbours, and positive interactions and assistance from professionals was not universal in our study. Rather, for many families in our study, struggle, and a sense of being out of control were the norm. To these families we now turn.

## **LESS RESILIENT FAMILIES**

### ***Life revolves around the child with disabilities.***

Almost two-thirds of participants in our study, as shown in Wave One of the survey data, indicated that their family's life revolved around their child with disabilities. In these families, participants described how their child required much of their time, resulting in little time for self, their spouses, or, in some cases, less time for their other children. Many parents indicated that it was difficult to take the time for self-care and as a result often compromised

their own physical and mental health. Time for exercise, healthy eating, sleep, and time for self or spouse were limited. Veronica and David (F0743), for instance, felt that their life revolved around their son and that they had no time for themselves. David states: “By the time everything is done, we’re beat, no time for ourselves” (F0743). In some cases, lack of time resulted in marital stress, as many couples struggled to have time together. Jessica (F0097), for instance, wished that her and her husband could go out together more. She stated:

*“Maybe if we had more support maybe we could actually go out and have a life every once in a while too” (F0097).*

Importantly, a lack of social support and sense of isolation was closely tied to the families who felt their lives revolved around the child with disability. Unlike those with social support who described being able to continue with “business as usual,” these families described a sense of being out of control.

**Lack of access to supports and services.** Many participants described significant struggles with accessing funding, services, and supports for their child with disability. There were two key reasons for this: the “red tape” involved in applying for services; and, the lack of availability of trained workers. A long, convoluted and confusing application process, including significant paper work and several interviews, made applying for funding cumbersome for families already struggling with multiple responsibilities. Sophia (F1279), for example, qualified for funding for a community aide. The aide came and was paid by Sophia. However, she (F1279) was not able to determine how to complete the paper work, so hadn’t actually been reimbursed. She indicated that she had asked for clarification, but did not receive the assistance she required. She stated that she found it frustrating working with the government agency responsible (F1279). Nancy (F0004) indicated that she found it challenging to keep up

with the paperwork required, and wished there was a more convenient way to receive it.

Another problem with access to services was the availability of the workers. Although there was a list of potential respite workers, actually finding someone who was available could be a struggle. Danielle (F0262) stated that she would sometimes call five or six workers, and still have no one to help her. Madeline (F1151) indicated that when she called the agencies that were supposed to provide respite workers they all stated that they had a lack of staff and that she would have to wait. Another problem with access was the lack of properly trained workers. Veronica (F0743), for example, indicated that although the workers she’s had were able to do basic babysitting, they were not qualified to care for her son’s complex needs. Danielle (F0262) was satisfied with the amount of therapy her son received, but found it challenging to find consistency; in one year her son had four different workers. Cindy (F0445) indicated that many of the workers were young and inexperienced and she therefore relied on her mother-in-law to do respite care for her once in a while. Cindy summed-up the sentiment of a number of parents:

*“There’s a lot of need for improvement with the services. Lots of need. Getting trained staff” (F0445).*

Because of the difficulty in accessing services and the lack of availability of trained workers, some parent-carers chose to pay for services or special equipment themselves. Abigail and Daniel, for example, (F0844) did not have adequate services available to them. As a result, they opted to buy the services themselves; however this required that they maintain long work hours in order to remain financially viable. In the past Mary and Jim (F0563) had very little time as a couple because funding was not available for respite. Recently they decided to pay for respite themselves, as they felt it was key in maintaining their relationship. Nancy (F0004) stated that



even though she was getting funding, there were many things that her son needed that the responsible government agency did not fund. For example, the government only paid for ten physical therapy sessions a year, so she paid for more herself. In addition, she also paid for speech therapy. She indicated that they were funded for massage therapy, but not for occupational therapy, and this was frustrating. She wished the government would fund what she really needed. It should be noted that some of these families were financially better-off and therefore able to purchase needed services. Most families, however, were not able to do this.

For many families, part of navigating the system included fighting for services and advocating for their child. This could be an overwhelming and tiring process for many. Elizabeth (F0016) was brought to tears when she described the constant fight for funding:

*“You have to fight for everything, you get tired of, you know, you get worn down after a while” (F0016).*

Mary (F0563) found that the government agency responsible always offered her the bare minimum of what she needed and that she has to fight for anything more. Erin (F0158) described accessing services as “horrible” and indicated that she had to “fight tooth and nail for it”. Calista indicated that she felt she had to beg for services and that her worker did not communicate what was available.

**Social isolation.** Participants indicated that they often felt socially isolated. For some, this led to hopelessness. According to our survey data, over half (56.2%) of the participants reported feelings of being down, depressed, or hopeless within the last two weeks from when they were surveyed. There were different factors involved in social isolation. Some parents found it too difficult to take their child with disabilities to public places or events due to several factors including: behavioural challenges,

the noise level, the preparation involved in going out, or inaccessibility for those in wheelchairs. As a result, some chose to stay at home, but felt they had lost connection with friends. Erin worked part-time before her daughter got sick. But due to her daughter’s care needs, she became a stay-at-home Mom. She often felt lonely and lacking in friends. She stated: “Any kind of friends would be nice...It is very hard. You know I feel very alone in the world” (F0158). Other parents found they did not have time to socialize. Giselle (F0676) felt as if she had lost touch with many of her friends due to her lack of time. Socializing had become a lot more complicated now that she had twins with Autism (F0676). Similarly, Tamara described social isolation as the toughest thing about raising her son:

*“Okay... the toughest thing is... sometimes we were just homebound... that’s tough. I remember when he was going through the worst of it, when he was little. I remember everyone was outside washing their cars, they were happy taking their kids to the park and I felt that I was looking through a window and I couldn’t get to the other side” (F0320).*

**Financial strain.** Financial strain was also described by many of the participants. Survey data indicated that over 50% of parents reported having some difficulty paying their bills in the last three months, and 20% expected that they would have to do without some basics over the next three months. This is not surprising when looking at the incomes of families in the study. One-third of our sample earned less than \$50,000 yearly, and just over 40% earned between \$50,000 and \$99,000. In Alberta, the median total income for a family in 2010 was \$85,380, showing that a considerable percentage of our sample earned below the average income (Statistics Canada, 2012).

The financial strain experienced by families stemmed from two key issues. First, many of the



mothers in the study left employment to care for their children (42%), thereby creating a one-earner rather than two-earner family. Jane described how her family was struggling financially because of her need to pull out of the workforce. She stated: "That was the end of my career though because my life just took on such another element. That was my full time job, taking care of her." Second, out-of-pocket costs which were later reimbursed by the government agency responsible created considerable financial hardship. Cindy (F0445), for example, indicated that despite her husband's long hours, her family still struggled financially. Cindy attributed this financial hardship to the reality that they often had to pay for services out of their own pocket before they were reimbursed. Similarly, Heather (F0354) was a single mother who has access to respite hours; however, she had to plan carefully when to use these hours due to the stress of paying upfront.

Notably, while many of the families in our study were struggling, almost two-thirds of them also indicated that having a child with disabilities had been positive for their families. This may seem like a contradiction. However, in family life this is not surprising. Research on satisfaction and wellbeing for parents in the general population shows that parenting entails both joy (Nelson, Kushley, English, Dunn & Lyubomrisky, 2013; Short-Thompson 2008) and, at the same time, considerable struggle, particularly when parenting infants (Luhmann, Hofmann, Eid & Lucas, 2012). Many parents, particularly mothers with young children, experience diminished wellbeing (Matthey, Barnett, Ungarer, Waters, 2000), decreased marital satisfaction (Dews & Wilcox, 2011; Twenge, Campbell, & Foster, 2003; White, Booth & Edwards, 1986), and struggles with work-family integration (Allen, Herst, Bruck & Sutton, 2000). Thus it seems that most parents, regardless of the disability status of their children, experience notable hardship. As family researchers, we

would expect significant complexity in the bundles of factors that create family life. Therefore, studying the complexity of experiences in all their messiness is important. Because of the general theoretical orientation of stress and coping theory when studying disability, we may have overlooked the inherent joys, albeit riddled with contradictory feelings, of parenting children with disability. It may be that parenting children with disability may be more comparable to parenting children without disability than we have assumed. More research is needed to compare family experiences in families with and without disability.

## **DISCUSSION AND CONCLUSION**

This study contributes to a nascent body of literature that reframes families with disability away from the "tragedy metaphor" (Risdal & Singer, 2004) to examining the bundle of factors that contribute to families doing well or not doing well. To do this, we have examined the concept of resilience in families raising children with disabilities through a socio-ecological lens. Consistent with this framework and with a qualitative approach, we have resisted the temptation to identify simple predictors of resilience, but instead have conducted this analysis in the spirit of looking at the complexity of the processes and factors that create a space for resilience to emerge (Ungar, 2011) in these families. In doing this, we have identified families that reported doing well, and those not doing well, to ascertain the interconnectedness of factors that contribute to their well-doing or lack of it. We have also attempted to examine this data with a lens of decentrality (Ungar, 2011); that is, we have broadened our gaze to examine some of the social ecological factors that assisted families to integrate disability into their lives rather than have the disability overtake their lives.

To summarize our results, the most salient finding in this study was that families displayed the most

resilience when they were able to continue with “business as usual” in their daily lives. This does not, of course, mean that there were no accommodations made and that families didn’t have to adapt. Rather, it meant that the family was able to find ways to continue with other regular activities that enhanced both individual well-doing and family life. Like Bernheimer and Weisner (2007), we found that these families made accommodations that enabled them to maintain routines and activities in their daily lives, or have what Knestrict and Kuchey (2009) called “rhythm” or “rules, rituals and routines.” Two elements of maintaining business as usual were: 1) social support from extended family, friends, neighbours; and, 2) success in navigating the system of support services to get the resources they needed. These elements made a big difference in the extent to which families with disability perceived themselves as experiencing well-doing. Inversely, those in our study who self-reported a diminished experience of well-doing and a sense that disability had overtaken their lives indicated fewer social supports, considerable social isolation, and struggles with finances. Furthermore, some of the families who struggled indicated that they had to fight for services and supports, which entailed considerable frustration and fatigue. Some of these families, experiencing an inability to manage their day-to-day lives resulted in considerations of, or actions toward, out-of-home placement. Although seeking out-of-home placement is cultural atypical for these families, it may have seemed like the only viable alternative. Movement toward this action can be explained by Ungar’s (2011) notion of atypicality, a non-normative but functional alternative given an environment that is not adequately set-up for families with disability.

One aspect of our findings that was unexpected was that financial resources were not described as key to well-doing, as found in Knestrict and Kuchey’s (2009) research. In contemplating this, we posit

families who had resources did not think to mention it. Inversely, families who lacked resources mentioned it a whole lot. It may be that financial resources are somewhat taken-for-granted as long as you have them. On the other hand, if a family finds itself without financial resources, family members notice. It may also be that the financial support and services offered by the government agency in Alberta helped to offset costs that may create substantial barriers in jurisdictions without these services. Clearly, the link between financial well-doing and overall well-doing in families with disability merits further analysis.

This study points to the tremendous importance of informal social support. Although the pathways are unclear, it seems that social support and stress are inextricably linked (Armstrong et al., 2005). In other words, social support seems to help parents cope in the face of life challenges, and so social support may help to offset the extra stressors that come with the extra care responsibilities and worries associated with having a child with disability (Crnic, Greenberg, Ragozin, Robinson & Basham, 1983; McConnell, Breitzkreuz & Savage, 2011). Families described in detail how the help from families, friends, and neighbours made a big difference in their ability to maintain their day-to-day activities. Although this may seem obvious, surprisingly little attention has been paid to this notion when looking at resilience in families with disability. Given the benefits of social support, ways to enhance social support merit additional attention when developing policies and programs to facilitate well-doing in families with disability. Emphasis on the development or enhancement of programs that facilitate parents’ peer networks could make a noticeable difference for families (Ainbinder et al., 1998).

A cautionary note regarding developing policies and programs to enhance parenting networks and other forms of social support requires mention, however. Intentionally enhancing social support does not

release government ministries from offering other services and programs to facilitate family well-doing. Rather, it is just one arm of a comprehensive strategy to enhance family well-doing. Family resilience happens within a context and requires multiple approaches, including institutional supports, to flourish.

Similar to the ecocultural niche theoretical approach employed by Maul and Singer (2009), a social ecology of resilience helps us to recast resilience as something beyond personal characteristics or agency to something that necessitates movement “toward resources that are made both available and accessible by those in power to those who are disadvantaged” (Ungar, 2011 p. 10). Viewed this way, a social ecology of resilience requires that we shift our gaze from individual family characteristics and focus on the family’s social and physical environments. This shift in focus “positions the discourse of resilience as one of process and resource provision....When navigation is thwarted, or the resources that are provided lack meaning, then it is more likely that the environment will fail in its facilitative role” (Ungar, 2011, p. 11). With this reframing, the accessibility, suitability, and fit of resources are central to resilience. Examples from our participants provide evidence that some services offered were immensely important, while others were not. Our study findings suggest that the accessibility and suitability required to facilitate resilience in families raising disabled children is still lacking, even with a program dedicated to supporting families with children with disability. This is due to the barriers to accessing services due to the government program’s system of reimbursement, the misfit between services and needs in some cases, and the considerable difficulty in finding qualified staff. More work is needed to enhance access to meaningful services, both to financial resources available through government programs, as well as to enhance the needs of families through putting sustained resources and

planning into training and hiring qualified staff.

Bernheimer and Weisner (2007) state: “Families’ stories offer a window into the way in which families make sense of their worlds” (p. 198) and these stories may not always match the constructs in the testing of existing theoretical models (Ferguson, 2002). We concur. Conceptualizations from theoretical frameworks such as that from stress and coping theory assume misfortune. Our participants’ stories, however, while detailing considerable hardship, also require that we rethink our understandings of why this struggle occurs.

This reframing relates to Ungar’s (2011) discussion of cultural relativity. Changing the underlying assumptions and discourse pertaining to disability might encourage a cultural shift to meaningful inclusion of those with disability. If resilience means, at its most basic level, “positive response to adversity”, we inevitably set up the notion that having a child with disability entails hardship. Here we suggest that this assumption needs rethinking. Instead, a more instructive way of thinking about disability is that it entails a different reality, not necessarily an adverse one. Because we live in a world set up for able-bodied children and adults, the challenges of disability are increased, and the adversity of disability is accentuated. If we could change the social and physical context to meaningfully include families of disabled children, we might change the discourse about disability to discuss different experiences rather than unfortunate ones. Here we suggest that resilience, in addition to being closely connected to external resources, is also a term that should encapsulate the notion of positive response to be different, not just positive response to adversity.

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### End Notes.

i. All participant names in this article have been change to pseudonyms to protect the confidentiality of the participants.

ii. We assume that the agency she's referring here to is the Family Support for Children with Disabilities Program, but this is not confirmed.

## 4

### **Benefit-finding or finding benefits?**

#### **The positive impact of children with disabilities**

**Purpose:** The primary aim of this study was to investigate the nature of parent reported benefits attributed to having a child with disabilities. The question is whether the benefits reported by parents are better viewed as (a) artifacts of stress-processing and a resource for coping, or as (b) veridical accounts of positive impact and transformation.

**Method:** A stratified (by child age group) random sample of 538 families raising children with disabilities in Alberta, Canada took part. Participants completed the Family Life Survey, which incorporated items tapping parent perceived benefits, and measures of family well-being and out-of-home placement propensity.

**Results:** The study findings are consistent with the view that, in general, the benefits reported by parents reflect true, deep, and lasting changes, or ‘transformational outcomes’. By contrast, our findings are inconsistent with the view that parent reported benefits are artifacts of stress-processing, or resources for coping.

**Conclusion:** Most parents report benefits, such as the strengthening of emotional bonds between family members, personal growth and perspective transformation, and enriched social relationships. Supports and interventions for families need to be directed to helping families realize the benefits and not solely at reducing stress.

The experience of raising a child with disabilities is imbued with contradiction. Parents report negative and positive aspects: costs *and* benefits, challenges *and* rewards, sorrows *and* joys (Greer, Grey & McClean, 2006; Kearney & Griffin, 2001; Myers, Mackintosh & Goin-Kochel, 2009; Ryan & Runswick-Cole, 2008; Scorgie & Sobsey, 2000). Family research in the disability field has focused on negative aspects. This research has revealed that negative psychological conditions, such as toxic stress and depression, are more common among parents of children with disabilities than among the general population. These findings have generally been interpreted as outcomes of their parenting experience. Far less research attention has been given to the positive aspects and outcomes of raising a child with disabilities (Blacher & Baker, 2007; Ferguson, 2002; Hastings & Taunt, 2002; Helff & Glidden, 1998). The extant data clearly shows that parent reports of benefits, or positive impacts, are not exceptional. Indeed, these may be just as common as parent reports of negative impacts, if not more so. Further, it appears that positive and negative outcomes frequently co-exist, and may be sourced in the same experience of challenge and hardship (Hastings & Taunt, 2002; Rapanaro, Bartu & Lee, 2008; Resch, Benz & Elliot, 2012). Such findings clearly warrant further investigation.

In this study, we investigated parent-carer reports of benefits attributed to having a child with disabilities. One aim was simply to determine how common such reports are in a representative sample of parent-carers in Alberta, Canada. The primary aim however was to investigate the nature of parent-carer reported benefits. The question is whether the benefits reported by parents are better viewed as (a) artefacts of stress-processing and a resource for coping, or as (b) veridical (i.e., corresponding to fact) accounts of positive impact and transformation. This question is not easily answered: By testing a series of theoretical propositions, our goal

was to determine the most fitting answer to this question in view of our data. In the process, we examine relations between child behaviour problems, financial hardship, social support, perceived stress, reported benefit, and out-of-home placement tendency (i.e., the extent to which parents have considered or taken steps to place their disabled child out-of-home).

## BACKGROUND

There is unequivocal evidence that parents of children with disabilities experience higher than typical incidence of social and emotional challenges, including but not limited to unhappiness, psychiatric disorders, and marital conflict (Emerson, 2003; Hatton, Emerson, Graham, Blacher & Llewellyn, 2010; Manuel, Naughton, Balkrishnan, Smith, & Koman, 2003; McConnell & Llewellyn, 2006; Olsson & Hwang, 2008; Singer, 2006; Vermaes, Janssens, Bosman & Gerris, 2005). However, the results from several systematic reviews and meta-analytic studies suggest that the incidence of such adverse social and emotional conditions may be lower than previously thought (Bailey, Golden, Roberts & Ford, 2007; Risdal & Singer, 2004; Yirmiya & Shaked, 2005). For example, Bailey et al. (2007) systematically reviewed 42 studies, published over a 25 year period, and determined the prevalence of depression among mother-carers to be in the range of 12-15%. This is approximately twice the base rate found in community samples of women, but it is probably lower than many researchers and practitioners might have predicted.

Until quite recently, researchers (implicitly) assumed that such adverse parent and family outcomes were caused by the disability *per se* (Ferguson, 2002; Helff & Glidden, 1998). Having a child with disabilities was thought to be *inherently* negative, and negative impacts were thought to be *inevitable*. Indeed, the assumption of negative impact was such that parents who reported positive

impacts were thought to be in denial (Darling, 1979; Taylor, Bogdan & Lutiffiya, 1995; Ferguson, 2002). Today, researchers are explicitly resisting such assumptions, and they are employing more sophisticated theoretical models in an effort to advance our understanding of *the contingencies* of adverse parent and family outcomes. This generation of research is revealing that parent and family experiences and outcomes are the result of continuous, complex, dynamic, and dialectical interplay between person and environment, agency and structure, expectations and experiences, resources and demands. Notwithstanding, it has become increasingly clear that—*although most parents adapt well*—they are predisposed to adverse outcomes by sociocultural constraints and socioeconomic deprivations.

### ***Sociocultural constraints***

Culture gets 'under the skin'. Advances in cognitive science have revealed that our perception of any given situation depends as much on what we bring to it as it does on the situation itself (Estany, 2011; Bargh, 1997). And what we bring to all but the most novel situations are widely shared cultural models (i.e., cognitive schema, strategies of action) that are built up out of experience. These cultural models both enable and constrain. They enable us to interpret (i.e., transform sensory input into the perception of something meaningful) and respond to stimuli in ways that are fast, automatic and largely unconscious (Bargh, 2007). Further, cultural models enable us to fluently interact and coordinate our actions with one another on the basis of taken-for-granted, shared understandings. Skinner and Weisner (2007) explain that we use cultural models to make sense of experience, to plan and take action in different situations, and to evaluate and anticipate the behaviours of others. However, cultural models also constrain or *limit the horizon of possibilities*, including possible ways in which any given situation may be defined, and the strategies of action that may be employed in any given situation.

In defining their situation, parent-carers pre-consciously draw upon the cultural model/schema of disability available to them (Landsman, 2005; Skinner & Weisner, 2007; Voysey, 1975). And the dominant western cultural model of disability is inexorably negative: disability is assumed to be abnormal, undesirable, tragic (Ferguson, 2002; Helff & Glidden, 1998). Parents are expected to grieve rather than celebrate the birth of a disabled child; they are more likely to receive condolences than congratulations from family, friends and health professionals; and, they are expected to do whatever they can, instructed by 'the experts', to remedy 'the problem'. When this cultural model is activated, having a child with disabilities will appear to be inherently negative. Over time however, and in light of their ongoing experience, parents may revise their definitions of their situation, including the meanings they ascribe to their child's 'condition' (Voysey Paun, 2006; Landsman, 2005). Landsman (2005), for example, found that many mothers come to reject the dominant cultural model, re-define the very notion of normal itself, and embrace non-normative qualities as integral to the identity of the child they love.

In defining their situation and adapting to it, parent-carers also draw upon the available cultural model of 'normal parenthood': "[p]arent adaptations are appropriately situated responses, organised by their own and others definitions of their situation, *in relation to that of normal parenthood* [italics added]" (Voysey Paun, 2006, p. 153). And the dominant, western cultural model of normal parenthood is oppressive, especially for mothers who are supposed to 'pour themselves out' for their children *and* find the daily drudgery of childrearing rewarding. Activities constituting normal parenthood include providing a home, the inhabitants of which are healthy and adjusted; allocating resources (e.g., time, money, affection) and workload equitably and in accordance with member's needs and competencies; and, ensuring that children observe wider societal standards (i.e., behavioural norms), especially



in the public eye, so that the proper impression of the family is maintained (Held & Rutherford, 2012; Small, 2011; Voysey Paun, 2006). This cultural model of normal parenthood bears a questionable relationship to the experience of any parent. It is a recipe for mother guilt and mother blame. Yet, mothers of children with disabilities are “more than normally held accountable ... [*and indeed hold themselves accountable to a conception of normal parenthood*] while their experience is less than normally manageable within its terms” (Voysey Paun, 2006, p.156).

### ***Socioeconomic deprivations***

The performance of normal parenthood is ‘less than normally manageable’ for parents of children with disabilities because they have to juggle more than normal demands with less than normal resources. Time-use studies have found that parents of children with disabilities devote considerably more time than parents of typically developing children to ordinary child care tasks (McCann, Bull & Winzenberg, 2012). In addition, most parent-carers are expected to devote considerable time, energy and financial resources to the amelioration of their child’s impairment and disabilities (e.g., keeping appointments with professionals, implementing home programs, and so on). Consequently, parent carers are more than normally time poor. Data from the 2006 Statistics Canada, Participation and Activity Limitations Survey, revealed that over six in ten parent-carers report sometimes or always having feelings of stress due to difficulty juggling work and family and care demands (Statistics Canada, 2008).

Parents of disabled children also have to meet the demands of normal parenthood with ‘less than normal’ economic resources. The opportunity for parent-carers to participate in the workforce and generate income is limited by inflexible employment conditions (e.g., inflexible work hours) and unequal access to community resources (Freedman, Litchfield & Warfield, 1995; Gordon, Rosenman &

Cuskelly, 2007; Owen, Gordon, Frederico & Cooper, 2003; Shearn & Todd, 2001; Seltzer, et al. 2001; Warfield, 2001). Resources such as formal and informal childcare are essential for many parents, enabling them to juggle work and family demands, but inclusive childcare settings are in short supply (Booth-Laforce & Kelly, 2004; Grace, Llewellyn, Wedgwood, Fenech & McConnell, 2008). Such inequalities explain, at least in part, why four out of ten parent-carers in Canada have reduced their work hours, and why one in five have quit work altogether (Statistics Canada, 2008). In turn, reduced workforce participation explains, at least in part, why families of children with disabilities are more likely to be exposed to relative socioeconomic disadvantage. Nearly one in five Canadian children with disabilities (19.1%) live in a household that falls below the Low-Income Cut-Off (LICO) compared with 13.4% of non-disabled children (Statistics Canada, 2008).

### ***Parent reported benefits***

Despite the prevailing sociocultural bias toward negative parent perceptions, and despite (*or perhaps because of*) the often stressful circumstances of their everyday lives, many parents report benefits *as a result of* having a child with disabilities. Parent reported benefits or positive impacts typically include but are not limited to perspective transformation (e.g., “I now understand what is really important in life”, “I am less bothered by trivial things”); personal growth (e.g., “I am a stronger and wiser person”; “I have developed new skills and abilities”); and, the strengthening of family and social relationships (e.g., “it has brought the family closer together”, “wonderful people have come into our lives”) (Grant, Ramcharan, McGrath, Nolan & Keady, 2002; Hastings, Beck & Hill, 2005; Kearney & Griffin, 2001; Phelps, McCammon, Wuensch, & Golden, 2009; Rapanaro, et al., 2008; Scallan, Senior & Reilly, 2010; Scorgie & Sobsey, 2000; Stainton & Besser, 1998). The available data suggest that such

positive parent perceptions are common (Behr, Murphy & Summers, 1992; Greer, et al., 2006; Hastings & Taunt, 2002; Scorgie & Sobsey, 2000). It is also clear that such positive perceptions frequently co-exist with feelings of stress, sadness, and even despair (Graungaard, Andersen & Skov, 2011; Hastings & Taunt, 2002; Larson, 1998; Myers, Mackintosh & Goin-Kochel, 2009). The question is, given that the odds are stacked against positive parent perceptions and outcomes, *how are these to be explained? What are we to make of parent reported benefits?*

### ***Coping or transformation***

One view is that parent-carer reported benefits are artefacts of stress-processing (i.e., a response to stress) and a resource for coping (Gupta & Singhal, 2004; Hastings & Taunt, 2002). There are two basic ideas here. One is that people are motivated by unresolved situations and negative psychological states, consciously or pre-consciously, to search for *and if necessary imagine* benefits (Affleck & Tennen, 1996; Folkman, 2008; Folkman & Moskowitz, 2000; Taylor, 1983; Taylor & Brown, 1994). Folkman (2008) calls this process “benefit-finding” and classifies it as a meaning-focused coping strategy. The second idea is that perceived (real or imagined) benefits, and the positive emotions these induce, are coping resources, which buffer the impact of stressful life events and circumstances, and help to sustain coping efforts *when things are going badly* (Affleck & Tennen, 1996; Folkman & Moskowitz, 2000; Taylor, 1983; Taylor & Brown, 1994). Notably, for Folkman (2008), whether reported benefits are real or imagined is less important, with respect to stress processing, than whether individuals believe the benefits are real.

This view of parent reported benefits has some, albeit limited, empirical support. For example, in a sample of 41 mothers of children with intellectual disabilities, Hastings, Allen, McDermott and Still (2002) found a statistically significant association

between positive perceptions (i.e., related to personal growth, happiness/fulfillment, and family cohesion) and the use of reframing coping strategies. The authors observe that this finding is consistent with the view that positive perceptions are artefacts of stress-processing (coping → benefits). However, the finding is ambiguous: A plausible alternative explanation is that the benefits reported by the mothers explain their use of positive reframing (benefits → coping). Further, conflicting findings have been reported. Greer, Grey and McClean (2006) partially replicated the Hastings et al. (2002) study and found no significant association between mother’s positive perceptions and their use of reframing coping strategies.

An alternative view—one that has been advocated by parents themselves—is that parent reported benefits reflect ‘true, deep and lasting’ changes, or rather, ‘transformational outcomes’ (Kearney & Griffin, 2001; Scorgie & Sobsey, 2000; Stainton & Besser, 1998). Scorgie and Sobsey (2000) argue that while coping implies finding ways to go on with life as it was before, transformation involves a fundamental re-structuring of one’s assumptive world and a re-patterning of one’s way of life. Transformation occurs when the world that one knows is fractured and has to be reset: when disorienting dilemmas disrupt taken-for-granted habits of thinking and doing, and lead one to practice new ways of thinking and doing that are more congruent with one’s experience (Mezirow, 1990). In this paradigm, reframing cannot be viewed as unitary concept that is inherently adaptive or maladaptive. Reframing that reduces stress and fosters future adaptation is transformational while reframing that suppresses stress and makes future adaptation more difficult is not. For example, reframing a child’s severe disability as minor delay that will disappear with time or be cured by a new discovery would not be transformational. Reframing one’s expectations for oneself and one’s child to find satisfaction in a life that is

achievable for both may be transformational. Transformational outcomes resulting from the struggle with a negative, traumatic experience have been conceptualised as post-traumatic growth (Butler, 2007; Tedeschi & Calhoun, 1995; Tedeschi, Calhoun & Cann, 2007). In theory however, the process of transformation could be initiated by a negative or positive experience, just so long as the experience is 'disorienting' (Mezirow, 1990). Disorientation or disequilibrium occurs when new information and experiences do not fit into our existing cognitive schema and therefore cannot be assimilated. To accommodate these new elements, new cognitive schema must be constructed. This process of accommodation is recognized as a normal stage in child development (Piaget, 1967), but may also take place in adulthood when an individual is flooded with information and experiences that challenge existing attitudes and beliefs.

In this study we investigated a series of theoretical propositions in an effort to determine whether parent-reported benefits are better viewed as artefacts of stress-processing and a resource for coping, or as transformational outcomes. We reasoned that if parent reported benefits are an artefact of stress-processing (i.e., *the benefit-finding hypothesis*), we would find a positive association between perceived stress and reported benefit. Further, we would expect to find that parent reported benefit moderates the relationship between stressors and perceived stress (i.e., *the stress-buffering hypothesis*), and between perceived stress and 'perseverance' (i.e., *the motivation to persevere hypothesis*). If, on the other hand, the benefits reported by parents represent transformational outcomes (i.e., *the finding-benefit hypothesis*), we reasoned that we should find a positive association between measures of benefit, family cohesion, and social support/integration (i.e., *parent claims should be corroborated by measures of family cohesion and social support*). And further, we should find that parent reported benefit is more stable (or

*trait-like*) than perceived stress (i.e., *the 'true, deep and lasting change' hypothesis*): present stressors such as financial hardship and/or child behaviour problems should explain more of the variance in perceived stress than in reported benefit.

## METHOD

This study was nested within a three year (survey plus interview) study of work-family-care integration and out-of-home placement of children with disabilities in Alberta, Canada. The analysis reported in this paper is based on Year one (2009) survey data. The sampling frame for the study consisted of all English-speaking families registered with the Family Supports for Children with Disabilities (FSCD) program (i.e., a provincial government program), and in receipt of child-focussed services. Following Ethics Board approval (File#B-060808), and with the assistance of FSCD personnel, a stratified (by child age group: early childhood, middle childhood, adolescence) random sample of families were invited to take part.

The recruitment procedure followed the Dillman (1978) method, which is widely regarded as best practice in survey administration in the social sciences. Firstly, families received a letter informing them about the forthcoming survey. Within two weeks, each family received a copy of the survey package, including the "Family Life Survey", cover letter, consent form, pencil, and a return postage paid envelope. Approximately two weeks later, a follow-up reminder postcard was mailed out. Then approximately two weeks after this, another copy of the survey package was dispatched to families who had not yet responded. All respondents received an honorarium of CAN\$30.00.

The Family Life Survey (available from the first author), completed by the primary parent-carer, incorporated items adapted from the National Longitudinal Survey of Children and Youth (NLSCY) (Statistics Canada, 2003) to collect demographic data,

including but not limited to data on household composition; primary parent-carer sex, age, ethnicity, educational attainment and employment status; and, the sex, age, impairment type and activity limitations of the (*nominated*) disabled child. In addition, the survey incorporated items derived from previously validated scales and researcher-generated items tapping behaviour problems in children 4-18 years (Taffe, Gray, Einfeld, et al., 2007); financial hardship (Barrera, Caples & Tein, 2001); social support/integration (Brevik & Dalgard, 1996); perceived stress (Cohen & Williamson, 1988); family functioning/cohesion (Epstein, Baldwin & Bishop, 1983); reported benefit (Scorgie, Wilgosh, Sobsey & McDonald, 2001); and, out-of-home placement tendency (Blacher, 1990). The indicators for each of these latent constructs are listed in the Appendix B.

### **Data analysis**

The data were analysed using PASW (SPSS) v.18 and AMOS v.19. Data were entered and then re-entered into SPSS. Any discrepancies were identified and errors corrected. After cleaning the data, a descriptive, demographic profile of study participants was generated. Data quality was high with no item having greater than 5% missing values. Bayesian estimation (i.e., utilising the Markov chain Monte Carlo algorithm) was employed to replace missing values with predicted values, and transform the ordered-categorical (i.e., partially missing) data into numeric data. This approach solves the problem of incomplete data through an iterative and progressive process, utilising what is known and what is learned, to replace missing values with 'most likely' values (Shafer, 2003; Arbuckle, 2010).

Structural equation modelling (SEM) was then employed to test a series of theoretical propositions for the purpose of determining whether reported benefits are better viewed as artefacts of, and resources for coping, or as transformational outcomes. SEM is a versatile data-analytic approach that enables simultaneous estimation of relations among latent con-

structs and their indicators (the measurement model), and of the relations among latent constructs (the structural model). A major strength of SEM is that it produces measures of global fit that can provide a summary evaluation of even complex models that involve a large number of linear equations (Tomarken & Waller, 2005). Another major strength of SEM is that it takes measurement error into account: Other approaches (e.g., multiple regression) make the unlikely assumption that the constructs of interest are measured without error.

Prior to the SEM analysis, exploratory factor analysis (principal axis factoring with oblique rotation) was employed to investigate the factor structure of the 24 survey items tapping child behaviour problems. A two factor solution fit the data best, with indicators of stereotypic behaviour loading on one factor, and indicators of disruptive behaviour loading on the other. After complex items (items loading on both factors), and items with low factor loadings (<.5) and/or low communalities (<.4) were removed, the two factors accounted for approximately 50% of the variance. The remaining variables were then subject to a confirmatory factor analysis. The four strongest indicators (i.e., items with the highest factor loadings) of stereotypic behaviour, and the four strongest indicators of disruptive behaviour were identified, and these were retained for the SEM analysis (see Appendix B). Confirmatory factor analysis was also employed to screen the survey items tapping family cohesion. Of these items, the five strongest indicators, shown in the Appendix B, were retained for the SEM analysis.

Three separate models were tested. The first model is concerned with relations among reported benefit, perceived stress, social support/integration and family cohesion (Figure 2). Common variance, which may be due to underlying cognitive bias and/or common method bias, was extracted by including a common latent factor in the model. The second model estimated the 'effect' of selected stressors (i.e., disability severity, child behaviour problems,



**Table 1.** *Child, parent-carer and family characteristics (n=538)*

		Mean (SD) or %	
Child	Age	9.49 (4.77)	
		0-5 years	30
		6-12 years	35
		13-18 years	35
	Sex	Male	65
		Female	35
	Impairment Type#	Intellectual disability	48
		Autism spectrum disorder*	36
		Cerebral Palsy	15
		Downs Syndrome	11
	Disability (activity limitations)	A little	15
Fair amount		23	
Quite a lot		23	
A great deal		39	
Parent	Age	41.08 (8.26)	
	Sex	Male	12
		Female	88
	Language spoken at home	English	96
	Highest educational attainment	Did not complete high school	9
		High school graduate	18
		Diploma/trade certificate	40
		University undergraduate	25
		University postgraduate	9
Family	Residence	Major urban	56
		Minor urban	19
		Rural	25
	Family type	Couple, single-earner	28
		Couple, dual-earner	48
		Couple, no-earner	3
		Lone parent, earner	15
		Lone parent, non-earner	6
		Total household income	< \$40,000
		\$40,000 - \$69,000	20
		\$70,000 - \$89,000	20
		\$90,000 +	33
	Total number of Children (<18 years)		2.23 (1.18)

\*not mutually exclusive categories

financial hardship) on perceived stress and reported benefit (Figure 3). The third model assessed the potential moderating effect of reported benefit on the relationship between selected stressors and perceived stress, and between perceived stress and one indicator of 'perseverance', namely, out-of-home placement tendency (Figure 4). Specifically, we conducted a multi-group moderation test to determine whether path coefficients (e.g., from perceived stress to out-of-home placement tendency) varied

depending on whether the parent reported relatively low ( $\geq .5$  SD below the mean), average (*within .5 SD from the mean*) or high ( $\geq .5$  SD above the mean) benefit. We report bootstrap estimates (from 1000 bootstrap samples) for all parameters due to multivariate non-normality (Tomarken & Waller, 2005). The fit of each model was assessed using multiple indices. Absolute fit was assessed using the  $\chi^2$  goodness-of-fit test. The  $\chi^2$  value is the traditional measure for evaluating overall model fit:



**Figure 1. Parent reported benefits**



a non statistically significant  $\chi^2$  value indicates close fit between the proposed model and the data. However, the  $\chi^2$  goodness-of-fit test has several limitations including but not limited to sample size sensitivity (Schermelleh-Engel, Moosbrugger & Müller, 2003). Therefore we report multiple supplementary indices, including the  $\chi^2$  value divided by its degrees of freedom ( $CMIN/DF < 3$  is good); the Comparative Fit Index, which compares the specified model to an independence model ( $CFI > .95$  is good); and, the 90% confidence interval around the root mean square error of approximation ( $RMSEA90$ ), which should contain 0.06 to indicate the possibility of close model fit (Schreiber, Nora, Stage, Barlow & King, 2006).

## RESULTS

A total of 1300 parent-carers were invited to take part in this study. Of these, 538 parent-carers (41%) completed the Family Life Survey. A demographic profile of study participants is presented in Table 1.

The majority of parent-respondents (63%) either agreed or strongly agreed with the statement “Overall, having a child with disabilities has been positive for our family”. The response distribution for each item tapping parent perceived benefits is shown in Figure 1.

The zero-order correlation matrix presented in Table 2 shows that level of parent-reported benefit is positively correlated with family cohesion and perceived social support, and negatively correlated with perceived stress, financial hardship and disruptive (but not stereotypic) child behaviour problems. Notably, a statistically significant point-biserial correlation was found between parent-carer gender and reported benefit, with male primary parent-carers generally reporting lower levels of benefit than their female counterparts.

Many of the parent-respondents indicated that they were having a tough time financially. One in three reported having ‘quite a bit’ or ‘a great deal’ of

**Table 2.** Zero-order correlation matrix with imputed data

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17
										n=475	n=475						
1. Benefits*																	
2. Placement tendency	-.18*																
3. Perceived stress*	-.23*	.30*															
4. Family cohesion*	.46*	-.24*	-.51*														
5. Social support*	.29*	-.27*	-.70*	.52*													
6. Financial hardship*	-.02	.15*	-.58*	-.29*	-.45*												
7. child age	-.01	.18*	.01	-.05	-.07	-.04											
8. child gender (male)	-.04	-.07	.02	-.03	.00	-.03	-.02										
9. disability severity*	.03	.16*	.14*	-.08	-.09*	.07	-.07	-.05									
10. Disruptive behav.* (n=475)	-.17*	.20*	.18*	-.16*	-.15*	.19*	-.23*	.01	-.07								
11. Stereotypic behav.* (n=475)	-.07	.10*	.21*	-.13*	-.21*	.18*	-.19*	.04	.23*	.56*							
12. Autism spectrum	-.09*	-.09*	.12*	-.06	-.13*	.05	-.03	.17*	-.06	.16*	.39*						
13. Cerebral palsy	.12*	.01	-.02	.06	.07	-.03	.02	-.03	.25*	-.26*	-.22*	-.28*					
14. Parent age	-.08	.15*	-.06	-.09*	.01	-.17*	.56*	.04	-.11*	-.12*	-.18*	-.05	-.07				
15. Parent gender (male)	-.14*	.017	-.12*	-.00	.06	-.11*	.04	.02	-.04	.07	-.04	-.04	.04	.13*			
16. Married/common-law	.05	-.10*	-.17*	.14*	.13*	-.34*	-.08	.04	.03	-.09	-.07	-.01	.00	.04	.10*		
17. Educational attainment	-.10*	-.09*	-.12*	.12*	.15*	-.38*	-.03	.06	.07	-.17*	-.14*	.08	.05	.15*	.11*	.17*	
18. Household income	-.02	-.10*	-.25*	.17*	.19*	-.61*	.05	.03	.01	-.16*	-.15*	.06	-.02	.14*	.08	.40*	.46*

\*composite factor score. \*p<.05 (2-tailed)

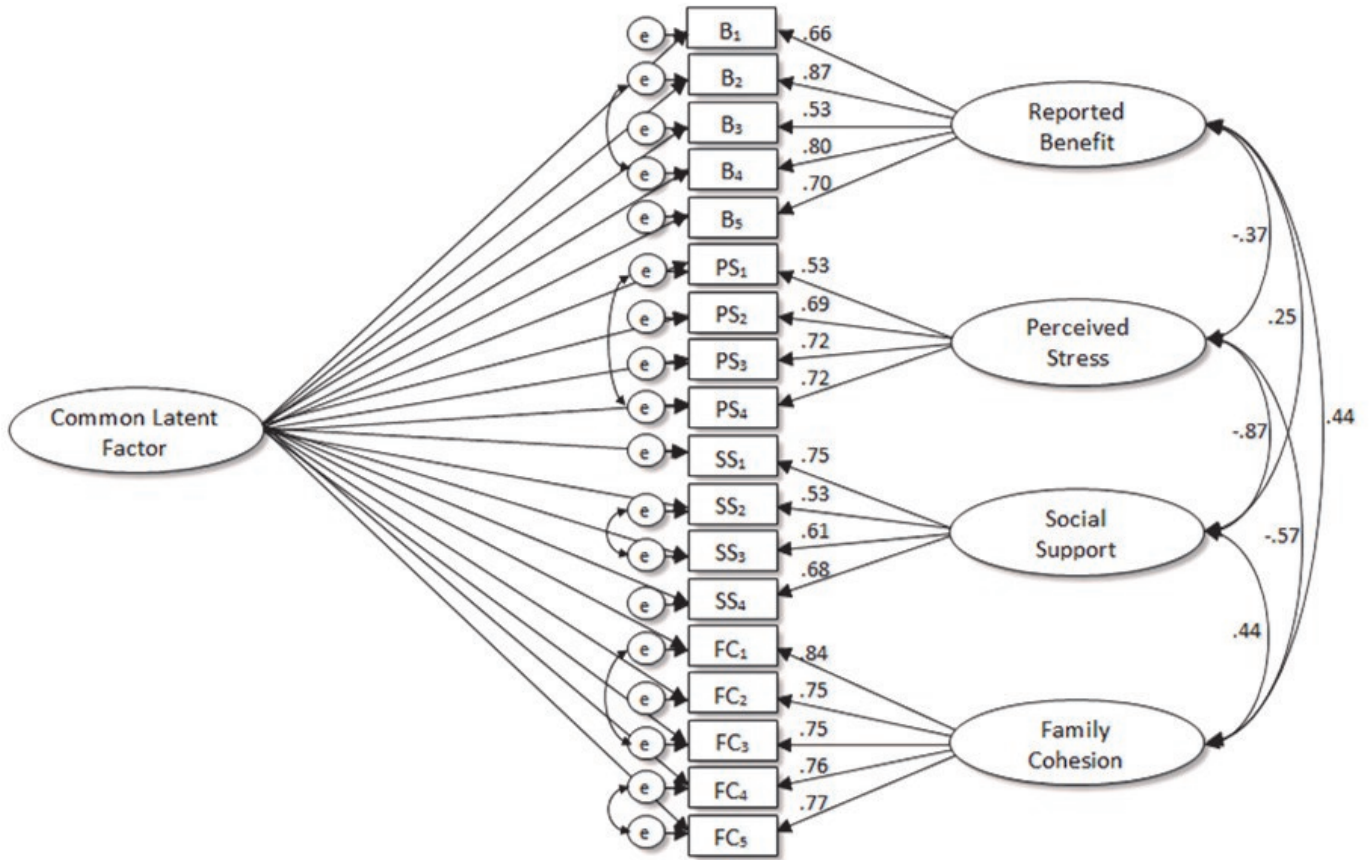
difficulty paying their bills, and approximately one in five expected that, over the coming three months, they would have to do without some of the basic things their family needs. In addition, many parent-respondents reported low levels of social support/integration. Almost one-third of the parent respondents (30%) said that people showed little or no interest or concern in how they or their family were doing. And fewer than half of the parent-respondents (47%) could identify more than one or two people they could count-on for support.

Financial hardship and social support were both highly correlated with perceived stress. Put simply, parents who reported greater financial hardship and/or lower levels of social support were also more likely to report that, in the past month, they had 'never' or 'almost never' felt like things were going their way (23%), and/or that they had 'fairly often' or 'very often' felt like difficulties were piling

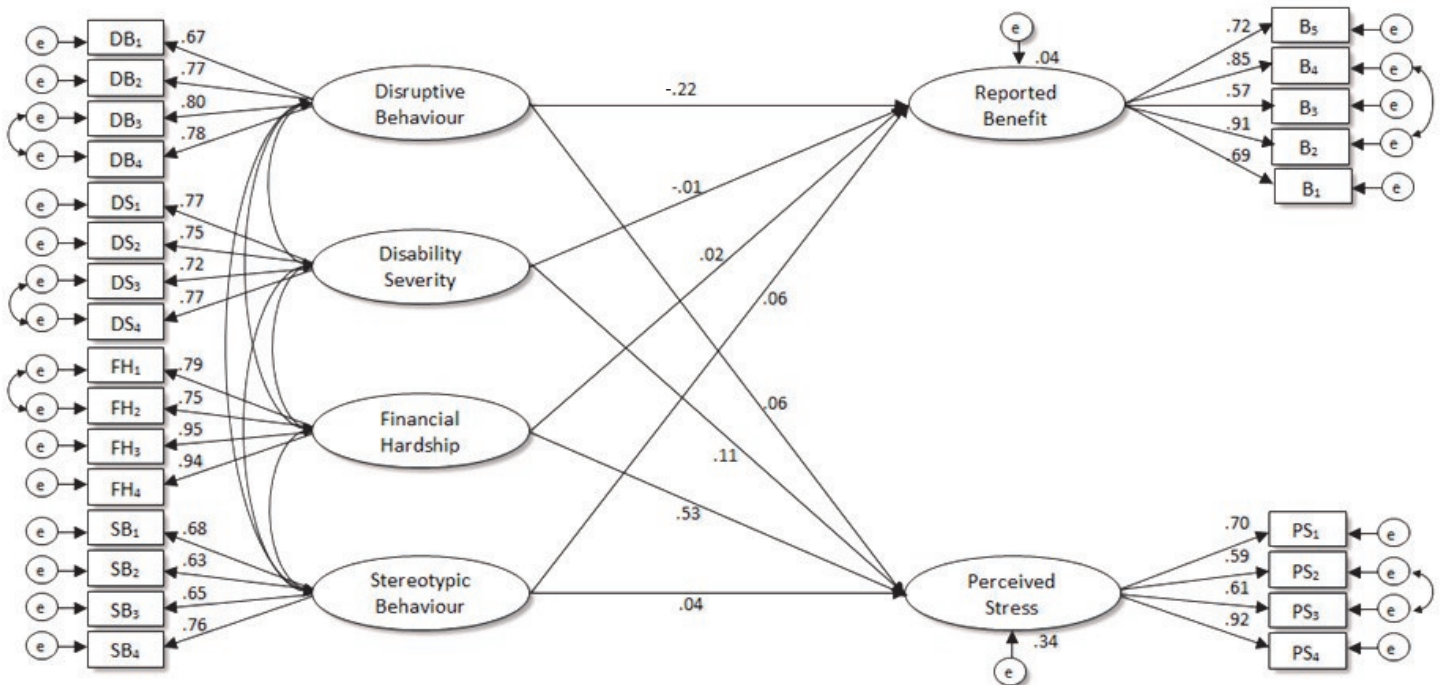
up so high that they could not overcome them (25%).

Approximately one in six parent-respondents (15.8%) reported having at least considered out-of-home placement as an option for their disabled child. A small number (3.4%) of parent-respondents indicated that they had already made the decision to place their disabled child out-of-home. Parents of older children and parents of children with more severe disabilities (i.e., more activity limitations) generally had higher placement tendency scores. A clear association between placement tendency and socioeconomic position was also evident. Parents with lower educational attainment and lower household incomes generally reported greater financial hardship, more disruptive and stereotypic child behaviour problems, lower levels of social support and family cohesion, elevated stress, and higher placement tendency scores (see Table 2).

**Figure 2.** SEM analysis: Corroborating parent claims, and the benefit-finding hypothesis

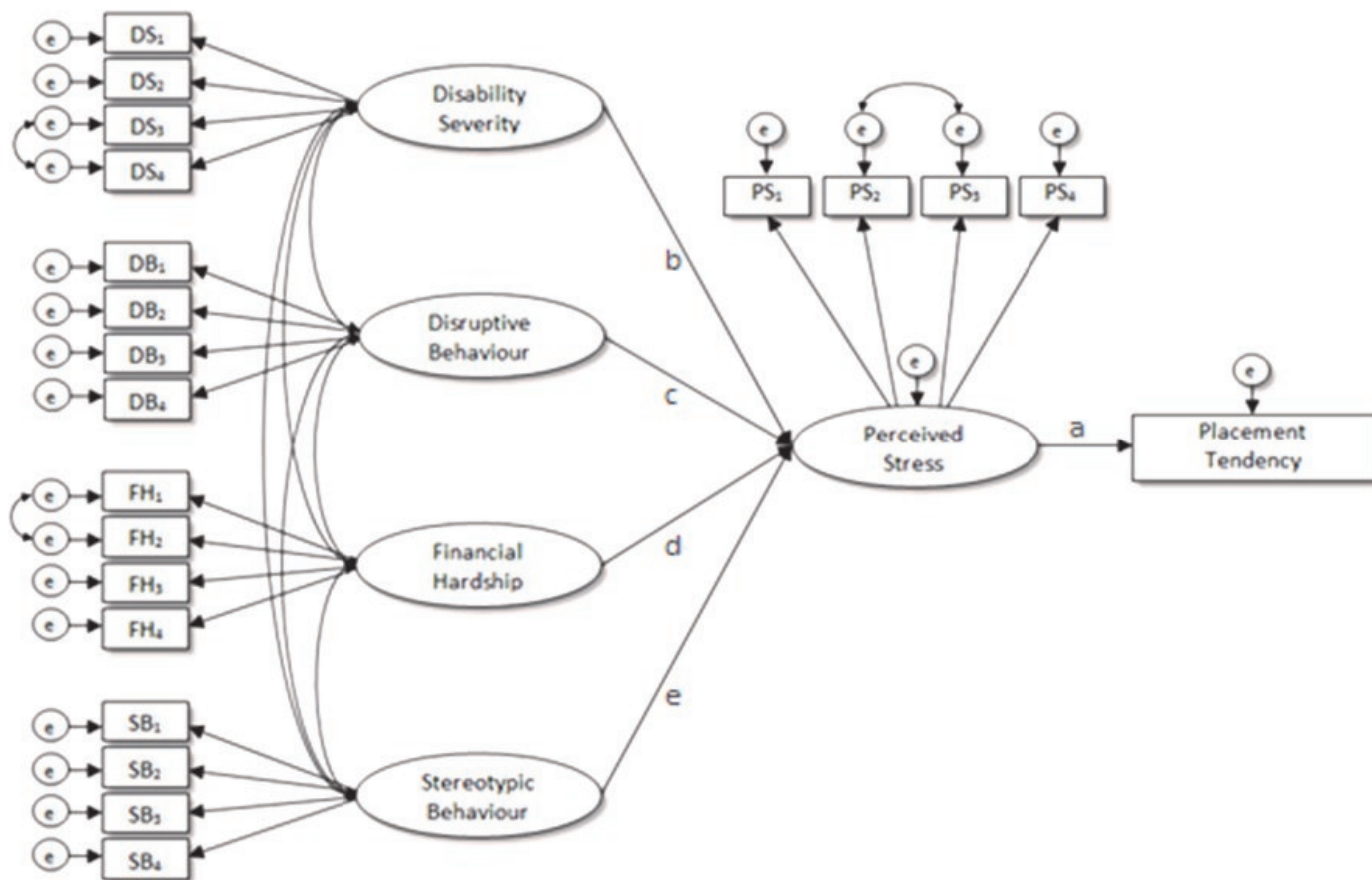


**Figure 3.** SEM analysis: The true, deep and lasting change hypothesis





**Figure 4.** SEM analysis: The 'stress-buffering' and 'motivation to persevere' hypotheses



**Corroborating parent claims, and the benefit-finding hypothesis**

SEM results showing (a) the correlation between reported benefit, perceived stress, social support/integration and family cohesion, and (b) relations between these latent constructs and their indicators, with the common variance extracted, are shown in Figure 2. The  $\chi^2$  goodness-of-fit test was significant ( $\chi^2=259.31$ ,  $df=122$ ,  $p<.01$ ), however the supplementary fit indices suggest that overall model fit was good (CMIN/DF=2.13, CFI = .971, RMSEA90 = .038, .054). With the common variance extracted, statistically significant, positive correlations were found between reported benefit and both social support/integration and family cohesion. In addition, a significant but negative correlation was found between perceived stress and reported benefit.

**The true, deep and lasting change hypothesis**

Figure 3 shows the results of an SEM analysis with four exogenous variables (disability severity, stereotypic behaviour, disruptive behaviour and financial hardship), and two endogenous variables (parent-reported benefits and perceived stress). Again, the  $\chi^2$  goodness-of-fit test was significant ( $\chi^2=431.506$ ,  $df=256$ ,  $p<.01$ ), but the supplementary fit indices suggest good overall model fit (CMIN/DF=1.686, CFI = .970, RMSEA90 = .032, .044). The endogenous variables explained a statistically insignificant 4% of the variance in parent-reported benefit ( $R^2=.036$ ,  $p=.07$ ), but a significant 34% of the variance in perceived stress ( $R^2=.337$ ,  $p=.03$ ). Notably, the model shows that disruptive behaviour predicted benefit (higher disruptive behaviour  $\rightarrow$  lower reported benefit), but not perceived stress. By contrast, financial hardship predicted perceived stress (greater financial hardship  $\rightarrow$  greater perceived stress), but not benefit.

**Table 3.** Multi-group moderation test: path coefficients

Path#	90%CI for the path coefficient		
	Low-benefit	Medium-benefit	High-benefit
a	.116, .487	.125, .387	.065, .385
b	-.224, .272	.034, .343	-.068, .307
c	-.277, .248	-.184, .129	-.259, .273
d	.429, .691	.402, .614	.402, .692
e	-.253, .367	-.083, .257	-.168, .311

# see Figure 4

### ***The ‘stress-buffering’ and ‘motivation to persevere’ hypotheses***

To investigate whether reported benefit moderates relations between present stressors and perceived stress, and between perceived stress and placement tendency, we conducted a multi-group moderation test, see Figure 4. The supplementary fit indices revealed good overall model fit (CMIN/DF=1.419, CFI = .954, RMSEA90 = .025, .035), although the  $\chi^2$  goodness-of-fit test was statistically significant ( $\chi^2=749.077$ ,  $df=528$ ,  $p<.01$ ). The 90% confidence interval for each path (a to e), for each group (low, medium and high reported benefit), is presented in Table 3. No statistically significant difference between any two groups was found for any path in the model. In other words, parent reported benefit did not moderate the effect of financial hardship (or any other proposed stressor) on perceived stress, and it did not moderate the effect of perceived stress on placement tendency.

### **DISCUSSION**

The notion that having a child with disabilities is inherently negative (or positive for that matter) is arguably indefensible. To defend or justify this idea there would have to be some external vantage point from which the ‘reality’ of having a child with disabilities could be apprehended. But as Dewey, Pierce,

Popper, Neurath and other philosophers of science have surmised, we have no direct access to reality per se: “Knowing is not the act of an outside spectator but of a participant inside the natural and social scene” (Dewey, 1960, p.196). However, as participants inside the natural and social scene, parent-carers are predisposed to negative perceptions by oppressive cultural models of disability and parenthood, and by contemporary social arrangements that take little or no account of their family’s needs, interests and circumstances. Yet, as this study and previous studies have found, the vast majority of parent-carers report positive as well as negative impacts (Blacher & Baker, 2007; Emerson, 2003; Kearney & Griffin, 2001; Phelps, et al., 2009; Scallan, et al., 2010). Indeed, two out of three parent-carers in this study agreed that, “overall, having a child with disabilities has been positive for our family”.

In this study we explored the nature of parent reported benefits. Our findings are consistent with the view that, in general, the benefits reported by parent-carers reflect true, deep, and lasting changes, or rather, ‘transformational outcomes’. Specifically, we found that parent claims were corroborated by measures of family cohesion and social support/integration. Further, we found that parent reported



benefit was more or less unaffected or unmoved by present stressors, including child behaviour problems and financial hardship. By contrast, our findings are inconsistent with the view that parent reported benefits are merely artefacts of, and resources for coping. Specifically, we found that parent reported benefit was negatively correlated with perceived stress; and, further, that parent-reported benefit did not moderate relations between selected stressors (e.g., child behaviour problems, financial hardship) and perceived stress, or between perceived stress and out-of-home placement tendency.

These findings should not, of course, be taken to mean that parent-carers do not employ benefit-finding as a cognitive coping strategy. Our findings simply suggest that the benefits reported by parent-carers in this study are not attributable to 'benefit-finding', at least not in general. This 'in general' caveat is important too. In fact, it is possible that most parents employ varying degrees of both benefit-finding and transformation at various times. Following the Piagetian model (Piaget, 1967/1971), it is likely that parents initially attempt to assimilate the flood of new information and experiences into their existing worldview and behaviour using various strategies including 'benefit-finding.' If assimilation is adequate to resolve the disequilibrium resulting from the new information and experience, transformation is unlikely and unnecessary. If assimilation is inadequate to resolve the disequilibrium, transformation of the parent's worldview and behaviour is likely and necessary to resolve the additional stress caused by the disequilibrium. Homeostatic coping (finding ways to hang-on to pre-existing schema and behaviour) may be adequate to address minor challenges to parents pre-existing schema, but maladaptive to address more extreme challenges. Child characteristics (e.g., nature and severity of disability, serious behavioural challenges, extreme medical fragility) may influence the degree of parental disequilibrium, but pre-existing parental

attributes, social factors, and possibly other elements also play a role. As Butler (2007) observed, "[m]any roads may converge at the final common pathway of reporting ...benefits" (p. 369). Notwithstanding, the findings of this study suggest that theories of transformation may be essential for understanding parent reported benefits.

It may be overly simplistic to assume that the positive impacts or transformational outcomes reported by parent-carers have their genesis in struggle or to view reported benefits as some kind of 'post-traumatic' growth. Alternatively, the benefits and growth reported by parent-carers may be just that, benefits and growth. Becoming a parent is a transforming experience, whether or not the child has disabilities. It creates a degree of disequilibrium that must be accommodated but we do not typically view it primarily as a trauma. Like parents of typically developing children, parent-carers may find benefits despite the hardships they face. Personal growth, the strengthening of family bonds, and the enrichment of their social networks would not seem to be contingent upon some negative antecedent. Further research is clearly needed to advance our understanding of how parent-carers come by the positive impacts and benefits they report.

Transformational theory suggests that substantially different approaches to family support may be considered. Focusing on parenting children with significant disabilities as a negative experience suggests an approach oriented toward reducing demands. Transformational theory suggests that it may be of equal or greater importance to strengthen their attachment to their children and view their caregiving experiences positively.

### ***Limitations***

This study has a number of strengths, including but not limited to the recruitment of a robust sample of parent-carers in Alberta, Canada. However, 'volunteer bias' may call into question the generalisability of the study findings. The participation rate

of 41% is reasonable vis a vis other survey studies. However, we do not know if the participants were different from the non-participants in any systematic way/s. Another limitation of the study is that the data is correlational. Consequently, directionality (XàY) can only be inferred from theory. For example, Models 2 and 3 infer that child behaviour problems cause perceived stress, but this relationship is most likely bi-directional (Hastings & Beck, 2004; Lecavalier, Leone & Wiltz, 2006; Olsson, 2008). A third limitation relates to the measurement of 'benefits'. Although the items used in this study to measure benefits were shown to be highly inter-related (demonstrating convergent validity), we should not assume that each benefit has the same 'underlying cause' or consequences. In future studies, it may be worthwhile differentiating between different 'classes' of benefit. A distinction might, for example, be drawn between benefits that reflect personal change (i.e., changes in cognitions), and benefits that reflect inter-personal change (i.e., the strengthening of family and social relationships).

### ***Conclusion***

In conclusion we would just echo the thoughts of Scorgie and Sobsey (2000) who assert that health and human services professionals have to resist 'catastrophising' disability. Having a child with disabilities may be painful and difficult: parents may, at first, be devastated. Moreover, the road ahead is not a predictable or easy road for most parent-carers to travel: Many parent-carers describe their experience as a constant fight – a fight for the support, consideration and respect that their child and family is entitled to. Yet, the experience of raising a child with disabilities is clearly not all negative. Indeed, most parent carers report real and meaningful benefits, such as the strengthening of emotional bonds between family members, personal growth and perspective transformation, and enriched social relationships. Supports and interventions for families need to be directed to helping families realize the

benefits and not solely at reducing stress. Professionals can share this insight with new or inexperienced parent-carers, or better still, create opportunities for them to meet and learn from experienced parent-carers who can speak from their experience about the benefits of having a child with disabilities. Perhaps, professionals and community organisations for persons with disabilities and their families could work together to make this happen if they are not already doing so.

## APPENDIX B Items tapping reported latent constructs

Key		Scale#
<b>Disability severity (DS)</b>		
DS1	To what extent does a long-term physical condition, mental condition, learning or health problem reduce the amount or the kind of (age-appropriate) activities this child can do?	0 - 4
DS2	Compared with other children his/her age, does this child have any difficulty with speaking?	0 - 2
DS3	Compared with other children his/her age, does this child have any difficulty with learning?	0 - 2
DS4	Compared with other children his/her age, does this child have any difficulty with personal care activities ...?	0 - 2
<b>Child behaviour problems—stereotypic behaviour (SB)</b>		
SB1	This child laughs or giggles for no obvious reason.	0 - 2
SB2	This child repeats the same word or phrase over and over.	0 - 2
SB3	This child smells, tastes, or licks objects.	0 - 2
SB4	This child wanders aimlessly.	0 - 2
<b>Child behaviour problems—disruptive behaviour (DB)</b>		
DB1	This child is jealous.	0 - 2
DB2	This child is stubborn, disobedient, or uncooperative.	0 - 2
DB3	This child is impatient.	0 - 2
DB4	This child kicks, hits others.	0 - 2
<b>Financial hardship (FH)</b>		
FH1	Thinking back over the past three months, how much difficulty have you had paying your bills?	0 - 4
FH2	Thinking again over the past three months, generally, at the end of each month did you end up with ...? (0 = more than enough money left, 4 = very short of money)	0 - 4
FH3	In the next three months, how often do you think that you and your family will experience bad times such as poor housing or not having enough food?	0 - 4
FH4	In the next three months, how often do you expect that you will have to do without the basic things that your family needs?	0 - 4
<b>Social support/integration (SS)</b>		
SS1	As a family we feel a strong sense of belonging in our community	0 - 3
SS2	How many people are so close to you that you can count on them if you have a serious personal or family problem? (0 = 0, 4 = 10 +)	0 - 4
SS3	How much concern or interest do people show in how you and your family are doing?	0 - 4
SS4	How easy is it to get practical help from your neighbours if you or your family should need it?	0 - 4

Key		Scale#
<b>Perceived stress (PS)</b>		
PS1	In the last month, how often have you felt that you were unable to control the important things in your life?	0 - 4
PS2	In the last month, how often have you felt confident about your ability to handle your personal problems?	0 - 4
PS3	In the last month, how often have you felt that things were going your way?	0 - 4
PS4	In the last month, how often have you felt that difficulties were piling up so high that you could not overcome them?	0 - 4
<b>Family cohesion (FC)</b>		
FC1	We confide in each other.	0 - 3
FC2	I often feel that our family stays together only out of necessity	0 - 3
FC3	In times of crisis we can turn to each other for support	0 - 3
FC4	There are lots of bad feelings in our family.	0 - 3
FC5	We don't get along well together.	0 - 3
<b>Reported benefit (B)</b>		
B1	Overall, having a child with a disability has been positive for our family	0 - 3
B2	As a result of having a child with a disability, our family unit has emerged stronger	0 - 3
B3	As a result of having a child with a disability, some wonderful people have come into our lives	0 - 3
B4	As a result of having a child with a disability, we have learned what is really important in life.	0 - 3
B5	As a result of having a child with a disability, we laugh more and are less bothered by trivial things	0 - 3
<b>Out-of-home placement tendency (PT)</b>		
PT	Have you ever considered placing this child out-of-home? (for example, in foster or residential care) (0 = no, we have never considered placement as an option for our child, 5 = we have placed our child out-of-home)	0 - 5

*#before transformation*

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## 5

### **Resilience in families raising children with disabilities and behaviour problems**

**Purpose:** The purpose of this study was to investigate the resilience displayed by families raising children with disabilities and behaviour problems. The question is why do some families do well when others, exposed to similar stressors, struggle to keep their family life running?

**Method:** A stratified (by child age group) random sample of 538 families raising children with disabilities in Alberta, Canada took part. Participants completed the Family Life Survey, which incorporated measures of child behaviour problems, social-ecological resources and family-level 'outcomes'.

**Results:** Families raising children with disabilities and behaviour problems 'do well' under conditions of high social support and low financial hardship. In contrast, families with low levels of social support and high levels of financial hardship typically struggle, even when the number or intensity of child behaviour problems is low.

**Conclusion:** The study findings are consistent with the view that 'resilience' has more to do with the availability and accessibility of culturally relevant resources than with intrinsic, individual or family factors. With respect to family-level outcomes, strengthening social relationships and ameliorating financial hardship may be more important than behaviour modification.

Despite well-documented challenges, most families bringing up children with disabilities 'do well'. However, child behaviour problems increase the risk of poor family outcomes. Behaviour problems can disrupt family routines and relationships, and tax family adaptive resources. Arguably, families who do well despite the stressors associated with bringing up a disabled child with behaviour problems display 'resilience'. A challenge for family researchers is to account for such resilience: *why do some families do well when others, exposed to similar stressors, struggle to keep their family life running?* In this study we investigate the proposition that such resilience is context-bound. Our principal hypothesis is that families of disabled children with behaviour problems do well, or at least better, under conditions of high social support and low financial hardship.

## BACKGROUND

Families of children with disabilities have to contend with many out-of-the-ordinary challenges. Some challenges may be directly related to the child's condition. Other challenges and hardships have little or nothing to do with the child's condition *per se*, but are rather caused by negative social responses and social arrangements that do not take their needs, interests and circumstances into account (Dowling & Dolan, 2001; Green, 2007; Olsson, 2008; Resch, Benz & Elliott, 2012; Ryan & Runswick-Cole, 2008). Many parents and siblings, for example, feel the sting of social stigma attached to disability (Farrugia, 2009; Francis, 2012; Gill & Liamputtong, 2011; Green, 2007; Voysey, 1972); some parents struggle to retain meaningful employment and in turn, an adequate standard of living due to a lack of reasonable workplace accommodations and/or inclusive childcare arrangements (Freedman, Litchfield, & Warfield, 1995; Gordon, Rosenman, & Cuskelly, 2007; Owen et al. 2002; Seltzer et al. 2001; Warfield, 2001); and, many are overwhelmed by the challenges involved in accessing and navigating

fragmented, inflexible and/or poorly resourced service systems (Browne, Rokeach, Wiener, Hoch, Meunier & Thurston, 2013; McManus, Carle, Acevedo-Garcia, Ganz, Hauser-Cram & McCormick, 2011; Reichman, Corman & Noonan, 2008; Rodger & Mandich, 2005).

In view of these and other challenges, heightened levels of maternal and family distress might be expected. Recent population-based studies and systematic reviews confirm that mothers of children with disabilities are two to three times more likely than mothers of non-disabled children to report clinically significant levels of depression, anxiety and/or stress (Bailey, Golden, Roberts & Ford, 2007; Emerson, Hatton, Llewellyn, Blacher & Graham, 2006; Emerson, McCulloch, Graham, Blacher, Llewellyn, & Hatton, 2010; Montes & Halterman, 2007; Singer & Floyd, 2006; Totsika, Hastings, Emerson, Lancaster & Berridge, 2011; Vermaes, Janssens, Bosman & Gerris, 2005; Yirmiya & Shaked, 2005). However, the *absolute risk* of such negative psychological conditions may not be as high as many people may think: a large majority of mothers and families bringing up children with disabilities appear to 'do well' (Baker, Blacher & Olsson, 2005; Blacher & Baker, 2007; Carnevale, Alexander, Davis & Rennick, 2006; Green, 2007; Glidden & Jobe, 2006; Olsson, 2008; Olsson, Larsman & Hwan, 2008; Seltzer, Greenberg, Floyd, Pettee & Hong, 2001; Ylvén, Björck-Åkesson, & Granlund, 2006). In the United Kingdom, for example, Emerson et al. (2010) conducted secondary analysis of data from the Millennium Cohort Study and found that fewer than 25% of mothers of children with early cognitive delay were at risk of psychiatric disorder. Similarly, in the United States, Montes and Halterman (2007) conducted secondary analysis of the 2003 National Survey of Children's Health and found that fewer than 20% of mothers of children with an autism spectrum disorder (ASD) reported poor mental or emotional health.



Less research attention has focussed on fathers, siblings and the family as a whole, and the limited available data are equivocal. Several studies have found little or no significant difference between families with and without children with disabilities on measures of father, sibling and/or family wellbeing (Glidden, Bamberger, Turek & Hill, 2010; Hatton, Emerson, Graham, Blacher & Llewellyn, 2010; Herzer, Godiwala, Hommel, et al. 2010; Lundebj & Tossebro, 2008; McCoyd, Akincigil & Paek, 2010; Risdal & Singer, 2004; Rodrigues & Patterson, 2007; Walsh & O'leary, 2013). However, other studies have found marked differences (Al-Krenawi, Graham & Gharaibeh, 2011; Hartley, Barker, Seltzer, Floyd, Greenberg, Orsmond & Bolt, 2010; Gau, Chou, Chiang et al., 2011; Higgins, Bailey & Pearce, 2005; Lewandowski, Palermo, Stinson, Handley & Chambers, 2010; Neece, Blacher & Baker, 2010; Pousada, Guillamon, Hernandez-Encuentra, et al., 2013; Wymbs, Pelham, Molina, & Gnagy, 2008). Hartley et al. (2010), for instance, employed survival analysis to investigate prevalence and risk of divorce in a matched sample of families with and without children with ASD and found that the prevalence of divorce was higher in the ASD group (24% vs. 14%), and the risk remained relatively high over an extended period.

To explain the observed variation in outcomes among families with disabled children, a great deal of research attention has focused on child-specific factors. One of the most consistent research findings is that risk of poor outcomes increases as the number and/or intensity of child behaviour problems increase (Barker, Hartley, Seltzer, Floyd, Greenberg, & Orsmond, 2011; Blacher & McIntyre, 2006; Eisenhower, Baker & Blacher, 2005; Gray, Piccinin, Hofer, et al. 2011; Hastings, Daley, Burns & Beck, 2006; Herring, Gray, Taffe, et al., 2006; Lecavalier, Leone & Wiltz, 2006; Orsmond, Seltzer, Krauss & Hong, 2003; Raina, O'Donnell, Rosenbaum, et al. 2005). Indeed, studies have consistently found that

maternal and other family outcomes are more strongly associated with child behaviour problems than with diagnosis or disability severity. Baker, Blacher, Crnic and Edelbrock (2002), for example, found that developmental delay in preschool age children did not contribute to maternal stress after controlling for child behaviour problems. Similarly, Herring et al. (2006) found that early behavioural and emotional problems in children with disabilities contributed more to later maternal stress and family dysfunction than diagnosis or delay.

The relationship between child behaviour problems and parent and family wellbeing is generally thought to be bidirectional (Hastings & Beck, 2004; Lecavalier, Leone & Wiltz, 2006; Olsson, 2008): In a downward spiral, child behaviour problems may heighten parent-carer stress and family dysfunction which, in turn, may lead to ineffective coping and/or parenting practices which, in turn, may increase child behaviour problems, and so on. However, the available evidence is not entirely consistent with this view. For example, in a longitudinal study of preschoolers with developmental delays, Eisenhower, Baker and Blacher (2009) found that child behaviour problems, measured at age three, predicted maternal health at ages four and five, but maternal health, measured at age three, failed to predict child behaviour problems at ages four and five. Totsika et al. (2013) also found a unidirectional relationship between behaviour problems and maternal wellbeing. However, they found that the 'arrow of causality' ran in the opposite direction: maternal wellbeing contributed to later behaviour problems in young children with ASD, but early behaviour problems did not contribute to maternal wellbeing over the long term.

### ***Explaining resilience***

Positive family adaptation in response to, or despite, the stressors associated with bringing up a child with disabilities and behaviour problems may

constitute evidence of resilience. The challenge for researchers lies in explaining such resilience: why do some families do well and not others? Early theories posited that family resilience was determined by within-family factors. McCubbin and McCubbin (1988), for instance, defined the study of resilience as the search for “characteristics, dimensions, and properties of families which help families to be resistant to disruption in the face of change and adaptive in the face of crisis situations” (p. 247). More recent theories place greater emphasis on social-ecological factors and transactional processes (i.e., the family in interaction with their environment/s). Ungar (2011), for example, suggests that “resilience is more dependent on the availability and accessibility of culturally relevant resources than individual or within-family factors” (p. 6, *our addition*). Similarly, with respect to individuals, Matsen, Hubbard, Gest, Tellegen, Garmezy and Ramirez (1999) observed that, if reasonably good resources are present, outcomes appear to be good, even in the context of severe stressors.

There is evidence to support the contention that the positive adaptation of families bringing up children with disabilities in general (i.e., with or without behaviour problems) is at least in part influenced by intrinsic, within-family factors. A number of studies have found that positive maternal and family adaptation is associated with better family functioning, and psychological variables such as parent-carer optimism, positive affect, internal locus of control, and the use of meaning-focused and problem-focused coping strategies (Baker, Seltzer & Greenberg, 2011; Bourke-Taylor, Pallant, Law & Howie, 2012; Dabrowska & Pisula, 2010; Ekas, Lickenbrock & Whitman, 2010; Greer, Grey & McClean, 2006; Hastings, Kovshoff, Brown, Ward, Degli Espinoza & Remington, 2005; Jones & Passey, 2005; Lightsey & Sweeney, 2008; Manning, Wainwright & Bennett, 2011; Plant & Sanders, 2007; Smith, Seltzer, Tager-Flusberg, Greenberg & Carter, 2008; Raina et al.,

2005; Trute, Benzie & Worthington, 2012; Trute, Benzie, Worthington, Reddon & Moore, 2010). For instance, in a recent longitudinal study involving families of children with an autism spectrum disorder, Baker, Seltzer and Greenberg (2011) found that family-level adaptability, measured in Year 1, was a unique predictor of maternal depression symptoms, measured in Year 3.

Less research attention has focused on social-ecological factors, yet there is some compelling data linking maternal outcomes to socioeconomic position (Eisenhower & Blacher, 2006; Emerson, Hatton, Llewellyn, Blacher & Graham, 2006; Emerson & Llewellyn, 2008; Emerson et al., 2010; Hatton & Emerson, 2009; Knestrict & Kuchey, 2009; Olsson & Hwang, 2008; Park, Turnbull & Turnbull, 2002). Emerson et al. (2006), for example, conducted secondary analysis of data from the United Kingdom Department for Work and Pension’s Families and Children Study and found no significant difference between mothers of children with and without early cognitive delay with respect to happiness when socioeconomic position, household composition and maternal characteristics (e.g., age, marital status) were taken into account. Similarly, Emerson and Llewellyn (2008) analysed data from the Longitudinal Study of Australian Children and found that higher exposure to poverty explained approximately 50% of the elevated risk of distress and psychiatric disorder in mothers of children ‘at risk’ for disability.

In addition, there is data linking maternal and family outcomes to social support: formal and informal (Benson, 2006; Bishop, Richler, Cain & Lord, 2007; Crnic & Low, 2002; Davis & Gavidia-Payne, 2009; Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001; Green, 2007; Horton & Wallander, 2001; Pakenham, Samios & Sofronoff, 2005; Pousada, et al., 2013; Resch, Mireles, Benz, Grenwelge, Peterson & Zhang, 2010; Tobing & Glenwick, 2006; Twoy, Connolly & Novak, 2007; Weiss, 2002). Davis and

Gavidia-Payne (2009), for instance, found that parent perceptions of professional support (i.e., perceived family-centeredness) and satisfaction with informal support from family and friends were significant predictors of family quality of life, together with child behaviour problems, in a sample of families in receipt of early childhood intervention services. Likewise, Smith, Greenberg and Seltzer (2012) found that perceived social support predicted changes, over an 18 month period, in the well-being of mothers of young adults with ASD, over and above the impact of behaviour problems.

There is however a dearth of research investigating mechanisms or pathways linking child behaviour problems, social-ecological factors and family-level outcomes. One possibility is that the relationship between child behaviour problems (i.e., 'the stressor') and family adaptation is mediated by social-ecological factors. Parents of disabled children with behaviour problems may, for example, have more difficulty finding suitable child care and in turn, participate less in the workforce leading to greater financial hardship (Coley, Ribar, & Votruba-Drzal, 2011; Freedman, et al., 1995; Kagan, Lewis, Heaton, & Cranshaw, 1999; Shearn & Todd, 2000). Alternatively, or in addition, these parents may find it more difficult to manage public perceptions of their child and family (i.e., to sustain the perception of 'normalcy'), and in turn struggle to maintain positive social relationships (Bromley, Hare, Davison & Emerson, 2004; Smith, Greenberg, & Seltzer, 2012). And, with more limited financial and social resources, these parents and families may have less control or 'power-over-destiny', resulting in heightened stress (Emerson, 2004; Lam, 2011). An alternative possibility is that social-ecological conditions 'moderate' the effect of child behaviour problems on the family (Boyd, 2002; Feldman et al., 2007; Hatton & Emerson, 2009). That is, child behaviour problems may not necessarily lead to greater financial hardship or social exclusion, but having greater

financial and social resources may 'buffer' or lessen the impact of child behaviour problems. Of course there may be multiple pathways connecting child behaviour problems to family level-outcomes, and social ecological factors may mediate *and* moderate this relationship.

### ***Ecocultural theory and family resilience***

Within-family and social-ecological factors are inter-linked in ecocultural theory. A central tenet of this theory is that families at once shape and are shaped by the social-ecological context in which they live (Gallimore, Weisner, Bernheimer, Guthrie & Nihira, 1993; Gallimore, Bernheimer & Weisner, 1999; Weisner, Matheson, Coots & Bernheimer, 2005). This theory posits that all families face the same enduring adaptive challenge: to create and maintain a sufficiently predictable daily routine, or way of life, that is congruent with their values and aspirations, and the needs, interests and competences of individual family members. In the everyday routine of family life parents endeavor to reconcile what they want for their child/ren, themselves and their family with what is possible given their circumstances (Weisner, et al, 2005).

Ecocultural theory and research suggests that family success in meeting this challenge depends, in part, on resource-fit (Bernheimer, Weisner & Lowe, 2003; Weisner et al., 2005; Weisner, 2009). In turn, resource-fit is understood to be a function of ecological constraints and resources (including within-family and social-ecological resources), and the family's values and aspirations. Variation in any of these factors may affect resource-fit. Ecocultural theory further posits that, to improve resource-fit, families make 'accommodations'. Family accommodations may include adjusting expectations or priorities, and/or situated and creative action to increase resource-availability (e.g., postponing, reorganizing, cutting-back, reaching-out, etc).

The purpose of this study was to investigate the relationship between child behaviour problems, social-ecological resource-fit and positive family adaptation. Resilience is defined here as positive family adaptation in response to, or despite exposure to child behaviour problems. In turn, and drawing on ecocultural theory, we equate positive family adaptation with higher levels of Family Life Congruence: families display positive adaptation when their everyday family routine is at once meaningful (i.e., congruent with their values and aspirations) and balanced (i.e., congruent with the needs and interests of family members). Our principal hypothesis was that families of disabled children with behaviour problems 'do better' under conditions of low financial hardship and high social support. Secondary hypotheses included: (i) There is a negative association between child behaviour problems and family life congruence; (ii) The relationship between child behaviour problems and family life congruence is partially mediated by social-ecological resource-fit; and, (3) social-ecological resource-fit moderates the relationship between child behaviour problems and family life congruence.

## **METHOD**

This study was nested within a three year—survey plus interview—study of work-family-care integration in families bringing up children with disabilities in Alberta, Canada. The analysis reported in this paper is based on Year one (2009) survey data. The sampling frame for the study consisted of all English-speaking families listed in the Alberta Department of Children and Youth Services, Family Supports for Children with Disabilities (FSCD), Child-Focused Services database. Following Ethics Board approval (File#B-060808), and with the assistance of FSCD personnel, a stratified (by child age group: early childhood, middle childhood, adolescence) random sample of 1300 families were invited to take part.

The recruitment procedure followed the Dillman (1978) method. Firstly, families received a letter informing them about the forthcoming survey. Within two weeks, each family received a copy of the survey package, including the "Family Life Survey", cover letter, consent form, pencil, and a return postage paid envelope. Approximately two weeks later, a follow-up reminder postcard was mailed out. Then approximately two weeks after this, another copy of the survey package was dispatched to families who had not yet responded. All respondents received an honorarium of CAN\$30.00.

The Family Life Survey, completed by the primary parent-carer, incorporated items to collect demographic data, including but not limited to data on household composition; primary parent-carer sex, age, ethnicity, educational attainment and employment status; and, the sex, age, impairment type and disability status of the child. In addition, the survey incorporated well validated scales, including but not limited a short form of the Developmental Behaviour Checklist (DBC-24), which is a measure of behaviour problems in children with disabilities 4-18 years of age (Taffe, Gray, Einfeld, et al., 2007), and the General Family Functioning scale of the McMaster Family Assessment Device (Epstein, Baldwin & Bishop, 1983). In addition, the survey incorporated previously validated and researcher-generated items tapping financial hardship (Barrera, Caples & Tein, 2001); social support and integration (Brevik & Dalgard, 1996); and, family life congruence (Llewellyn, Bundy, McConnell, Emerson & Brentnall, 2010). The items tapping each of the latent constructs that form the focus of this paper are listed in Appendix C.

## ***Data analysis***

The data were analysed using PASW (SPSS) v.18 and AMOS v.20. Data were entered and then re-entered into SPSS. Discrepancies were identified and data-entry errors corrected. Data from families of



**Table 1.** *Child, parent-carer and family characteristics (n=475)*

			Mean (SD) or %
Child	Age		10.4 (4.3)
	Sex	Male	66.7
		Female	33.3
	Impairment Type	Intellectual disability	26.3
		Autism spectrum disorder*	38.3
		Cerebral Palsy	12.4
		Other	22.9
	Disability (functional limitations)	Mild	34.7
		Moderate	35.8
Severe		29.5	
Parent	Age		42.0 (7.9)
	Sex	Male	12.2
		Female	87.8
	Language spoken at home	English	96
	Highest educational attainment	Did not complete high school	9.1
		High school graduate	17.9
		Diploma/trade certificate	38.9
		University undergraduate	25.3
		University postgraduate	8.8
Family	Residence	Urban	81
		Rural	19
	Family type	Lone Parent	22.6
		Couple, single-earner	36.3
		Couple, dual-earner	41.1
	Total household income	< \$40,000	26.4
		\$40,000 - \$69,000	20.6
		\$70,000 - \$89,000	19.0
		\$90,000 +	33.9
	Total number of Children (<18 years)		

\*with or without intellectual disability

children under four years of age, for whom no data on behaviour problems were collected, were then excluded. After cleaning the data, a descriptive, demographic profile of participants was generated, and a composite measure of child behaviour problems was created by taking the mean raw DBC-24 item score. Excluding items comprising the DBC-24, Bayesian estimation (utilizing the Markov chain Monte Carlo algorithm) was employed to replace

missing values with predicted values, and transform ordered-categorical data into numeric data. The Bayesian approach solves the problem of incomplete data through an iterative and progressive process, utilizing what is known and what is learned, to replace missing values with best estimates (Arbuckle, 2010; Chen, Shao, & Ibrahim, 2000, Jackman, 2000; Shafer & Hall, 2010). Confirmatory factor analysis was then employed to develop and



**Table 2.** Zero-order correlation matrix

		1	2	3	4	5	6	7	8	9
1	FL Congruence									
2	GF Functioning	.69*								
3	Social support	.74*	.58*							
4	Financial hardship	-.39*	-.31*	-.46*						
5	Child age	-.02	-.04	-.03	-.04					
6	Child disability	-.24*	-.10*	-.15*	.09*	.04				
7	DBC behaviour problems	-.33*	-.26*	-.32*	.24*	-.16*	.13*			
8	Autism spectrum (ASD)#	-.15*	-.08	-.13*	.06	-.11*	-.02	.31*		
9	Intellectual disability#	-.08	-.02	-.01	-.08	.27*	.39*	.03	-.13*	
10	Cerebral palsy#	.06	.08	.06	-.04	.11*	.22*	-.26*	-.27*	.06

# dichotomous; \* $p < .05$

validate measures (i.e., demonstrating convergent and discriminant validity) of each latent construct: child disability, financial hardship, social support/integration, general family functioning and family life congruence. The overall fit of the CFA model was assessed using multiple indices, including the  $\chi^2$  value divided by its degrees of freedom (*CMIN/DF < 3 is good*); the Comparative Fit Index (*CFI > .95 is good*); and, the 90% confidence interval around the root mean square error of approximation (*RMSEA90*), which ought to contain a values less than 0.06 to indicate the possibility of close model fit (Schreiber, Nora, Stage, Barlow & King, 2006). Regression-based composite scores (i.e., factor scores) were then derived for each latent variable, and these were used in the proceeding analyses.

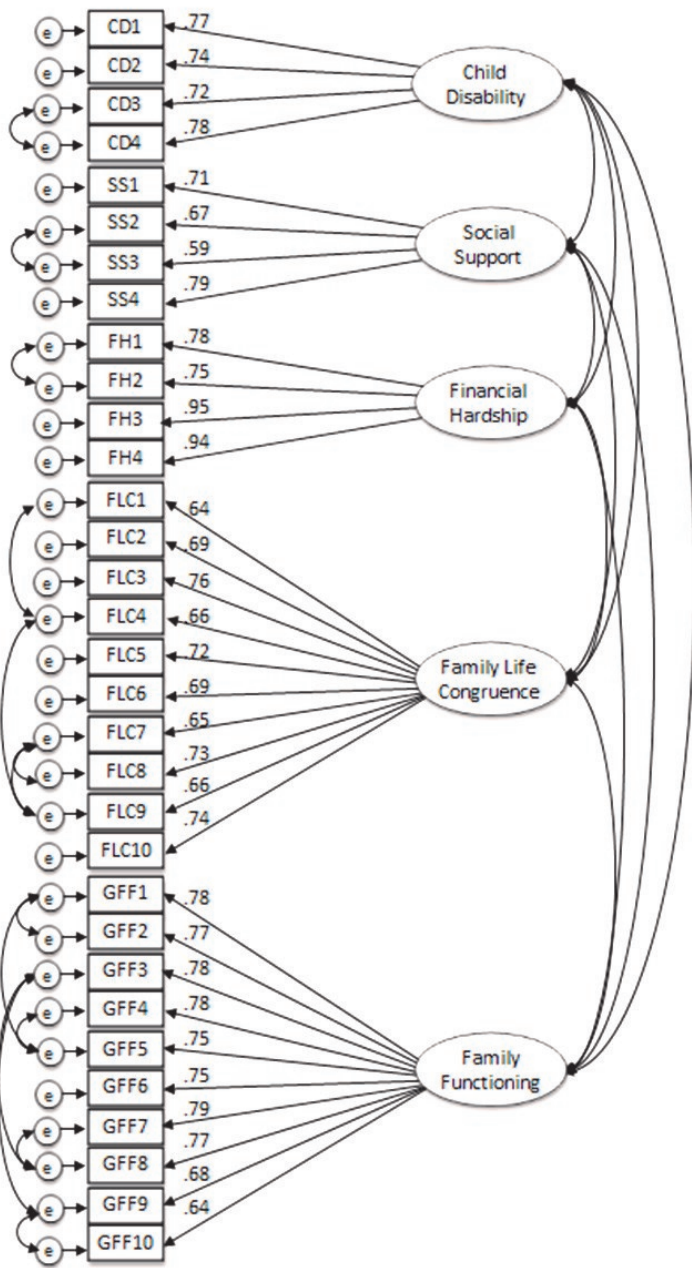
The next step involved the computation of a zero-order correlation matrix, and the use of graphs to explore the relationship between child behaviour problems and family life congruence under varying social-ecological conditions. For the purposes of this analysis, child behaviour problems, social support, and financial hardship scores were re-coded: Scores

below the 25<sup>th</sup> percentile were re-coded as 'low = 0' (e.g., low behaviour problems), scores in the mid range were coded as 'moderate = 1', and scores above the 75<sup>th</sup> percentile were re-coded as 'high=2' (e.g., high social support). After graphing this data, path analysis (i.e., structural equation modeling with observed or composite variables) was employed to investigate the 'effects' of child-specific, within-family and social-ecological factors on family life congruence.

## RESULTS

A total of 538 parents (41%) accepted the invitation to take part in the study and completed the Family Life Survey. Of these, 475 were caring for a child with disability between the ages of four and eighteen. Demographic data on these 475 families are presented in Table 1. The data shows that these families were diverse with respect to socioeconomic factors, household composition and place of residence (urban/rural), child age and diagnosed condition. The majority of respondents were mothers, and most were caring for a child with an autism spectrum disorder and/or intellectual disability.

**Figure 1.** Latent factors with items loadings



Model Fit Indices:  $\chi^2 = 926.03$ ,  $DF = 440$ ,  $p < .05$ ,  
 CMIN/DF = 2.105, CFI = .95, TLI = .94, RMSEA90 = .044 - .053

**General family functioning and family life congruence: convergent and discriminant validity**

The five factor CFA model shown in Figure 1 fit the data well, as evidenced by the fit indices. This, together with the moderate to high path coefficients for all items (i.e., latent factor loadings), provides

evidence of convergent validity. The discriminant validity of the general family functioning and family life congruence factors was assessed by comparing the fit of the five factor model to the fit of a four factor model, that is by constraining the variance of both of these factors and the covariance between them, to be equal to one. The five factor model provided a significantly better fit to the data ( $\chi^2$  difference = 711.6,  $p < .001$ ), suggesting that general family functioning and family life congruence are discrete, albeit inter-related constructs.

**Correlations between study variables**

A statistically significant negative correlation was found between child behaviour problems and family life congruence (see Table 2). Higher levels of child behaviour problems were also associated with higher levels of financial hardship, and lower levels of both social support and general family functioning. Notably, families of children with an ASD typically reported lower levels of family life congruence than families of children with other conditions. However, this relationship might be explained by the higher levels of child behaviour problems observed in this group. Looking into this possibility, we examined the relationship between ASD and family life congruence under varying conditions of child behaviour problems. Figure 2 shows that the relationship is conditional, that is, upon the presence of high child behaviour problems: When child behaviour problems are reportedly low, there is no association between ASD and family life congruence.

**Effect of child behaviour problems under varying social-ecological conditions**

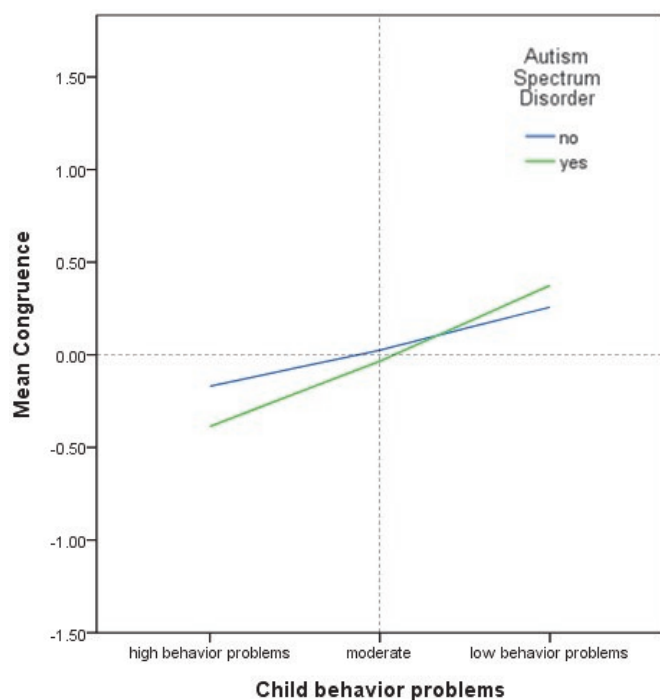
The relationship between child behaviour problems and family life congruence is graphically displayed in Figure 3. This graph shows the mean family life congruence score (with 95% CI) for each of three groups differentiated by child behaviour problems: low, moderate, high. [Table 3 presents a behaviour profile for children in high and low behaviour

**Table 3.** Behaviour profile\*: low and high behaviour problem groups

	"Very true or often true"	
	Low (n=112)	High (n= 111)
This child laughs or giggles for no obvious reason.	3.5%	63.1%
This child repeats the same word or phrase over and over.	1.8%	47.1%
This child smells, tastes, or licks objects.	0.0%	40.4%
This child switches lights on and off, pours water over and over.	1.8%	48.6%
This child wanders aimlessly.	0.0%	38.5%
This child is jealous.	0.9%	23.4%
This child is stubborn, disobedient, or uncooperative.	0.0%	48.6%
This child is impatient.	8.0%	79.3%
This child kicks, hits others.	0.9%	32.4%
This child becomes overexcited.	5.3%	76.6%

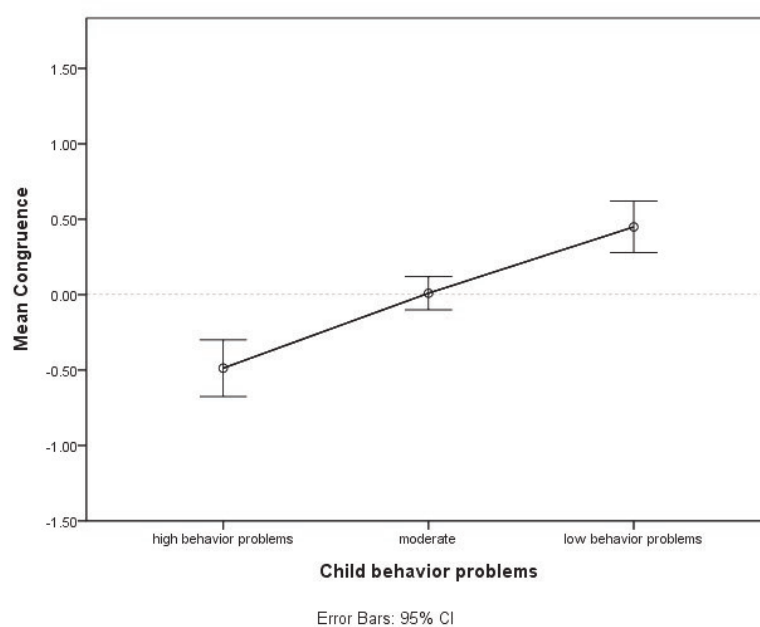
\*selected items from the DBC-24

**Figure 2.** Relationship between ASD, child behaviour problems and family life congruence



problem groups based on the proportion of parent-carers who responded "very true or often true" to a sample of DBC-24 items]. The graph shows that families of disabled children with high behaviour

**Figure 3.** Relationship between child behaviour problems and family life congruence



problem scores typically had below average family life congruence, and families of disabled children with low behaviour problem scores typically had above average family life congruence.

Figures 4 and 5 present line graphs showing the relationship between child behaviour problems (low, moderate and high) and family life congruence under varying social-ecological conditions. The horizontal reference line corresponds to the sample mean. These data show that—*irrespective of the level of child behaviour problems*—(a) families typically do better under conditions of high social support and low financial hardship; and, (b) families fare relatively poorly under conditions of low social support and/or high financial hardship. Tellingly, while 36 of the 111 families in the high behaviour problems group reported above average family life congruence (and might be described as resilient), only 2 of 111 did so when they reported high behaviour problems, low social support and high financial hardship.

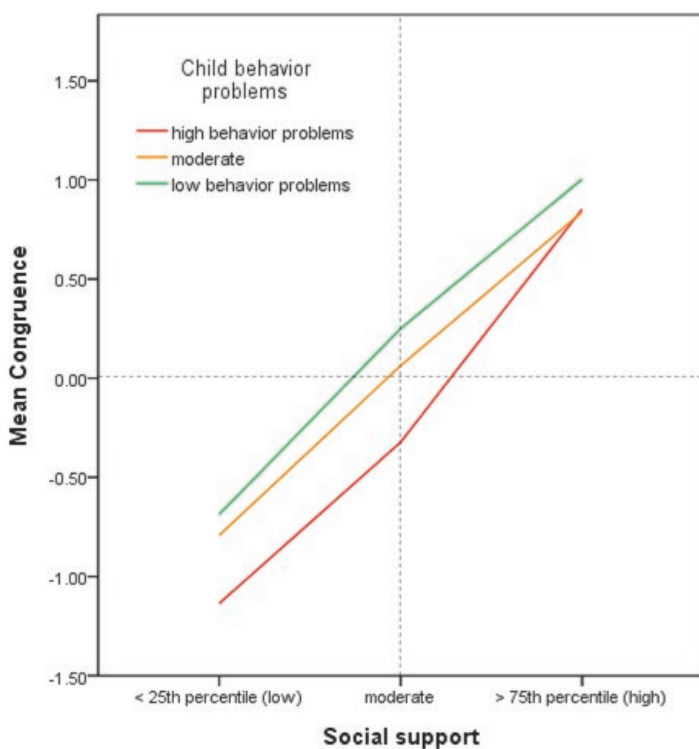
A new scale/variable, ‘cumulative advantage’, was created to examine the additive effect of low child behaviour problems, high social support, and low

financial hardship on family life congruence by simply summing the recoded (and where necessary, reverse scored) scores. Cumulative advantage scores could therefore range from 0 to 6. To obtain a score of 6, indicating maximal advantage, a family had to have child behaviour problem and financial hardship scores below the 25<sup>th</sup> percentile, and a social support score above the 75<sup>th</sup> percentile. The relationship between cumulative advantage and family life congruence is graphically displayed in Figure 6.

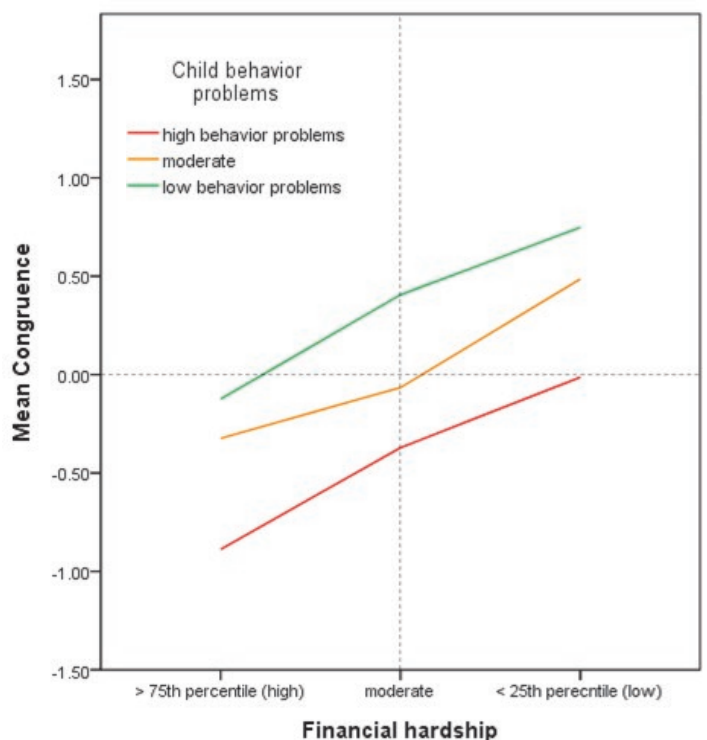
### ***Social-ecological factors as ‘mediators’***

To investigate the direct, indirect and total effects of child-specific, within-family and social-ecological factors on family life congruence, the path model shown in Figure 7 was tested. The model accounted for a substantial 68% (95%CI for  $R^2 = .63 - .72$ ) of the variance in family life congruence. Direct, indirect and total effects are reported in Table 4.

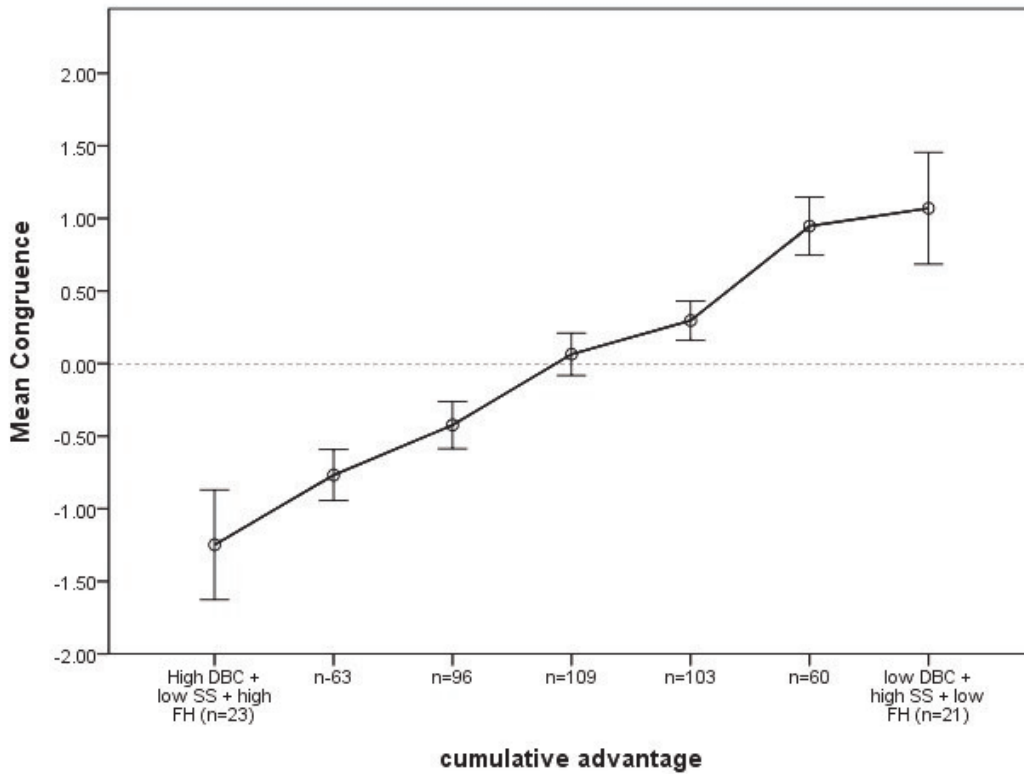
**Figure 4.** *Child behaviour problems, social support and family life congruence*



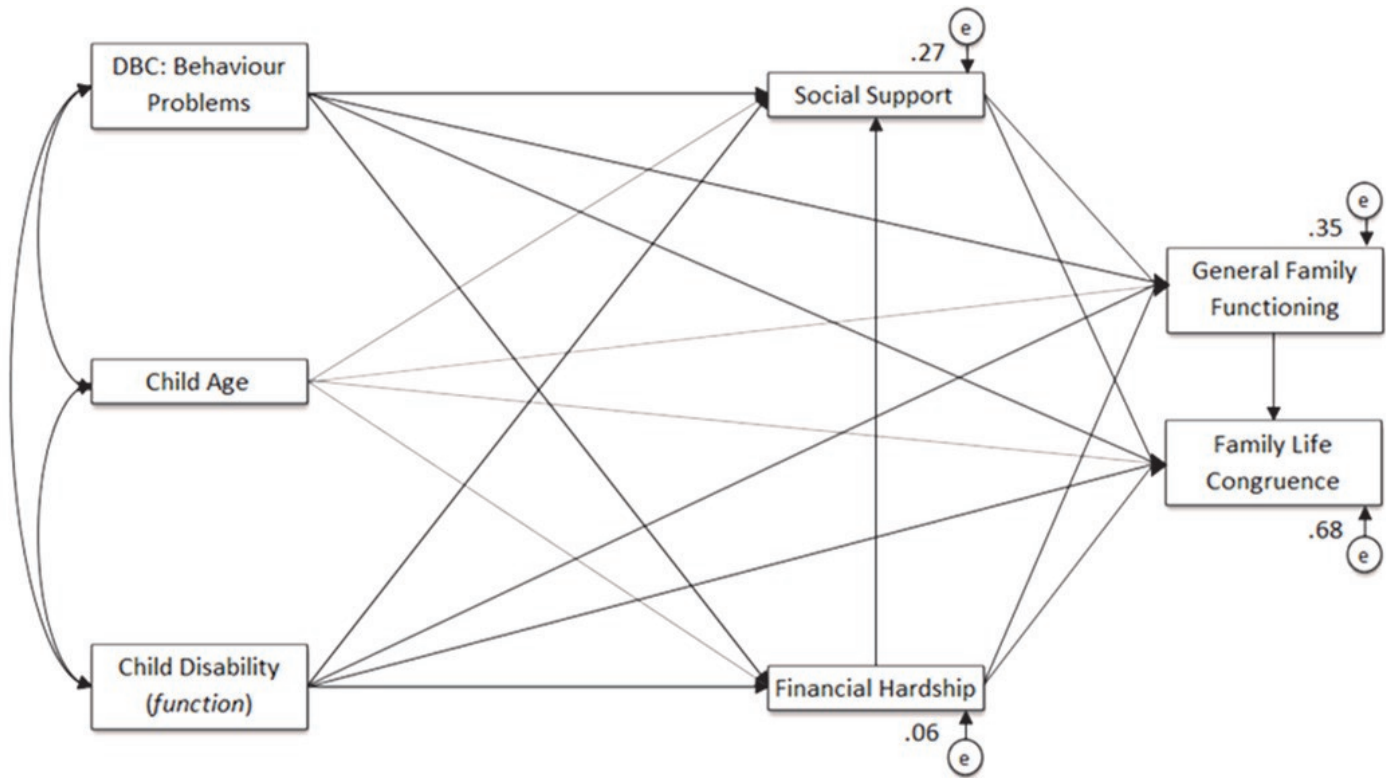
**Figure 5.** *Child behaviour problems, financial hardship and family life congruence*



**Figure 6.** Cumulative advantage and family life congruence



**Figure 7.** Path model: direct and indirect effects of child-specific and social-ecological factors



Error Bars: 95% CI



**Table 4.** Standardized direct, indirect and total effects with bootstrap standard errors

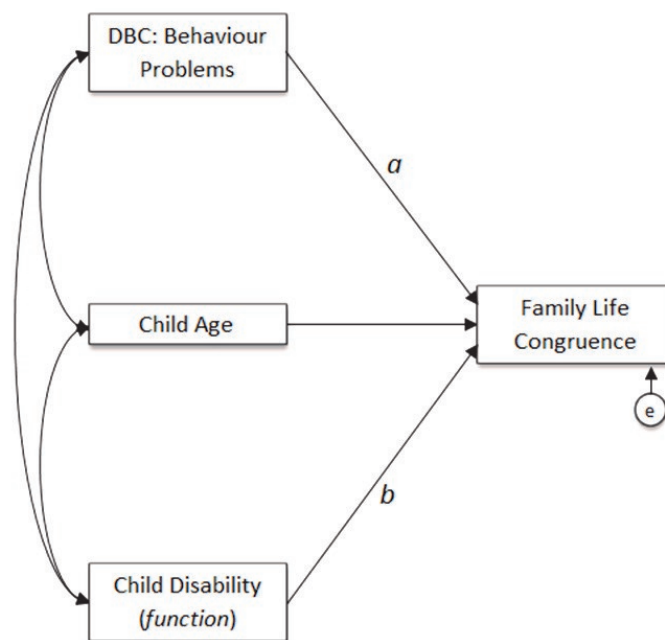
Measures		Effects Decomposition		
Predictor ->	Criterion	Direct (SE)	Indirect (SE)	Total (SE)
Family functioning	FL Congruence	.38 (.04)*		.38 (.04)*
Social support	FL Congruence	.47 (.04)*	.20 (.02)*	.67 (.03)*
	Family Functioning	.53 (.04)*		.53 (.04)*
Financial hardship	FL Congruence	-.03 (.03)	-.29 (.03)*	-.32 (.05)*
	Family Functioning	-.05 (.04)	-.21 (.03)*	-.26 (.05)*
	Social Support	-.40 (.04)*		-.40 (.04)*
Behaviour problems	FL Congruence	-.06 (.03)*	-.26 (.04)*	-.31 (.05)*
	Family Functioning	-.09 (.05)	-.18 (.03)*	-.27 (.05)*
	Social Support	-.22 (.04)*	-.09 (.02)*	-.31 (.05)*
	Financial Hardship	.24 (.04)*		.24 (.04)*
Disability (functioning)	FL Congruence	-.12 (.03)*	-.08 (.03)*	-.20 (.05)*
	Family Functioning	-.01 (.04)	-.06 (.02)*	-.07 (.05)
	Social Support	-.08 (.04)	-.03 (.02)	-.11 (.04)*
	Financial Hardship	.06 (.04)		.06 (.04)
Child age	FL Congruence	.01 (.03)	-.06 (.03)*	-.06 (.04)
	Family Functioning	-.04 (.04)	-.04 (.02)	-.08 (.05)
	Social Support	-.08 (.04)	.00 (.02)	-.07 (.04)
	Financial Hardship	-.01 (.05)		-.01 (.05)

\*p < .05.

These data suggest that social support contributed the most to family life congruence: Social support had a substantial direct effect on family life congruence, controlling for all other variables in the model. General family functioning and financial hardship also contributed to family life congruence, although the effect of financial hardship was all but fully mediated by social support.

In addition, the data show that, controlling for child age and disability severity, child behaviour problems had significant direct effects on social support and financial hardship, and significant indirect effects on general family functioning and family life congruence. The effect of child behaviour problems on family life congruence was almost fully mediated by social support and general family functioning. Notably, disability (i.e., child functioning) also had a modest but significant effect on family life congruence over and above the effect of child behaviour problems.

**Figure 8.** Path model: Moderating effects of social support and financial hardship



**Table 5.** Multi-group moderation tests: standardised regression weights (bootstrap SE)

Path#	Condition			Critical ratios	
	Low SS	Moderate SS	High SS	Sig.	
a	DBC -> FLC	-.28 (.10)*	-.24 (.07)*	-.03 (.08)	ns
	Age -> FLC	-.01 (.10)	-.12 (.05)*	.02 (.10)	
b	Disability -> FLC	-.15 (.07)	-.18 (.07)*	-.24 (.09)*	ns
	High FH	Moderate FH	Low FH		
a	DBC -> FLC	-.27 (.10)*	-.30 (.07)*	-.17 (.10)	ns
	Age -> FLC	-.02 (.10)	-.10 (.06)*	-.02 (.08)	
b	Disability -> FLC	-.27 (.08)*	-.19 (.07)*	-.11 (.12)	ns

\*p<.05, ns =not statistically significant

### ***Social-ecological factors as ‘moderators’***

To test the hypothesis that social-ecological factors moderate the relationship between child behaviour problems and family life congruence we conducted multi-group moderation tests. Specifically, for each of the paths shown in Figure 8, we computed the regression coefficients for the low, moderate and high social support and financial hardship groups, and the critical ratios for pairwise parameter comparisons. The standardized regression weights, presented in Table 5, suggest that child behaviour problems contribute more to family life congruence under conditions of low social support and high financial hardship by comparison with high social support and low financial hardship conditions.

Indeed, under the conditions of high social support and low financial hardship, no statistically significant association was found between child behaviour problems and family life congruence. However, although the critical ratios for pair wise parameter comparisons approached 1.96, no critical ratio exceeded this threshold for statistical significance.

### **DISCUSSION**

Child behaviour problems have been linked to poorer maternal and family wellbeing in a considerable number of studies. Some studies suggest that child behaviour problems may fully or almost fully account for the increased risk of negative psychological conditions observed in mother-carers (e.g. Baker et al., 2002; Eisenhower et al., 2009; Gray et al., 2011; Herring et al., 2006). However, the mechanisms or pathways via which child behaviour problems impact family life have received scant research attention. In this study, we found that the relationship between child behaviour problems and family life congruence was mostly indirect, and mediated by social-ecological conditions. In short, higher levels of child behaviour problems were associated with higher financial hardship and lower social support, and these were in turn associated with lower family life congruence. However, we also found that child behaviour problems were not a reliable proxy for social support or financial hardship. Indeed, Figure 7 shows that behaviour problems, disability and child age together accounted for only a small amount of the variance in these social-ecological factors.

Our principal hypothesis was that families bringing up disabled children with behaviour problems would 'do well' under conditions of high social support and low financial hardship. In other words, we hypothesised that resilience is context-bound. This hypothesis was well supported: We found that families with high levels of social support and/or low levels of financial hardship typically enjoyed average or above average levels of family life congruence, even when the number and intensity of child behaviour problems was high. Indeed, we found that while one in three families raising disabled children with high behaviour problems reported above average family life congruence, in the absence of high social support and low financial hardship this figure was closer to one in one hundred. We also found that families with low levels of social support and high levels of financial hardship typically struggled—with lower than average family life congruence—even when the number or intensity of behaviour problems was low.

Of all the variables included in the path model (Figure 7), social support/integration emerged as the single strongest predictor of family life congruence. It is intriguing to consider that parent-carer responses to four simple questions concerning their social relationships can be indicative of how well the family is doing. Paraphrasing, these are (1) How much concern or interest do people show in how you and your family are doing? (2) As a family, do you feel a strong sense of belonging to your community? (3) How easy is it to get practical help from your neighbours if you or your family should need it? And (4) How many people can you and your family count on for support to deal with a serious personal or family problem? Of course, the data from this study will be unsurprising to researchers in other fields who, over the last three decades, have found that measures of maternal social support and integration are associated with a wide range of outcomes. These include but are not limited to pre and post-natal depression (Collins, Dunkel-Schetter, Lo-

bel & Scrimshaw, 1993; Cutrona & Troutman, 1986); foetal growth and birth weight (Feldman, Dunkel-Schetter, Sandman & Wadhwa, 2000); parenting stress and sense of competence (Adamakos et al., 1986); maternal warmth and responsiveness (Burchinal, Follmer & Bryant, 1996; Crnic, Greenberg, Ragozin, Robinson & Basham, 1983; Pascoe, Loda, Jeffries & Earp, 1981); risk of child abuse and neglect (Bishop & Leadbeater, 1999; Garbarino & Crouter, 1978; Kotch, Browne, Dufort, Winsor, & Catellier, 1999; Wandersman & Nation, 1998); and, child cognitive, emotional and social development (Melson, Ladd & Hsu, 1993; Pianta & Ball, 1993; Sameroff, Seifer, Baldwin & Baldwin, 1993).

Overall, the study findings support a social-ecological approach to understanding and building resilience: if a family has reasonably good social-ecological resources, outcomes are likely to be good even in the context of severe stressors. This basic insight has far-reaching implications for policy and practice. One implication is that, in general, policies and programs designed to improve social-ecological conditions (e.g., ameliorate financial hardship and promote social integration) will logically have a greater impact on family-level outcomes than policies and programs that focus on remedying disability or modifying child behaviours. However, policies and programs to improve social-ecological conditions may not be equally effective for all. For example, a small number of families may need to adjust their expectations, or need professional assistance to develop positive coping repertoires, that is before they can fully benefit from any increase in social-ecological resources. Further research is needed to determine who will benefit from which kinds of supports and services, when and under what circumstances.

To create more favorable social-ecological conditions for families raising children with disabilities a number of strategies might be considered. One such strategy, and arguably the most common practice at this point, is to equip parents with skills for effec-

tively managing child behaviour problems. The findings from this study however suggest that even if child behaviour problems are eliminated, families will likely struggle if the social-ecological conditions in which they live remain unfavorable (see figures 4 and 5). A more promising strategy may be to remove barriers to parent-carer workforce participation. Facilitating parent-carer workforce participation may not only increase household income, but also reduce social isolation and, assuming that the work is meaningful, enhance psychological wellbeing (Freedman et al., 1995; Shearn & Todd, 2000; Warfield, 2001). This may involve increasing the availability of affordable, high quality, inclusive child care and, legislating reasonable workplace accommodations (e.g., more flexible work hours). In addition, the social-ecological conditions in which families live could potentially be improved by making the service system easier (i.e., less time consuming) to navigate. This would include the development and implementation of policy that gives parent-carers greater control and/or flexibility with respect to how any funds they receive for disability related family supports and services are spent. Overall, carefully listening to the barriers that parents voice in accessing services could facilitate the creation of a more user-friendly provision of services to families with disability. Another potential strategy that disability and other human service providers might consider is creating opportunities for parents to come together and support one another. There is some evidence that parent-to-parent groups can reduce social isolation and empower parents with useful information and ideas (Boyd, 2002; Ekas et al., 2010; Kerr & McIntosh, 2000). Intentionally creating opportunities for parent-to-parent support could be an effective and relatively simple strategy to improve family life congruence. In sum, policies and programs aimed at creating a positive social-ecological environment for families of children with disability, including enhancing labour-force opportunities for parent-carers,

accessible and inclusive child care options, a more user-friendly and client-centered service system, and more opportunities for support between families raising children with disabilities could arguably enhance family life congruence in substantial ways, enabling all family members to thrive.

### ***Study limitations***

The recruitment of a robust sample of families raising children with disabilities in Alberta, Canada, is one of the strengths of this study. However, volunteer bias warrants caution with respect to the generalisation of the study findings. The participation rate of 41% is reasonable vis a vis other survey studies. However, we do not know if the participants were different from non-participants in any systematic way/s. Another limitation of this study is that the data are correlational. Consequently, directionality can only be inferred from theory. For example, the path model presented in Figure 7 infers that child behaviour problems 'cause' unfavorable social-ecological conditions and poorer family functioning, but the relationship between these variables is most likely bi-directional (Hastings & Beck, 2004; Lecavalier, Leone & Wiltz, 2006; Olsson, 2008). With future waves of data collection, we will be able to test the hypothesis of bidirectional influence.

Another limitation of this study is that it relied on just one informant, the primary parent-carer, for information about the family. Other family members may have differing views. Understanding their views is an important and to date, a somewhat neglected task. However, relying on the primary parent-carer, who is usually the mother, for information about family life is justifiable on several grounds. As Voysey Paun (2006) observed, the primary parent-carer is usually at the centre of family life: orchestrating the everyday routine to accommodate the needs, interests and activities of all family members. Therefore, the primary parent-carer has a unique vantage point, or special insight into

family life. Furthermore, as the person who is typically most instrumental in creating and sustaining the daily routine, her/his view arguably exerts the greatest 'force': the perspective of the primary parent-carer is the 'primary mover' with respect to the everyday family routine. This situation may change as fathers 'step up', but mothers continue to bare the lion's share of the domestic and child care workload, despite their increased participation in the workforce (Cohen & Petrescu-Prahova, 2006; Gordon et al., 2007; Scott, 2010; Shearn & Todd, 2000; Warfield, 2001). Therefore, the mother's or primary parent-carer's view is arguably the most important with respect to predicting what the future may hold for the family.

### ***Conclusion***

Ungar (2011) has argued that resilience has more to do with the availability and accessibility of culturally relevant resources than individual or intrinsic factors. The findings from this study are consistent with this view. The data suggest that there is a need to broaden or rather balance the research and policy agenda, that is to give due consideration to the social-ecological context in which families raising children with disabilities live. A more balanced agenda will address the social and cultural determinants of family life congruence (along with child-specific and within-family factors), including but not limited to policies and processes that create inequity and exclude families raising children with disabilities.



## APPENDIX C Latent constructs and their manifest variables

Key		Scale#
<b>Child Disability (CD)</b>		
CD1	To what extent does a long-term physical condition, mental condition, learning or health problem reduce the amount or the kind of (age-appropriate) activities this child can do? [not at all = 1, great deal = 5]	1 - 5
CD2	Compared with other children his/her age, does this child have any difficulty with speaking? [no difficulty = 1, a lot of difficulty = 3]	1 - 3
CD3	Compared with other children his/her age, does this child have any difficulty with learning? [no difficulty = 1, a lot of difficulty = 3]	1 - 3
CD4	Compared with other children his/her age, does this child have any difficulty with personal care activities ...? [no difficulty = 1, a lot of difficulty = 3]	1 - 3
<b>Financial hardship (FH)</b>		
FH1	Thinking back over the past three months, how much difficulty have you had paying your bills? [no difficulty = 1, a great deal = 5]	1 - 5
FH2	Thinking again over the past three months, generally, at the end of each month did you end up with ...? [more than enough money left = 1, very short of money = 5]	1 - 5
FH3	In the next three months, how often do you think that you and your family will experience bad times such as poor housing or not having enough food? [almost never = 1, almost always = 5]	1 - 5
FH4	In the next three months, how often do you expect that you will have to do without the basic things that your family needs? [almost never = 1, almost always = 5]	1 - 5
<b>Social support (SS)</b>		
SS1	How easy is it to get practical help from your neighbours if you or your family should need it? [very difficult = 1, very easy = 5]	1 - 5
SS2	How much concern or interest do people show in how you and your family are doing? [no concern = 1, a lot of concern = 5]	1 - 5
SS3	How many people are so close to you that you can count on them if you have a serious personal or family problem? [0 = 0, 4 = 10 +]	1 - 5
SS4	As a family we feel a strong sense of belonging in our community... [strongly disagree = 1, strongly agree = 4]	1 - 4

*#before transformation*

Key		Scale#
<b>Family Life Congruence (FLC)</b> [strongly disagree =1, strongly agree = 4]		
FLC1	We are able to do things together that are important to us.	1 - 4
FLC2	We are always on edge wondering "what next"? (r)	1 - 4
FLC3	We exist: any hopes or dreams we had now seem out of reach (r)	1 - 4
FLC4	I am creating the life I want for my children.	1 - 4
FLC5	We are trapped by our daily routine (r)	1 - 4
FLC6	I feel trapped by my duties as a parent and caregiver (r)	1 - 4
FLC7	I often worry that I do not spend enough quality time with my other children (r)	1 - 4
FLC8	I often worry that my other children are missing out (r)	1 - 4
FLC9	Our family routine revolves around our child with disabilities (r)	1 - 4
FLC10	Overall, we are able to balance the needs and wants of each family member.	1 - 4
<b>General Family Functioning (GFF)</b> [strongly disagree =1, strongly agree = 4]		
GFF1	We confide in each other.	1 - 4
GFF2	In times of crisis we can turn to each other for support	1 - 4
GFF3	We express feelings to each other.	1 - 4
GFF4	There are lots of bad feelings in our family (r)	1 - 4
GFF5	We don't get along well together (r)	1 - 4
GFF6	Planning family activities is difficult because we misunderstand each other (r)	1 - 4
GFF7	We cannot talk to each other about the sadness we feel (r)	1 - 4
GFF8	We avoid discussing our fears or concerns (r)	1 - 4
GFF9	Making decisions is a problem for our family (r)	1 - 4
GFF10	We are able to make decisions about how to solve problems.	1 - 4

#before transformation  
(r) = reverse scored

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## 6

### **Recruiting Parents as Interventionists: Parent Adherence and Adverse Effects**

**Purpose:** The purpose of this study was to investigate parent implementation of home based therapy regimens, and the relationship between parent implementation and family-level outcomes.

**Method:** A stratified (by child age group) random sample of 538 families raising children with disabilities in Alberta, Canada took part. Participants completed the Family Life Survey, which incorporated child and family measures, and items tapping parent implementation of home based therapy regimens.

**Results:** Parents are more likely to implement therapeutic regimens when these are 'enfolded' into daily activities and routines. If parents have to 'find a slot' in the daily routine to implement therapy they will sacrifice personal leisure, participation in paid work, and time spent with other family members to do so. This may create an imbalance that ultimately undermines family wellbeing.

**Conclusion:** As a general rule, children do well when their families do well. And families do well when they have the resources they need to juggle work and family and care demands. Recruiting parents as interventionists can tax family resources. So, in the interests of both the child and family, health professionals must weigh the pros and cons of parent mediated intervention, and consider ways in which 'therapy' could be enfolded into the everyday family routine.



The potential benefits of parent mediated intervention for children with disabilities are well documented. However, in the face of multiple, changing and competing demands, parents may struggle to “find a slot” in their daily routine to implement home therapy regimens (Bernheimer & Weisner, 2007; Crettenden, 2008; Leiter, Krauss, Anderson & Wells, 2004; Leiter, 2004; McCann, Bull & Winzenberg, 2012). Further, there is data suggesting that the recruitment of parents as interventionists may have adverse effects. The additional demands placed on parents may heighten stress and undermine family wellbeing. In this study we surveyed parents to investigate parent implementation of home based therapy regimens, and the relationship between implementation and family wellbeing.

## BACKGROUND

Child learning and development is driven and shaped by the continuous, dynamic and dialectical interplay of biology with experience (Sameroff, 2010; Shonkoff, 2010). This developmental drama plays out in the ordinary, planned and unplanned, adult-directed and child-initiated activities that comprise the architecture of everyday child and family life (Dunst, 2007; Weisner, 2002; Weisner, Matheson, Coots & Bernheimer, 2005). In the context of ordinary, everyday activity settings (i.e., natural learning environments) such as meal times, bath times, play dates, domestic chores, and bed time rituals, children interact with others and their physical surroundings in situation-specific, functional and adaptive ways. Through such situated interactions children acquire a sense of self and social identity, learn to regulate their emotions and behaviour, and develop culturally meaningful competences and adaptive skills that, in turn, enable participation in other development-enhancing activities (Dunst, 2007; Dunst, Bruder, Trivette & Hamby, 2006; Miller & Goodnow, 1995; Weisner, 1998, 2009).

As the ‘architects’ of everyday family life, parents are usually the primary agents—although certainly not the only agents—in their child’s early learning and development. Parents select, create, structure, and adapt activity settings for their children based on their individual and shared beliefs, values and goals and their material, social and cultural resources (Weisner, 2002). Material resources include time, energy, money, and community infrastructure (e.g., parks, playgrounds, recreation centres, early childhood services). Social resources include those people who parents can turn to (e.g., family, friends and neighbours) for information or advice, emotional support and validation, and/or practical-tangible aid such as help with child care and domestic workloads. Cultural resources include *organized sets of ideas* (i.e., cultural models or ethnotheories), including but not limited to ideas about childrearing and family life (Goodnow, 1996; Skinner & Weisner, 2007; Super & Harkness, 1986; Worthman, 2010); and, *repertoires of deployable meanings and competences* that we use to make sense of the events and circumstances of our lives, and to construct *strategies of action* (Swidler, 1986).

The cultural, material, and social resources available to parents of children with disabilities are often limited. Most parents rarely have experiences of disability prior to the birth or diagnosis of their child (Ryan & Runswick-Cole, 2008). Encountering disability, perhaps for the first time, parents may wonder whether or to what extent ‘old rules, recipes and roadmaps’ apply (i.e., cultural resources for raising a ‘typical’ child). Parents may, for example, wonder whether routine methods of child care are appropriate; be unsure of how to allocate existing family resources, or of what sacrifices should be made and by whom; be uncertain what behaviour to expect from their child at home or in public places; and, they may have limited knowledge of how best to promote their child’s participation in everyday activities, and in turn, enhance their child’s learning and

development (Voysey Paun, 2006). Greenspan (1998) summed up the situation as 'parenting without a developmental map'.

### ***Early (and later) intervention***

Health professionals, such as occupational, speech and physical therapists, can help compensate for this lack in cultural resources and promote a child's participation in everyday activities in a variety of ways. One way is by working directly with the child, either in the clinic and/or in the home, school or community to reduce impairment and remedy skill deficits. Interventions may be delivered directly by a health professional and/or by a trained assistant or aide. There is evidence that such direct intervention can have positive effects on child learning and development, particularly in the early years, although the evidence is mixed (Bailey, Hebbeler, Spiker, Scarborough, Mallik & Nelson, 2005; Guralnick, 2005; Blauw-Hospers & Hadders-Algra, 2005; Orton, Spittle, Doyle, Anderson & Boyd, 2009). However, there is also evidence suggesting that direct delivery of interventions in the home at least can have unintended adverse effects, including heightened parent-carer stress (Dunst, Bruder, Trivette & Hamby, 2006; Dunst, Hamby & Brookfield, 2007).

Alternatively, or in addition to direct intervention, health professionals may enlist parents as interventionists. This is a cost-effective strategy, that is, for government and/or insurance companies; and, the increased 'dose' of intervention may translate into better child outcomes. Positive effects from parent-mediated interventions have been documented in a variety of areas including but not limited to promoting the social and communication skills of children with autism, and improving the upper limb functioning of children with cerebral palsy (Kasari, Gulsrud, Wong, Kwon & Locke, 2010; Ketelaar, Vermeer, Helders & Hart, 1998; Novak, Cusik & Lannin, 2009; Ozonoff & Cathcart, 1998; McConachie & Diggle, 2007; Meadan, Ostrosky, Zaghawan & Yu, 2009;

Tang, Lin, Lin, Chen, Tsai & Chang, 2011). Enlisting parents as interventionists however also may have some unforeseen negative consequences. If interventions are not contextualized, that is enfolded into the everyday family routine, parents have to release time, usually by sacrificing work or leisure, or by cutting back on family time or on the activities of other family members (Brandon, 2007; Brotherson & Goldstein, 1992; Bernheimer & Weisner, 2007; Carnevale, Rehm, Kirk & McKeever, 2008; Crettenden, 2008; Leiter, 2004; Leiter, Krauss, Anderson & Wells, 2004).

There is mounting evidence that time pressure, and time spent providing health care, including implementing therapeutic interventions, is associated with heightened parent-carer stress and mental health problems (Breen, 2009; McManus, Carle, Acevedo-Garcia, Ganz, Hauser-Cram & McCormick, 2011; Neely-Barnes & Marcenko, 2004; Plant & Sanders, 2007; Sawyer, Bittman, Greca, Crettenden, Borojevic, Raghavendra & Russo, 2011; Sawyer, Bittman, Greca, Crettenden, Harchak & Martin, 2010; Trudgeon & Carr, 2007; Rone-Adams, Stern & Walker, 2004; Schwichtenberg & Poehlmann, 2007). For example, in Australia, Sawyer et al. (2011) collected time-use and mental health data from 156 mothers of children with cerebral palsy and found a significant positive association between time devoted to care-work and maternal mental health problems, including depressive symptoms. In another study involving 216 mothers of children with autism, Sawyer et al. (2010) found that it was the experience of time pressure rather than hours of caregiving that predicted maternal mental health problems.

### ***Parents as interventionists***

Enlisting parent participation in the implementation of therapy/rehabilitation is a long-standing practice, and perceived parental 'non-adherence' with home programs and therapy regimens is a long-standing

and seemingly intractable ‘problem’ (Law and King, 1993; Rone-Adams, et al., 2004; Tetreault, Parrot & Trahan, 2003; Wiart, Ray, Darrah & Magill-Evans, 2010). Despite the emergence and spread of family-centered practice/s—including the practice of involving parents in the process of designing interventions for their children—it appears that many parents struggle to find a slot in their daily routine for implementing home based programs. Typically, families implement some but not all components of an intervention, and/or they implement these some, but not all of the time (Law & King, 1993; Rone-Adams, et al., 2004). Reported rates of parent implementation are wide ranging, depending on the population studied and the nature of the intervention. At the high end of the spectrum, Law and King (1993) found that two-thirds of the parents of children with cerebral palsy involved in a trial were able to complete all or some of the prescribed activities more than 75% of the time.

A small but growing number of studies have investigated factors influencing parent implementation of home therapy regimens. To date, most studies have been exploratory and descriptive: Research has been guided by theory, but rarely have explicit theoretical propositions been tested. One theory that has guided research on this topic is ecocultural (ecological + cultural) theory (Gallimore, Goldenberg & Weisner, 1993; Gallimore, Bernheimer & Weisner, 1999; Weisner et al., 2005). This theory offers a framework for understanding how parents allocate resources including, for example, whether and how much time and energy is allotted to implementing therapy regimens. A core premise of ecocultural theory is that all families face the same central adaptive challenge, that is sustaining a daily routine, given available resources, that is congruent (or fitting) with their beliefs, values and goals; and, the needs, interests and competences of individual family members. A second core premise is that everyday family life is culturally patterned: families uti-

lize cultural resources (i.e., consciously and pre-consciously) to make sense of the events and circumstances of their lives, and to create—and adapt—their everyday routine. A third core premise is that while families utilize cultural resources, they also develop new *repertoires of deployable meanings and competencies*, and use these to construct new, perhaps even subversive strategies of action, such as cutting back on time spent implementing therapy regimens.

### ***Factors influencing parent implementation***

The extant data suggest that the extent to which parent-carers implement home therapy regimens (i.e., level of parent ‘adherence’) is influenced by a multiplicity of inter-related ecocultural factors. One is the level of concordance between parent and professional interpretations of what the child needs. To the extent that parents and professionals utilize the same cultural resources (e.g., dominant cultural models of disability and childrearing) a high level of concordance could be expected. For example, the model of disability that is most immediately available to parents—the model into which they themselves have been enculturated—is the medical/rehabilitation model (Landsman, 2005). Parents are therefore predisposed to viewing disability as abnormal and intrinsic to their child, and in turn, may feel compelled to take on the role of parent-therapist (Leiter, 2004; Landsman, 2005). Leiter (2004) described this as *the therapeutic imperative*. However, as expectation meets experience, many parents begin to redefine themselves, their situation, and the very concept of normal itself (Landsman, 2005; Ryan & Runswick-Cole, 2008). Landsman (2005) observed that “in one’s home, alone with the child and apart from the stresses of competitive mothering or medical diagnoses, a mother comes to understand her child as simply himself/herself, neither terribly unusual nor comparable to other children on any scale that makes sense” (p. 138). Subsequently, parent and

professional interpretations of what the child needs may diverge, and implementing home therapy regimens may become a lesser priority for parents with the passage of time.

Several studies have documented a disconnect between parent and professional goals, with professionals focusing more on impairment reduction, and parents focusing more on the child's subjective well-being (Cohn, Miller & Tickle-Degnen, 2000; Thompson, 1998; Wiart, et al., 2010). In one recent study, Wiart et al. (2010) conducted a series of focus groups exploring parent perspectives on goals and goal setting in relation to occupational and physical therapy for children with cerebral palsy. The participating parents did not see any "obvious connection" between therapy goals and their own goals for their children. Parents prioritized their child's happiness over therapy goals. And what the parents perceived as integral to their child's happiness was being accepted for who they are, making friends, and the opportunity to make life choices without societal barriers. Notably, Wiart et al. (2010) found that many parents reported forgoing therapy to focus on their child's enjoyment and/or to simply enjoy family life.

Another ecocultural factor potentially influencing parent implementation is the level of fit between family resources (e.g., time, energy, skills) and demands (Brotherson & Goldstein, 1992; Hinjosa & Anderson, 1991; Segal & Beyer, 2006; Tetreault, et al., 2003; Wiart, et al., 2010). In the face of competing demands and priorities, parents may find it difficult to find a slot in their daily routine to implement interventions, even if they believe that taking on the role of parent-therapist is 'the right thing to do'. Parents may, for example, have to contend with competing moral imperatives, such as the need to ensure that their other children are not always missing out on quality time and so on, or parents may have to fulfill other obligations (e.g., paid work) before allocating or re-allocating resources to thera-

peutic interventions. Notwithstanding, if parents believe that taking on the role of parent-therapist is the morally right thing to do (*and should therefore be prioritized*), they may free-up resources by sacrificing time for self, paid work and/or family activities (Carnevale, Rehm, Kirk, et al., 2008; Leiter, Krauss, Anderson & Wells, 2004).

A third factor that may influence parent implementation is level of contextualization (i.e., the extent to which interventions are enfolded into everyday activities and routines). When time is in short supply, higher levels of contextualization may translate into higher levels of parent implementation. Professionals may work with parents to contextualize interventions, or parents may exercise their own initiative (Hinjosa & Anderson, 1991; Segal & Beyer, 2006). Hinjosa and Anderson (1991), for example, found that contextualizing is a common adaptive strategy used by parents to integrate multiple and potentially competing roles and responsibilities. The extent to which interventions are contextualized however may depend on the complexity, intensity and adaptability of the therapeutic intervention or home program itself: simple, low intensity interventions are more likely to be contextualized and implemented than are complex or time intensive interventions (Gajdosik, 1991; Rone-Adams, et al., 2004; Tetreault, et al., 2003; Thompson, 1998).

### ***Theoretical propositions***

In this study we tested a series of propositions derived from ecocultural theory and prior research. First, we reasoned that the degree to which parents implemented home-based therapy regimens would be associated with (a) the level of concordance between parent and professional need interpretations, (b) level of difficulty finding a slot in the daily routine to implement therapy, and (c) level of contextualization (i.e., extent to which interventions are enfolded into everyday activities and routines). Second, we reasoned that, to 'free-up' the time required



to implement therapy, parents would make sacrifices or trade-offs (e.g., cutting back on personal leisure, family time and/or paid work), and that such sacrifices would have adverse effects on family wellbeing.

## **METHODS**

The study reported here was nested within a three year—survey plus interview—study of family life and out-of-home placement of children with disabilities in Alberta, Canada. The analysis reported in this paper is based on survey data collected in Year one (2009) of this study. The sampling frame for the study consisted of all English-speaking families registered with the Family Supports for Children with Disabilities (FSCD) program, a provincial government registry of Albertan families raising children with disabilities. Following Ethics Board approval (File#B-060808), and with the assistance of FSCD personnel, a stratified (by child age group: early childhood, middle childhood, adolescence) random sample of registered English speaking families in receipt of child-focused services were invited to take part.

The recruitment procedure was based on the Dillman (1978) method, which is widely regarded as best practice in survey administration in the social sciences. First, families were sent a letter informing them about the forthcoming survey. Within two weeks, each family received a copy of the survey package, including the “Family Life Survey”, cover letter, consent form, pencil, and a return postage paid envelope. Approximately two weeks later, a follow-up reminder postcard was mailed out. Then approximately two weeks after this, another copy of the survey package was dispatched to families who had not yet responded. All respondents received an honorarium of CAN\$30.00.

### ***Family Life Survey***

The Family Life Survey, which was completed by the primary parent-carer, incorporated previously vali-

dated items and scales, and new items created for the purpose of this study. Prior to administration, the Family Life Survey was reviewed (i.e., pilot tested) by a parent-carer advisory group. Members of the advisory group completed the survey individually and then critiqued the survey together as a group. Based on the feedback received, changes were made to the layout of the survey, and some potentially confusing ‘routing’ instructions (i.e., If X, go to Z) were revised.

Demographic data: The survey incorporated items used in the National Longitudinal Survey of Children and Youth (NLSCY) (Statistics Canada, 2003) to collect demographic data including but not limited to data on household composition; primary parent-carer sex, age, ethnicity, educational attainment and employment status; and, the sex, age, impairment type and activity limitations of the (nominated) disabled child.

Disability severity: Disability severity was measured by a series of items including “To what extent does a long term physical condition, mental condition, learning or health problem reduce the amount or the kind of (age-appropriate) activities this child can do?”, with five response categories ranging from 1 = “not at all”, through to 5 = “a great deal”. Four additional items asked respondents to indicate how much difficulty (i.e., ‘no difficulty’, ‘some difficulty’ or ‘a lot of difficulty’) the child has with speaking, walking, learning and personal care, compared with other children his/her age. The mean raw score was calculated.

Adherence: Level of parent-carer implementation or adherence with the home therapy regimen was measured by the item “To what extent do you carry out the activities/exercises prescribed by a health professional for this child?”, with five response categories ranging from 1 = “we do not carry out any at all” to 5 = “we routinely carry out all”.



Time implementing: Time spent implementing home-based programs was measured by the item: “In a typical week, approximately how much time [i.e., in hours] do you spend implementing home (therapy) programs for your child with disabilities”. Due to a number of extreme values (outliers) the raw data was re-coded: ‘0 = 0 hours’, ‘1 = 1-3 hours’, ‘2 = 4-6 hours’, ‘3 = 7-9 hours’, ‘4 = 10-12 hours’, ‘5 = 13-15 hours’, and ‘6 = greater than 15 hours’.

Difficulty ‘slotting’: Difficulty finding time to implement therapeutic regimens or home programs was measured by the item, “How much difficulty have you had finding a slot in your daily routine to carry out the prescribed activities/exercises for this child?” with five response categories ranging from 1 = “no difficulty at all” through to 5 = “a great deal of difficulty”.

Contextualisation: To obtain a measure of *contextualisation* (i.e., the extent to which therapeutic interventions are enfolded or integrated into other activities), we adapted the approach used by Dunst, et al. (2000). Parent-carers were asked “How often are the activities/exercises prescribed for this child integrated into (*that is, just a routine part of*) each of the following activities...”. Six activities were listed including meal times; bath times (including dressing and undressing); play/leisure time at home; bed time; play/leisure at a local park, playground or recreation centre; and, grocery shopping and other routine community outings. For each activity, parent-carers reported frequency of integration using a four point scale ranging from 1 = “never” to 4 = “often”. The mean frequency of integration score was then calculated.

Trade-offs: A series of yes/no questions asked parents about trade-offs or ‘sacrifices’ they had made. Parents were asked, “To keep your family life running in the last 12 months, have you or your partner (1) “reduced your participation in leisure or sports?”, (2) “cut-back on family activities or time

together?”, (3) “worked fewer hours?”, (4) “taken a less demanding job?”, (5) “turned down a promotion or a better job?” and/or (6) “quit working altogether?”. To obtain a measure of trade-offs we summed the number of reported trade-offs to a maximum score of 3. To obtain a score of 3, a parent would have to respond “Yes” to items (1) and (2), and yes to any one or more of the work related items (i.e., items 3-6).

Concordance: No direct measure of *concordance* between parent and professional need interpretations was obtained. However one item was used as a proxy indicator. Specifically, parent-carers were asked to respond, using a five-point scale (0 = strongly disagree through to 5 = strongly agree) to the statement “In general, professionals respond to our family’s needs and priorities”. We reasoned that parents would be more likely to agree with this statement when there was a high level of concordance, and the home therapy regimen addressed their hopes or goals for their child.

Family wellbeing: Two aspects of Family Wellbeing were measured: Family cohesion and family life congruence. Family cohesion is a measure of the strength of emotional bonds between family members. It was measured with five items each having four response categories ranging from strongly disagree to strongly agree. Four of these items were derived from the General Family Functioning scale of the Family Assessment Device (Epstein, Baldwin & Bishop, 1983), and one was researcher generated. Family life congruence is a measure of how well the family is doing with respect to the adaptive challenge of sustaining a daily routine that is congruent or ‘fitting’ with their beliefs, values and goals, and the needs, interests and competences of individual family members. It was measured with ten items, using the same four point scale. Of these ten items, eight were sourced and adapted from the Family Life Interview (Llewellyn, et al., 2010), and two were new to this study.

**Perceived stress:** Stress was measured using the four-item Perceived Stress Scale (PSS-4, Cohen & Williamson, 1988). With five response categories ranging from “never” to “very often”, parent-respondents were asked “In the last month, how often have you felt” (1) “that you were unable to control the important things in your life?”, (2) “confident about your ability to handle your personal problems?”, (3) “that things were going your way?”, and (4) “difficulties were piling up so high that you could not overcome them?”.

### ***Data analysis***

The data were analyzed using PASW (SPSS) v.18 and AMOS v.20. Data were entered and then re-entered into SPSS. Any discrepancies were identified and errors corrected. After cleaning the data (e.g., reverse scoring items where necessary), a descriptive, demographic profile of study participants was generated.

Bayesian estimation, utilizing the Markov chain Monte Carlo algorithm, was then employed to replace missing values with predicted values, and transform ordered-categorical data into numeric data. This approach has a number of advantages over traditional approaches to the treatment of missing data, such as listwise or pairwise deletion or mean substitution, which can result in a significant loss of data and/or biased estimates. In essence, the Bayesian approach solves the problem of incomplete data through an iterative and progressive process, utilizing what is known and what is learned, to replace missing values with highly likely values (Jackman, 2000; Gill, 2003). After imputation, the correlations between raw and imputed scores were computed and all correlations exceeded 0.94.

Confirmatory factor analysis was then employed to establish the convergent and discriminant validity of the family cohesion and family life congruence scales, and once established, to derive factor scores. Data from parents who indicated that they were not

expected to implement any kind of therapeutic intervention or home program were then excluded from further analyses. Path analysis (i.e., structural equation modeling with observed variables)—an extension of multiple regression analysis—was then used to test our theoretical propositions, controlling for child age and disability severity. Based on Mardia’s coefficient of multivariate kurtosis, the CFA and path models met the assumption of multivariate normality.

### **RESULTS**

A total of 538 families (41%) accepted the invitation to take part in the study and completed the Family Life Survey. Of these, 390 (72%) indicated that they were expected to carry out therapeutic activities/exercises (or home program) with their disabled child. On average, these families spent 6.32 hours (5% trimmed mean) implementing therapy each week. At one end of the spectrum, one in five families spent no time at all implementing therapy, despite the expectation that they would do so. At the other, one in five spent the equivalent of at least two working days (15 + hours), every week, implementing therapy with their child. A demographic profile of the 390 families who were expected to implement therapeutic interventions is presented in Table 1.

Almost two-thirds of parent-respondents (64%) agreed or strongly agreed with the statement “... professionals/services respond to our family’s needs and priorities. This may indicate a high level of concordance with respect to parent and professional interpretations of what the child needs. However, only 11.5% of parent-respondents reported fully implementing the home therapy regimen. The majority reported either carrying out some activities/exercises “but not as often as we should” (38.1%), or routinely carrying out some but not all of the activities/exercises (20.9%).

Finding a slot in the daily routine to implement the therapeutic activities/exercises was difficult for

**Table 1.** *Child, parent-carer and family characteristics (n=390)*

		Mean (SD) or %	
Child	Age	8.48 (4.70)	
		0-5 years	38.7
		6-12 years	33.5
		13-18 years	27.8
	Sex	Male	64.5
		Female	35.5
	*Impairment Type	Intellectual disability	47.9
		Autism spectrum disorder	38.1
		Cerebral Palsy	16.5
		Downs Syndrome	10.8
	Disability (activity limitations)	A little	13.5
Fair amount		20.6	
Quite a lot		24.3	
A great deal		41.5	
Parent	Age	40.00 (8.28)	
	Sex	Male	12.9
		Female	87.1
	Language spoken at home	English	96.1
	Highest educational attainment	Did not complete high school	7.2
		High school graduate	16.5
		Diploma/trade certificate	40.5
		University graduate	35.9
Family	Residence	Major urban	51.3
		Minor urban	19.3
		Rural	27.3
	Family type	Couple, single-earner	29.6
		Couple, dual-earner	49.5
		Couple, no-earner	2.3
		Lone parent, earner	12.4
		Lone parent, non-earner	6.2
	Total household income	< \$40,000	27.3
		\$40,000 - \$69,000	19.0
		\$70,000 - \$89,000	21.6
		\$90,000 +	32.1
	Total number of Children (<18 years)		2.24 (1.21)

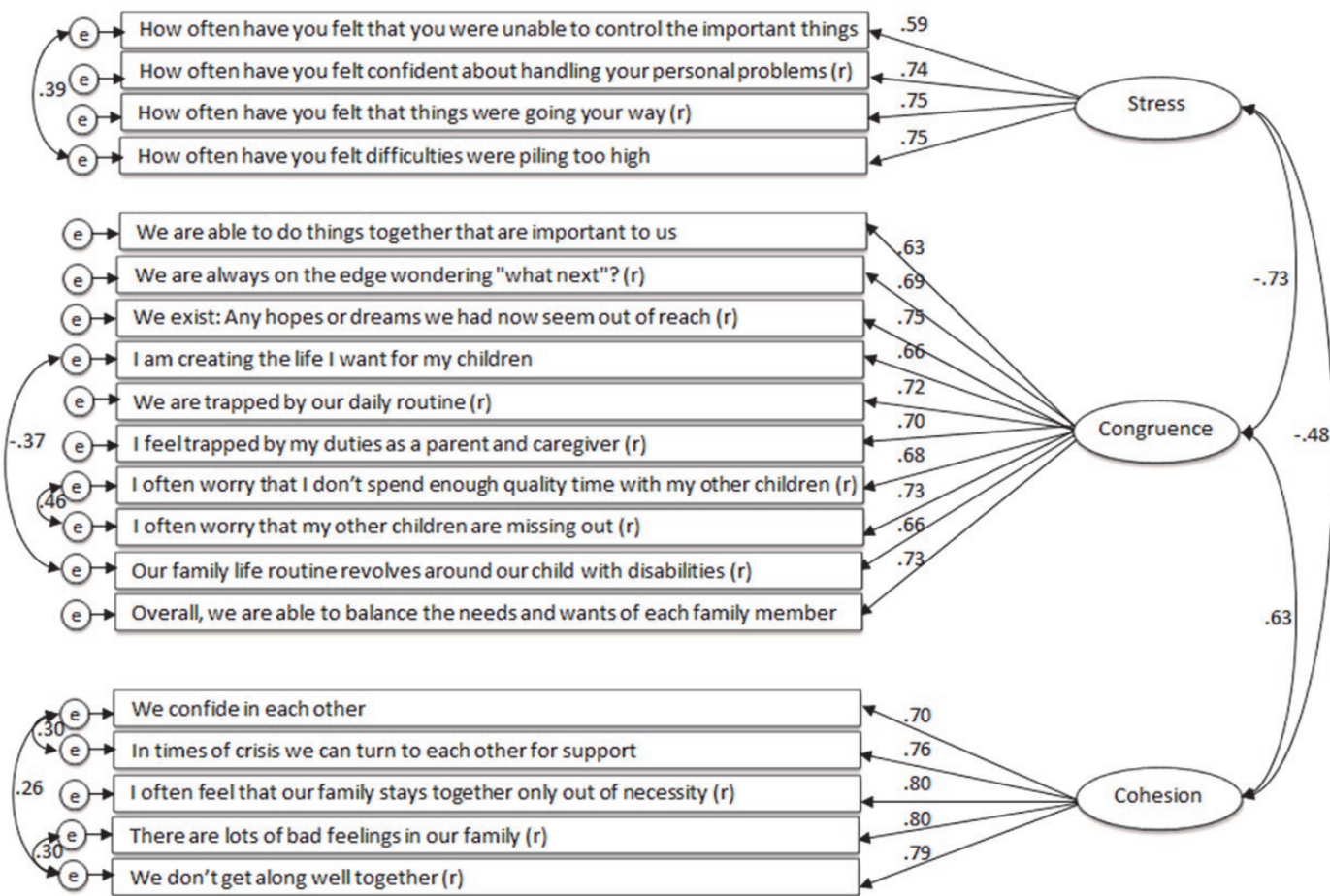
\*not mutually exclusive categories

most. Only 6.2% of parent-respondents reported having no difficulty, while 41.4% of the parent-respondents reported “quite a bit” or “a great deal” of difficulty. Time-crunch was clearly an issue for the majority of parent-respondents. To keep their family life running, in the preceding twelve months 83% had turned down or cut-back on employment related activities, 80% had sacrificed personal leisure time, and 52% had cut-back on family activities and time together.

### ***Family cohesion and family life congruence: convergent and discriminant validity***

The three factor model presented in Figure 1 fit the data well, as evidenced by the high CFI and low RMSEA indices. Discriminant validity was assessed by comparing the three factor model with alternative two factor models. Firstly, a two factor model—constraining the variance of stress and congruence, and the covariance between them to be equal to one—was rejected in favor of the three factor model

**Figure 1. CFA: Family life congruence**



Note. r = item was reverse scored  
 Model fit indices:  $\chi^2 = 369.39$ ,  $DF = 143$ ,  $p < .05$ ,  $CMIN/DF = 2.58$ ,  $CFI = .96$ ,  $TLI = .95$ ,  $RMSEA90 = .045-.061$

( $\chi^2$  difference = 171.7,  $p < .001$ ). Next, a two factor model, with the same constraints applied to congruence and cohesion, was rejected in favor of the three factor model ( $\chi^2$  difference = 424.6,  $p < .001$ ). And finally, a two factor model, constraining stress and cohesion, was rejected in favor of the three factor model ( $\chi^2$  difference = 850.2,  $p < .001$ ). These findings are consistent with the proposition that stress, cohesion and congruence are discrete, albeit inter-related constructs.

**Correlations between study variables**

Correlations between study variables are shown in Table 2. Notably, a statistically significant negative correlation was found between child age and time

spent implementing interventions (i.e., increasing child age = decreasing implementation time). Statistically significant correlations were also found between parent adherence, hours spent implementing therapeutic interventions, contextualization and degree of “difficulty finding a slot in the daily routine”. Further, statistically significant correlations were found between parent trade-off/sacrifices, hours spent implementing, family life congruence, family cohesion, and perceived stress. Notably, concordance (i.e., perceived responsiveness of professionals/services) was positively correlated with both family cohesion and family life congruence, and negatively correlated with difficulty slotting therapy into the daily routine and perceived stress.



**Table 2.** Correlation matrix using imputed, standardized data (n=390)

	1	2	3	4	5	6	7	8	9	10
1. Family life congruence										
2. Family cohesion	.681*									
3. Perceived stress	-.822*	-.556*								
4. Time implementing	-.128*	-.003	.136*							
5. Level of adherence	.004	.041	-.012	.314*						
6. Difficulty finding time	-.323*	-.108*	.272*	.071	-.316*					
7. Tradeoffs/sacrifices	-.491*	-.284*	.433*	.125*	.037	.328*				
8. Contextualisation	-.011	-.049	-.031	.251*	.468*	-.185*	-.027			
9. Concordance	.341*	.274*	-.374	-.014	.056	-.104*	-.163*	.061		
10. Child age	-.001	-.049	-.018	-.215*	-.117*	.080	.061	-.134*	-.142*	
11. Disability severity	-.240*	-.052	.154*	.086	.009	.231*	.217*	-.063	.002	.033

Standardized (M = 0, SD = 1.0); \*p<.05 (2-tailed)

### ***Parent implementation/adherence***

Controlling for the potentially confounding effects of child age and disability severity, we found that contextualization and “difficulty finding a slot in the daily routine” predicted parent adherence. Figure 2 shows the standardized path coefficients for each of the independent (i.e., predictor) variables included in the model, and the partial correlation coefficients between the independent variables. The five independent variables together explained a modest but statistically significant 28% of the variance in parent adherence ( $R^2=.28$ ,  $p = .015$ ). Contextualization, that is the extent to which therapeutic activities were enfolded into other activities, was the single strongest predictor of adherence. No significant association was found between parent-professional concordance and parent adherence with the home therapy regimen for their child. However, the measure of concordance used in this study was a blunt, proxy measure. With a more sensitive measure of concordance a significant association may be found.

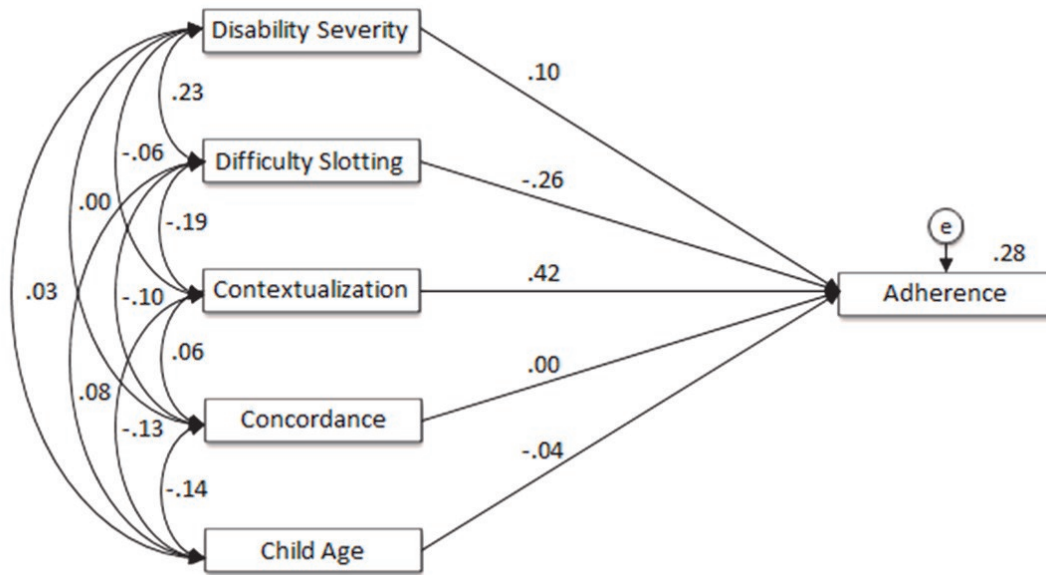
### ***Parent trade-offs/sacrifices, family wellbeing and perceived stress***

We speculated that, in a cultural context where implementing therapy is viewed as a moral imperative, parents would sacrifice personal leisure time, career opportunities and/or work hours, and even ‘family time together’ in order to free-up the time needed to implement therapy. In turn, we speculated that such sacrifices may have a negative impact on family wellbeing. These hypotheses are depicted in the structural path model shown in Figure 3.

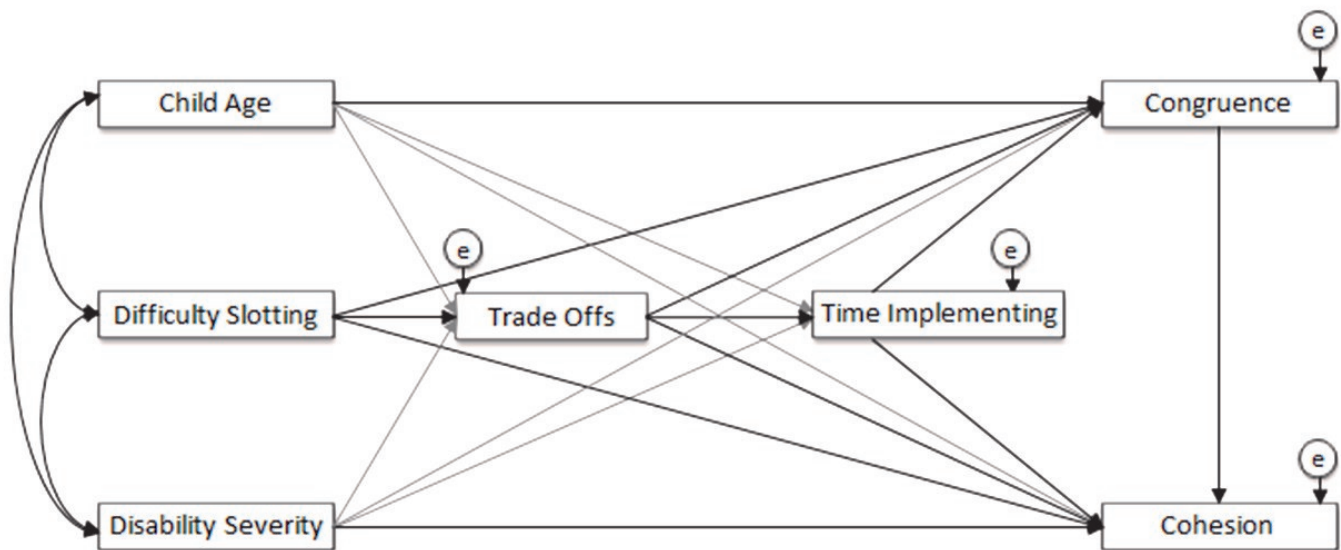
The  $\chi^2$  goodness-of-fit test was found to be non-significant, indicating that the path model fit the data well ( $\chi^2 = .519$ ,  $df 1$ ,  $p = .471$ ). The model accounted for a modest but statistically significant 29% of the variance in family life congruence ( $R^2=.2$ ,  $p = .01$ ), and a more substantial and statistically significant 50% of the variance in family cohesion ( $R^2=.50$ ,  $p = .008$ ).



**Figure 2.** Predictors of parent adherence



**Figure 3.** Implementation and family wellbeing: a path model



Bias corrected, bootstrap estimates of direct, indirect and total effects are reported in Table 3. Controlling for child age and disability severity, 'difficulty finding a slot in the daily routine' was found to have a statistically significant direct 'effect' on parent trade-offs/sacrifices (i.e., more difficulty = more sacrifices), which in turn, had a significant direct effect on hours of implementation (i.e., more

sacrifices = more time implementing). In turn, and as anticipated, parent-trade-offs/sacrifices was found to have a significant direct negative effect on family life congruence (i.e., more sacrifices = poorer family life congruence) and a significant indirect negative effect on family cohesion (i.e., more sacrifices = lower cohesion).

**Table 3.** Standardized direct, indirect and total effects with bootstrap standard errors ( $n = 390$ )

Measures		Effects Decomposition		
Predictor ->	Criterion	Direct (SE)	Indirect (SE)	Total (SE)
Congruence	Cohesion	.762* (.036)		.762* (.036)
	Time implementing	-.049 (.045)		-.049 (.050)
Trade-offs	Cohesion	.071 (.039)	-.037 (.034)	.033 (.050)
	Congruence	-.410* (.041)	-.006 (.007)	-.416* (.040)
	Cohesion	.030 (.047)	.308* (.037)	-.279* (.051)
Difficulty slotting	Time implementing	.124* (.053)		.124* (.053)
	Congruence	-.162* (.048)	-.121* (.022)	-.283* (.047)
	Cohesion	.105* (.040)	-.204* (.039)	.100* (.051)
	Time implementing		.036* (.017)	.036* (.017)
Child age	Trade-offs	.291* (.044)		.291* (.044)
	Congruence	.033 (.044)	-.003 (.023)	.030 (.048)
	Cohesion	-.048 (.039)	-.008 (.036)	-.040 (.047)
	Time implementing	-.225* (.048)	.004 (.006)	-.221* (.049)
Disability	Trade-offs	.033 (.047)		.033 (.047)
	Congruence	-.111* (.047)	-.065* (.022)	-.176* (.052)
	Cohesion	.096* (.038)	.124* (.039)	-.027 (.055)
	Time implementing	.067 (.053)	.018* (.011)	.085 (.051)
	Trade-offs	.149* (.049)		.149* (.049)

## DISCUSSION

Balancing work and family demands is an integral part of everyday life for all families. Over 200,000 Canadian families face an additional challenge: balancing work and family and the out-of-the-ordinary demands associated with caring for a child with disabilities. Implementing home based therapy regimens is one such out-of-the-ordinary demand. The majority of parent-carers in this study reported having difficulty finding a slot in their daily routine for implementation, and in turn, few reported high levels of adherence: About one in ten parents reported fully implementing the activities/exercises prescribed for their child.

Contextualizing, that is enfolding interventions into other activities and routines, is one strategy that parents employ to manage their time effectively (Hinjosa & Anderson, 1991). In this study, a nega-

tive correlation was found between contextualizing interventions and 'difficulty finding a slot in the daily routine' (i.e., more contextualizing = less difficulty), and it was the single strongest predictor of adherence. However, we also found that parents were making trade-offs or sacrifices—cutting back on employment, personal leisure, and/or family time—to free-up time for implementation (among other things). Indeed, four out of five parents reported cutting back on employment related activity and/or on personal leisure time, and more than one in two reported cutting back on family time and activities.

Cutting back on career/work related activities, personal leisure time and/or family time together may be an effective strategy, that is, for the purpose of freeing-up time for implementation. However, our data suggests that there may be some, perhaps unforeseen adverse effects. Specifically, parents who reported making more sacrifices—and who in turn

spent more time implementing therapeutic activities/exercises for their child—generally reported lower levels of family life congruence and family cohesion. The observed effect sizes are not large, but they are not trivial either: A one standard deviation increase in ‘trade-offs/sacrifices’ was associated with a one-third standard deviation decrease in family life congruence. Notably, the observed effect of parent trade-offs was larger than the observed effect of disability severity on family wellbeing.

### ***Study limitations***

The structural path model shown in Figure 3 demonstrated good-fit with the data. However, it is important to note that other models could potentially fit the data just as well: No model comparisons were made in this study. Another limitation is that the path model is recursive. It is possible, and perhaps even likely, that at least some of the relationships specified in the model are bi-directional. For instance, the study findings suggest that parent trade-offs/sacrifices may lead to lower family life congruence, but low family life congruence likely leads to parent trade-offs/sacrifices.

Another significant limitation of this study is that although the path model is ‘proposed causal’, and the results are reported in terms of ‘effects’, the data is correlational. Therefore, causal relationships can only be inferred from theory or simple logic. For example, it is not logical to suggest that, if parents spend less time implementing therapy their children will get older, or to suggest that cutting back on work hours or personal leisure time leads to difficulty finding a slot in the daily routine for implementation. Notwithstanding, the most sure way of demonstrating cause-effect is by way of experimental design. In a randomized controlled trial, a research team could, for example, compare current practice with a modified home therapy regimen that maximized contextualization and otherwise minimized the demands placed on parent-carers and their families.

### ***Conclusion***

The study findings add to the growing body of evidence suggesting that the recruitment of parents as interventionists, and the intrusion of ‘therapy/rehabilitation’ into the home and family life may have adverse effects (Brandon, 2007; Crowe and Florez, 2006; Sawyer, et al., 2010). This growing body of evidence behooves health professionals, including but not limited to physical, speech and occupational therapists, to consider less taxing (for the family) alternatives to both direct intervention in the home and to the recruitment of parents as interventionists. For example, a third way in which health professionals may help compensate for the lack of cultural resources available to parent-carers, and in turn, promote a child’s learning and development, is by simply supporting parents in the parenting role. This is different from recruiting parents as interventionists because there is no program or intervention per se to be implemented. The assumption here is that parents are already ‘in the business’ of creating activity settings and promoting child learning and development. The role of the health professional is then to advise or coach parents on how best to adapt existing everyday activity settings, and how to more fully exploit the natural learning opportunities therein. Health professionals may, for example, provide information and guidance with respect to organizing and provisioning the physical environment (e.g., advice on toys and assistive technologies), and/or on eliciting and positively reinforcing functional, adaptive and socially desirable behaviours. In essence, this approach is awareness-raising and capacity building: parents are not necessarily asked to do more, but rather, with an eye-for-opportunity, to get the most out of what they are already doing.

An example of this ‘third way’ was recently described by Darrah, Law, Pollock, et al. (2011), who developed and pilot tested an approach to intervention for children with cerebral palsy which they

termed “context therapy”. In contrast to traditional approaches which typically focus on impairment reduction, context therapy focuses exclusively on meaningful (to the child and parent), functional goals, and on goal attainment by way of task and/or environment modification. In essence, a therapist works with the parent to adapt natural learning environments or ‘activity settings,’ and in turn, promote child participation, learning and development. The pilot study demonstrated that meaningful, functional goals could be achieved without direct hands-on intervention (i.e., to ‘modify the child’). One illustrative example given by the authors is of a child who had difficulty boarding her school bus due to the height of the steps. Instead of working on improving the child’s strength and coordination, the therapist phoned school administrators, explained the problem, and requested a bus with steps that were not so steep. The school complied and soon the child was boarding the bus independently.

As a general rule, children do well when their families do well. And families do well when they have the resources they need to juggle work and family and care demands. Recruiting parents as interventionists can tax family resources. So, in the interests of both the child and family, health professionals must carefully weigh the pros and cons of parent-mediated intervention, and they may need to help some parents (i.e., those who may feel compelled to do whatever they can to ‘fix’ their child) do the same. Alternatives such as Context Therapy or other ‘contextualized’ intervention/s (see, for example, Moes & Frea, 2000) may not only be less taxing, they might also be more effective in achieving the goals that are meaningful to the child and family. This is an important direction for ongoing, future research.

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# family life

## survey



FAMILY AND DISABILITY STUDIES INITIATIVE  
UNIVERSITY OF ALBERTA



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ALBERTA



Alberta Association for  
Community Living



0910 EXR CRS 10889

**Thank you for taking the time to complete this survey.** The information you share will help us better understand the challenges that families with children with disabilities face, and the resources that parent-carers need to juggle multiple roles and responsibilities.

The survey includes questions about you and your family's health and wellbeing, and the strategies and resources you need to keep your family life running. You can complete this questionnaire yourself or, if you prefer, we could complete it together over the phone.

If you would prefer to complete this survey over the phone, please call Amber Savage at 780 492 8568.

Most of the questions in this survey ask you to choose from a list of possible answers, such as "I agree", or "I disagree". You select your answer by filling in the corresponding circle. For example

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**Question: Do you live in Canada?**

Yes                       No

Once you have completed the survey, please return it to us together with the signed consent form in the postage paid envelope provided. Thank you.

The first section of this questionnaire asks about your participation in paid work and other activities.

**1 In a typical week, approximately how much time do you spend**

- > in **paid work** (including any unpaid overtime) \_\_\_\_\_ hours
- > doing **unpaid volunteer work** or service for any organisation/group \_\_\_\_\_ hours
- > doing **unpaid housework** activities including cooking, cleaning, shopping, home budgeting, yard work or home maintenance \_\_\_\_\_ hours
- > **actively / physically looking after your children** (bathing, dressing, transporting, etc) \_\_\_\_\_ hours
- > **caring for an elderly family member** \_\_\_\_\_ hours
- > **implementing home** (therapy) **programs** for your child/ren with disabilities \_\_\_\_\_ hours
- > **attending appointments** with health, education or other professionals \_\_\_\_\_ hours

**2 Given the choice, would you like less, the same number, or more hours of paid work?**

- Less                       Same number of hours                       More

If you do not spend any time in paid work, please go to question 19 on page 4.

**3 Which of the following best describes the hours you usually work?**

- Regular daytime schedule or shift
- Regular evening shift
- Regular night shift
- Rotating shift (for example, change from days to evenings to nights)
- Split shift (for example, some hours in the day and the remainder in the evening or night)
- On call
- Irregular schedule

**4 Do you work mainly...**

- for others, that is for wages, salary or commission
- in your own business, farm or professional practice
- other (please specify)

The next questions are about how much control you have over your work:

		Never	Rarely	Sometimes	Often
5	"I have a say in what I do at work."	①	②	③	④
6	"I can work from home if I wish."	①	②	③	④
7	"I have a say in how I do my job."	①	②	③	④
8	"I have a say in my own work speed."	①	②	③	④
9	"My scheduled work hours are flexible."	①	②	③	④
10	"I can decide when to take a break."	①	②	③	④
11	"My work demands a high level of skill or expertise."	①	②	③	④
12	"My job requires me to take the initiative."	①	②	③	④
		Definitely not	No, I don't think so	Yes, I think so	Definitely yes
13	"I can take leave, paid or unpaid, to care for my children (to see a doctor, or meet with a teacher etc) if I need to."	①	②	③	④
14	"I can take extended leave without pay if I need to." (for example, to be home for the children, care for a family member etc)	①	②	③	④



The next questions ask about the balance between work and family activities:

	All the time	Most of the time	Sometimes	Never
15 How often do you come home from work too tired to do the chores that need to be done?	①	②	③	④
16 How often is it difficult to fulfill family responsibilities because of the amount of time you spent on your job?	①	②	③	④
17 How often do you arrive at work too tired to function well because of the household or child care work you had done?	①	②	③	④
18 How often is it difficult to concentrate or fulfill your work responsibilities because of your family responsibilities?	①	②	③	④

19 What is your marital status?

- currently married and living together, or living with someone in a marital-like relationship
- never married and never lived with someone in a marital-like relationship
- Separated
- Divorced or formerly lived with someone in a marital-like relationship
- Widowed

If you are **not currently married or living with someone** in a marital-like relationship, please go to question 38 on page 6.

20 In a typical week, approximately how much time does your partner spend...

- > in **paid work** (including any unpaid overtime) \_\_\_\_\_ hours
- > doing **unpaid volunteer work** or service for any organisation/group \_\_\_\_\_ hours
- > doing **unpaid housework** activities including cooking, cleaning, shopping, home budgeting, yard work or home maintenance \_\_\_\_\_ hours
- > **looking after your children** (bathing, dressing, transporting, etc) \_\_\_\_\_ hours
- > **caring for an elderly family member** \_\_\_\_\_ hours
- > **implementing home** (therapy) **programs** for your child/ren with disabilities \_\_\_\_\_ hours
- > **attending appointments** with health, education or other professionals \_\_\_\_\_ hours

21 Given the choice, do you think your partner would like less, the same, or more hours of paid work?

- Less
- Same number of hours
- More

If your **partner does not spend any time in paid work**, please go to question 38 on page 6.

**22 Which of the following best describes the hours your partner usually works?**

- Regular daytime schedule or shift
- Regular evening shift
- Regular night shift
- Rotating shift (for example, change from days to evenings to nights)
- Split shift (for example, some hours in the day and the remainder in the evening or night)
- On call
- Irregular schedule

**23 Does your partner work mainly...**

- for others, that is for wages, salary or commission
- in his/her own business, farm or professional practice
- other (please specify)

The next questions are about how much control your partner has over his/her work.

	Never	Rarely	Don't know	Sometimes	Often
<b>24 My partner has a say in what he/she does at work.</b>	①	②	③	④	⑤
<b>25 My partner can work from home if he/she wishes.</b>	①	②	③	④	⑤
<b>26 My partner has a say in how he/she does their job.</b>	①	②	③	④	⑤
<b>27 My partner has a say in his/her own work speed.</b>	①	②	③	④	⑤
<b>28 My partner has flexible work hours.</b>	①	②	③	④	⑤
<b>29 My partner can decide when to take a break from work.</b>	①	②	③	④	⑤
<b>30 My partner needs to have a high level of skill or expertise to do his/her job.</b>	①	②	③	④	⑤
<b>31 My partner is required to take the initiative at work.</b>	①	②	③	④	⑤

	Definitely not	No, I don't think so	I don't know	Yes, I think so	Definitely yes
<b>32 My partner can take leave, paid or unpaid, to care for the children</b> (to see a doctor, meet with a teacher etc)	①	②	③	④	⑤

<b>33 My partner can take extended leave without pay if need be</b> (to be home for the children, care for a family member etc)	①	②	③	④	⑤
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The next questions ask about the balance between your partner's work and family activities.

	Never	Sometimes	I don't know	Most of the time	All of the time
<b>34 How often does your partner come home from work too tired to do the chores that need to be done?</b>	①	②	③	④	⑤

<b>35 How often is it difficult for your partner to fulfill family responsibilities because of the amount of time he/she spent on their job?</b>	①	②	③	④	⑤
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<b>36 How often does your partner arrive at work too tired to function well because of the household or child care work he/she had done?</b>	①	②	③	④	⑤
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<b>37 How often is it difficult for your partner to concentrate or fulfill his/her work responsibilities because of their family responsibilities?</b>	①	②	③	④	⑤
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The next section of the questionnaire asks about your family life and resources.

<b>38 How many people are so close to you that you can count on them if you have a serious personal or family problem?</b>	<input type="radio"/> None	<input type="radio"/> 1 or 2	<input type="radio"/> 3 to 5	<input type="radio"/> 6 to 9	<input type="radio"/> 10 or more
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<b>39 How much concern or interest do people show in how you and your family are doing?</b>	<input type="radio"/> No concern or interest	<input type="radio"/> Little concern or interest	<input type="radio"/> Uncertain	<input type="radio"/> Some concern or interest	<input type="radio"/> A lot of concern or interest
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<b>40 How easy is it to get practical help from neighbours if you or your family should need it?</b>	<input type="radio"/> Very difficult	<input type="radio"/> Difficult	<input type="radio"/> Possible	<input type="radio"/> Easy	<input type="radio"/> Very easy
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**41 In general, professionals/services respond to our family's needs and priorities**

- Strongly disagree
- Disagree
- Uncertain
- Agree
- Strongly agree

Please use this space if you would like to explain further

The next four questions are about financial strain.

**42 Thinking back over the past three months, how much difficulty have you had paying your bills?**

- No difficulty at all
- A little difficulty
- Some difficulty
- Quite a bit of difficulty
- A great deal of difficulty

**44 In the next three months, how often do you think that you and your family will experience bad times such as poor housing or not having enough food?**

- Almost never
- Once in a while
- Sometimes
- A lot of the time
- Almost always

**43 Thinking again over the past three months, generally, at the end of each month did you end up with**

- More than enough money left
- Some money left
- Just enough money left
- Somewhat short of money
- Very short of money

**45 In the next three months, how often do you expect that you will have to do without the basic things that your family needs?**

- Almost never
- Once in a while
- Sometimes
- A lot of the time
- Almost always

The next four questions are about your personal sense of control over things in your life.

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**46** In the last month, how often have you felt that you were unable to control the important things in your life?

- Never
- Almost never
- Sometimes
- Fairly often
- Very often

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**48** In the last month, how often have you felt that things were going your way?

- Never
- Almost never
- Sometimes
- Fairly often
- Very often

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**47** In the last month, how often have you felt confident about your ability to handle your personal problems?

- Never
- Almost never
- Sometimes
- Fairly often
- Very often

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**49** In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?

- Never
- Almost never
- Sometimes
- Fairly often
- Very often



The next questions ask about the meaningfulness of your family life.

		Strongly disagree	Disagree	Agree	Strongly agree
50	I am creating the life I want for my children.	①	②	③	④
51	We are a close-knit family.	①	②	③	④
52	As a family we feel a strong sense of belonging in our community.	①	②	③	④
53	All we seem to be doing is reacting to one crisis after another.	①	②	③	④
54	We are able to do things together that are important to us.	①	②	③	④
55	I worry that we do not spend enough quality time together as a family.	①	②	③	④
56	We are always on edge wondering "what next?"	①	②	③	④
57	It is difficult for us to get into any kind of routine because our circumstances keep on changing.	①	②	③	④
58	Overall, having a child with a disability has been positive for our family.	①	②	③	④
59	As a result of having a child with a disability, our family unit has emerged stronger.	①	②	③	④
60	As a result of having a child with a disability, some wonderful people have come into our lives.	①	②	③	④
61	As a result of having a child with a disability, we have learned what is really important in life.	①	②	③	④
62	As a result of having a child with a disability, we laugh more and are less bothered by trivial things.	①	②	③	④
63	Generally, I think all members of our family feel valued and appreciated.	①	②	③	④

		Strongly disagree	Disagree	Agree	Strongly agree
64	We are trapped by our daily routine.	①	②	③	④
65	I often feel that our family stays together only out of necessity.	①	②	③	④
66	We exist: any hopes or dreams we had now seem out of our reach.	①	②	③	④
67	Planning family activities is difficult because we misunderstand each other.	①	②	③	④
68	In times of crisis we can turn to each other for support.	①	②	③	④
69	We cannot talk to each other about the sadness we feel.	①	②	③	④
70	Individuals (in the family) are accepted for what they are.	①	②	③	④
71	We avoid discussing our fears or concerns.	①	②	③	④
72	We express feelings to each other.	①	②	③	④
73	There are lots of bad feelings in our family.	①	②	③	④
74	Making decisions is a problem for our family.	①	②	③	④
75	We are able to make decisions about how to solve problems.	①	②	③	④
76	We don't get along well together.	①	②	③	④
77	We confide in each other.	①	②	③	④

The next questions explore the extent to which your family life balances the needs of your child with disabilities with the needs of all other family members.

	Does not apply	Strongly disagree	Disagree	Agree	Strongly agree
78 Overall, we are able to balance the needs and wants of each family member.		①	②	③	④
79 Our family life routine revolves around our child with disabilities.		①	②	③	④
80 Generally, every person in our family does their fair share of the chores.		①	②	③	④
81 Responsibility for keeping our family life running is shared.		①	②	③	④
82 I often worry that my other children are missing out.	<input type="radio"/>	①	②	③	④
83 My other children are usually able to do the things they like to do.	<input type="radio"/>	①	②	③	④
84 I often worry that I do not spend enough quality time with my other children.	<input type="radio"/>	①	②	③	④
85 I often worry about how the lives of my other children are affected by having a brother/sister with disabilities.	<input type="radio"/>	①	②	③	④
86 I am generally satisfied with how my life has turned out.		①	②	③	④
87 I have had to give up more of my life to meet my child/ren's needs than I ever expected.		①	②	③	④
88 I have as much time for myself as any other parent with children this age.		①	②	③	④
89 I feel trapped by my duties as a parent and caregiver.		①	②	③	④
90 I think my partner is generally satisfied with how his/her life has turned out.	<input type="radio"/>	①	②	③	④

		Does not apply	Strongly disagree	Disagree	Agree	Strongly agree
91	I think my partner feels trapped by his/her duties as a parent and caregiver.	<input type="radio"/>	<input type="radio"/> ①	<input type="radio"/> ②	<input type="radio"/> ③	<input type="radio"/> ④
92	I think my partner has as much time for him/herself as any other parent with children this age.	<input type="radio"/>	<input type="radio"/> ①	<input type="radio"/> ②	<input type="radio"/> ③	<input type="radio"/> ④
93	I think my partner has had to give up more of his/her life for the children than he/she ever expected.	<input type="radio"/>	<input type="radio"/> ①	<input type="radio"/> ②	<input type="radio"/> ③	<input type="radio"/> ④

The next section of the questionnaire asks about the people in your household, and your child or children with disabilities.

- 94 How many people live in your household?
- 95 How many of them are under the age of 6?
- 96 How many are 6 to 12 years of age?
- 97 How many are 13 to 17 years of age?
- 98 Including yourself, how many of them are 18 years of age or older?
- 99 How many children in your household have a long-term physical condition, mental condition, learning or health problem that reduces the amount or kind of activities they can do?

Please tell us a little about your child with a long-term physical condition, mental condition, learning or health problem. If you have more than one child with a condition or health problem, **please tell us about the same child you described in the 2009 survey.**

Compared with other children his/her age, does this child have any difficulty with...

100 **What is this child's gender?**

- Male       Female

101 **What is this child's age?**  
(years and months)

**What is this child's name?**

**What is this child's birthdate?**

102 **To what extent does a long-term physical condition, mental condition, learning or health problem reduce the amount or the kind of (age-appropriate) activities this child can do?**

- Not at all  
 A little  
 Fair amount  
 Quite a lot  
 Great deal

103 **... speaking?**

- no difficulty  
 some difficulty  
 a lot of difficulty

104 **... walking?**

- no difficulty  
 some difficulty  
 a lot of difficulty

105 **... learning?**

- no difficulty  
 some difficulty  
 a lot of difficulty

106 **... personal care activities like bathing, dressing and eating?**

- no difficulty  
 some difficulty  
 a lot of difficulty



The next questions are about this child's social inclusion and participation.

107 **Is this child integrated into a regular early childhood service** (such as daycare or preschool) **or school?**

- Yes  No

108 **Does this child participate in any integrated (with non-disabled children) organised playgroups, sports or other recreational activities?**

- Never  
 Occasionally  
 Regularly

109 **Does this child participate in any playgroups, sports or other recreational activities that are organised especially for children with disabilities?**

- Never  
 Occasionally  
 Regularly

110 **Does this child belong to any mainstream community groups/clubs** (such as 4H, Girl Guides, Scouts etc)?

- Yes  No

111 **Does this child belong to any community groups/clubs that are just for children with disabilities?**

- Yes  No

112 **Does this child have any friends or playmates, about his/her own age, that do not have disabilities?**

- Yes  No

If yes, about how many would you say?

- 1 or 2  
 3 to 5  
 6 to 9  
 10 or more

113 **Does this child have any friends/playmates, about his/her own age, that have disabilities?**

- Yes  No

If yes, about how many would you say?

- 1 or 2  
 3 to 5  
 6 to 9  
 10 or more

114 **If this child is 12 years of age or older, does he/she do any paid work** (e.g. works at McDonalds)?

- Yes  No  Does not apply

The next set of questions ask about early intervention and home programs for this child. That is, any strategies or therapeutic activities that have been prescribed by a health professional, such as an occupational or physical therapist, to promote this child's learning and development.

**115** Are you expected to carry out any prescribed activities/exercises (or home program) to promote this child's learning and development?

- Yes       No

If "no" to the previous question please go to question 124 on page 16.

**116** How much difficulty have you had finding a slot in your daily routine to carry out the prescribed activities/exercises for this child?

- No difficulty at all
- A little difficulty
- Some difficulty
- Quite a bit of difficulty
- A great deal of difficulty

**117** To what extent do you carry out the activities/exercises prescribed by a health professional for this child?

- We do not carry out any at all
- We carry out some, but not as often as we should
- We routinely carry out some
- We carry out all of them, but not as often as we should
- We routinely carry out all

How often are the activities/exercises prescribed for this child integrated into (that is, just a routine part of) the following activities?

	Never	Rarely	Sometimes	Often
<b>118</b> Meal times	①	②	③	④
<b>119</b> Bath times, including dressing and undressing	①	②	③	④
<b>120</b> Play/leisure time at home	①	②	③	④
<b>121</b> Bed times	①	②	③	④
<b>122</b> Play/leisure time at a local park, playground or recreation centre	①	②	③	④
<b>123</b> Grocery shopping and other routine community outings	①	②	③	④

**124 Does this child have any of the following long-term conditions which have been diagnosed by a health professional?** Please fill all that apply

- Vision impairment
- Hearing impairment
- Intellectual disability (mental handicap)
- Asthma or severe allergies
- Heart condition or disease
- Kidney condition or disease
- Diabetes
- Epilepsy
- Cystic Fibrosis
- Autism Spectrum Disorder
- Fetal Alcohol Spectrum Disorder
- Cerebral palsy
- Spina Bifida
- Muscular Dystrophy
- Down syndrome
- Missing or malformed arms, legs, fingers or toes
- Attention Deficit Disorder (ADD) or Attention Deficit Hyperactivity Disorder (ADHD)
- Emotional, psychological or nervous difficulties
- Complex medical care needs
- Other condition/s (please specify)

**125 How would you describe this child's general health?**

- Poor
- Fair
- Good
- Very good
- Excellent

**126 What is your relationship to this child?**

- Mother (biological or adoptive)
- Step mother
- Foster mother
- Father (biological or adoptive)
- Step father
- Foster father
- Other (please specify)

If this child is **less than 4 years of age**, please go to question 151 on page 19.

The next questions ask about this child's behaviours.

		Not true	Somewhat or sometimes true	Very true or often true
127	This child becomes overexcited.	①	②	③
128	This child chews or mouths objects or body parts.	①	②	③
129	This child confuses the use of pronouns. (e.g. uses you instead of I)	①	②	③
130	This child doesn't show affection.	①	②	③
131	This child grinds his/her teeth.	①	②	③
132	This child has nightmares, night terrors, or walks in his/her sleep.	①	②	③
133	This child is impatient.	①	②	③
134	This child has inappropriate sexual activity with another.	①	②	③
135	This child is jealous.	①	②	③
136	This child kicks, hits others.	①	②	③
137	This child laughs or giggles for no obvious reason.	①	②	③
138	This child is preoccupied with only one or two particular interests.	①	②	③
139	This child refuses to go to school, activity center, or workplace.	①	②	③

		Not true	Somewhat or sometimes true	Very true or often true
140	<b>This child repeats the same word or phrase over and over.</b>	①	②	③
141	<b>This child smells, tastes, or licks objects.</b>	①	②	③
142	<b>This child switches lights on and off, pours water over and over, or similar repetitive behaviour.</b>	①	②	③
143	<b>This child is stubborn, disobedient, or uncooperative.</b>	①	②	③
144	<b>This child says he/she can do things that he/she is not capable of.</b>	①	②	③
145	<b>This child sees, hears, something that isn't there, has hallucinations.</b>	①	②	③
146	<b>This child tells lies.</b>	①	②	③
147	<b>This child is tense, anxious, worried.</b>	①	②	③
148	<b>This child under-reacts to pain.</b>	①	②	③
149	<b>This child gets upset or distressed over small changes in routine or environment.</b>	①	②	③
150	<b>This child wanders aimlessly.</b>	①	②	③



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**151 Have you ever considered placing this child out-of-home?**  
(for example, in foster care or residential care)

- ① No, we have never considered placement as an option for our child.
- ② Occasionally the subject of placement comes up, but we do not seriously consider it.
- ③ Yes, we have thought about it a lot, but have done nothing.
- ④ We have inquired about placement, but done nothing else.
- ⑤ We have taken steps to place our child, paper work is in progress.
- ⑥ We have placed our child out-of-home.

If you have seriously considered or taken steps to place this child ③ ④ ⑤ ⑥  
please tell us, in your own words, what was your main reason for doing so?

The next questions ask about child care arrangements for this child.

**152** Is there anyone living in your household, apart from you or your partner/spouse, who takes care of this child on a regular basis?

- Yes       No

**153** If you answered "yes" to question 152, who is this person/these people living in your household who take care of this child on a regular basis?

- grandparent/s
- the child's brother and/or sister
- other relative
- non-relative, including a live-in nanny

**154** Do you currently use any other child care arrangement/s for this child?

- Yes       No

If Yes to question 154, please go to question 158 on page 21

**155** If you answered "no" to question 154, would you like to use child care (for example, day care or before and after school programs) for this child?

- Yes       No

If you do not use any child care arrangement, please go to question 163 on page 22.

**156** What kind of care would you prefer to use?

- Care in someone else's home by a non-relative
- Care in someone else's home by a relative
- Care in child's home by a non-relative
- Care in child's home by a relative other than child's brother or sister
- Care in child's home by child's brother or sister
- Daycare centre (this does not include a home based daycare)
- Before and after school program
- Nursery school/ Preschool

Other child care arrangement (please specify)

**157** Why are you not using child care?

- Cost for preferred arrangement is too high
- Preferred arrangement is not available in my community
- Hours of preferred arrangement does not fit my schedule
- On a waiting list
- Preferred arrangement did not have places for children with special needs
- Transportation to/from preferred arrangement is a problem

Other (please specify)

**158 About how many hours per week do you use each of the following child care arrangements?**

- > Care in someone else's home by a non-relative \_\_\_\_\_ hours
- > Care in someone else's home by a relative \_\_\_\_\_ hours
- > Care in child's home by a non-relative \_\_\_\_\_ hours
- > Care in child's home by a relative other than child's brother or sister \_\_\_\_\_ hours
- > Care in child's home by child's brother or sister \_\_\_\_\_ hours
- > Daycare centre (this does not include a home based daycare) \_\_\_\_\_ hours
- > Before and after school program \_\_\_\_\_ hours
- > Nursery school/ Preschool \_\_\_\_\_ hours
- > Other child care arrangement \_\_\_\_\_ hours  
(please specify)

**159 Does your main child care provider understand the needs of this child?**

- Yes
- No

**160 Given the choice, would you like to use less, the same number, or more hours of child care?**

- Less
- Same number of hours
- More

**161 If you answered "more" to question 161, why are you not using more child care?**

- Cost for preferred arrangement is too high
- Preferred arrangement is not available in my community
- Hours of preferred arrangement does not fit my schedule
- On a waiting list
- Preferred arrangement did not have places for children with special needs
- Transportation to/from preferred arrangement is a problem
- Other (please specify)

**162 What is the main reason why you chose your current childcare arrangements?**

- Close to home
- Affordable
- Hours fit my schedule
- Was recommended by friend/relative
- Only option available
- Recommended by a health care professional
- Other (please specify)

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**163** Has a child care program or service ever refused to take care of this child because of his/her condition or health problem?

- Yes       No

The next section asks about you and your health and wellbeing

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**164** How would you describe your general health?

- Poor  
 Fair  
 Good  
 Very good  
 Excellent

---

**165** Over the past two weeks, have you felt down, depressed, or hopeless?

- Yes       No

---

**166** Over the past two weeks, have you felt little interest or pleasure in doing things?

- Yes       No

---

**167** Do you have a long-term physical condition, mental condition, learning or health problem that reduces the amount or the kind of activity you can do?

- Yes       No

---

**168** If "yes" to question 167, to what extent does a long-term physical condition, mental condition, learning or health problem reduce the amount or the kind of activity you can do?

- Not at all  
 A little  
 Fair amount  
 Quite a lot  
 Great deal

---

**169** Do you have any of the following long-term conditions which have been diagnosed by a health professional? (please fill any that apply)

- Asthma  
 Heart condition or disease  
 Kidney condition or disease  
 Diabetes  
 Epilepsy  
 Intellectual disability (mental handicap)  
 Depression and/or anxiety disorder  
 Other (please specify)

In the last year, have any of the following happened to you?

170 You suffered a serious illness, injury or assault

Yes  No

179 You were seeking work unsuccessfully for more than one month

Yes  No

171 A serious illness, injury or assault happened to a close relative

Yes  No

180 You had a major financial crisis

Yes  No

172 Your parent, partner or child died

Yes  No

181 You had problems with the police and a court appearance

Yes  No

173 A close family friend or another relative (aunt, cousin, grandparent) died

Yes  No

182 Something you valued was lost or stolen

Yes  No

174 You broke off a steady romantic relationship

Yes  No

183 Someone in your household had an alcohol problem

Yes  No

175 You had a serious problem with a close friend, neighbour or relative

Yes  No

184 Someone in your household had a drug-use problem

Yes  No

176 You had a crisis or serious disappointment in your work or career

Yes  No

185 Your partner lost his / her job, but not by choice (fired / redundant, contract ended)

N/A  Yes  No

177 You thought you would soon lose your job

Yes  No

186 Your partner was seeking work unsuccessfully for more than one month

N/A  Yes  No

178 You lost your job, but not by choice (fired / redundant, contract ended)

Yes  No

187 You had a separation due to relationship or marital difficulties

N/A  Yes  No



**188** Over the last 12 months, what was your total household income?

- Less than \$20,000
- \$20,000 to \$29,999
- \$30,000 to \$39,999
- \$40,000 to \$49,999
- \$50,000 to \$59,999
- \$60,000 to \$69,999
- \$70,000 to \$79,999
- \$80,000 to \$89,999
- \$90,000 to \$99,999
- \$100,000 to \$149,999
- \$150,000 to \$199,999
- \$200,000 to \$249,999
- More than \$250,000

The next and final section of this questionnaire asks about decisions you have made, and actions you have taken in order to keep your family life running (that is, to free-up time, increase family resources, or reduce demands).

**To keep your family life running in the last 12 months, have you and/or your partner**

	Yes	No
<b>189</b> not taken a job?	①	②
<b>190</b> quit working altogether?	①	②
<b>191</b> turned down a promotion or a better job?	①	②
<b>192</b> taken a less demanding job?	①	②
<b>193</b> worked fewer hours?	①	②
<b>194</b> reduced your participation in community organisations/groups?	①	②
<b>195</b> reduced your level of contact with professionals and other services?	①	②
<b>196</b> made a deliberate decision to have fewer children?	①	②

To keep your family life running in the last 12 months, have you and/or your partner

		Yes	No			Yes	No
197	cut-back on family activities and time together?	①	②	207	increased your use of childcare?	①	②
198	reduced your own participation in leisure or sports?	①	②	208	called on friends or neighbours for assistance?	①	②
199	cut-back on time spent implementing home programs for your disabled child?	①	②	209	turned to other families with disabled children for support?	①	②
200	changed work hours to different times of day or night?	①	②	210	increased your use of respite care?	①	②
201	decided to do more of your paid work from home?	①	②	211	employed a nanny or housekeeper?	①	②
202	become self-employed?	①	②	212	enlisted as much help as you can from professionals and other services?	①	②
203	asked any of your children to take-on some extra responsibility?	①	②	213	called on members of your extended family for support?	①	②
204	renegotiated the division of household labour ? (i.e. taken on a greater/lesser share)	①	②	214	taken a job or worked more hours?	①	②
205	made modifications to your home or vehicle?	①	②	215	increased your involvement with a community organisation or group?	①	②
206	moved to a different place (city, neighbourhood etc) to be closer to support?	①	②	216	gathered as much information as you can about a problem or challenge?	①	②

To keep your family life running in the last 12 months, have you and/or your partner

		Yes	No			Yes	No
217	purposely avoided negative or needy friends/family?	①	②	224	called on child's peer group for assistance?	①	②
218	reduced time spent with non-family members?	①	②	225	purchased items to increase your child's home based activities (gaming systems, computer)?	①	②
219	chosen jobs based on better benefits?	①	②	226	enrolled child in day camp or summer camp?	①	②
220	became an advocate, took political action?	①	②	227	cut down on spending on non-necessities?	①	②
221	furthered education in hopes of better employment (more money, fewer hours)?	①	②	228	made an effort to have 'dates' with your partner?	①	②
222	became less rigid about household chores?	①	②	229	made your family life more structured and stronger in routine?	①	②
223	independently fundraised for devices, supports your child needed?	①	②				

---

230 Please describe any other decisions you have made or actions you have taken in order to keep your family life running (that is, to free-up time, increase family resources or reduce demands)?

A large, empty rectangular box with a thin black border, intended for the respondent to write their answers to question 230. The box is positioned centrally below the question text and occupies most of the page's vertical space.

**Thank you so much for assisting us with this important project.**

To acknowledge the time you put into this project, we would like to send you a cheque in the amount of \$30.00. We will also be interviewing a small number of parent-carers to explore, in more depth, strategies for juggling work and family and caregiving. A member of the research team may contact you to see if you would be willing to be one of the interview participants. Please note, the information you have given us will remain strictly confidential.

Address:

Telephone:

Cell number:

Code no. F





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FACULTY OF REHABILITATION MEDICINE  
Family and Disability Studies Initiative

