FAMILY LIFE

Family and Disability Studies Initiative

2009 Preliminary Findings

Thank you for taking the time to complete the 2009 Family Life Survey. The information you provided is helping us to gain an understanding of how parent-carers juggle multiple roles and responsibilities, and the resources they need to keep their family life running. The Family Life Survey was completed by 538 parent-carers from around Alberta. We hope you will continue to participate in this three year project (2009-2011).

Please take a moment to read a little of what we have discovered so far.

Raising a child with disabilities can be rewarding:

As a result of having a child with disabilities over 70% of parent-carers said that their family unit had emerged stronger.

As a result of having a child with disabilities almost 90% said that wonderful people had come into their lives.

As a result of having a child with disabilities, almost 90% said that they had learned what was really important in life. And,

As a result of having a child with disabilities, over 50% said that they now laugh more and are less bothered by trivial things.

63% said that overall, having a child with disabilities had been positive for their family.

At the same time, juggling the demands of work and family and caring for a child with disabilities can be immensely challenging.

Approximately one-half of the participating families said that all they seemed to be doing was re-acting to one crisis after another, and were always on edge wondering 'what next?

"There is very little 'ME' time, but he is worth it ALL"

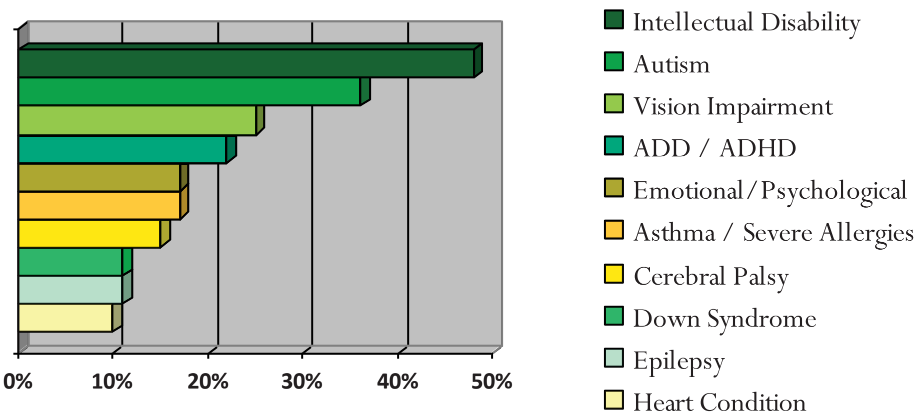
Almost two-thirds of parent-carers said that their family life revolved around their child with disabilities, and were concerned that their other children were 'missing out'.

Over three-quarters of parent-carers said that they have had to give up more of 'their life' than they had ever expected, and had less time for themselves than other parents with children the same age.

More than one-half of the participating parent-carers reported feeling 'trapped' by their daily routine, and almost one-third said that any hopes and dreams they had now seemed out-of-reach.

Families are caring for children with diverse needs.

Some of the more common conditions include:



Finding time for home therapies and appointments is a challenge.

We found that almost three out of every four parent-carers were expected to carry out prescribed activities or exercises at home to promote their child's learning and development.

Of these families, 94% reported experiencing at least some difficulty finding a slot in their daily routine to carry out prescribed activities or exercises.

On average, families spend 10 and a half hours each week implementing home therapy programs and attending appointments with health, education or other professionals.

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.

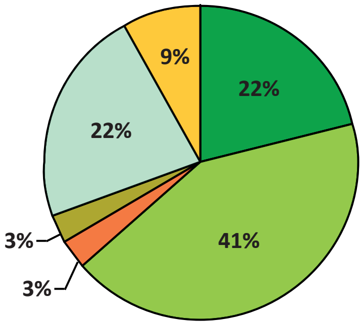
Families vary in the way they organize earning and caring activities:

22% are lone-parent families (single earner, single carer).

9% are two-parent families in which the parents work similar hours and contribute equally to care-work.

41% are two-parent families with ‘traditional’ roles: the father is the primary earner and the mother is the primary carer.

22% are two-parent families in which the mother works full-time and also does ‘the lion’s share’ of the care-work.



It is difficult for many parent-carers to find a balance between work and family.

27% of parent-carers say that they very often or always find it difficult to fulfill family responsibilities because of the amount of time spent on work related responsibilities.

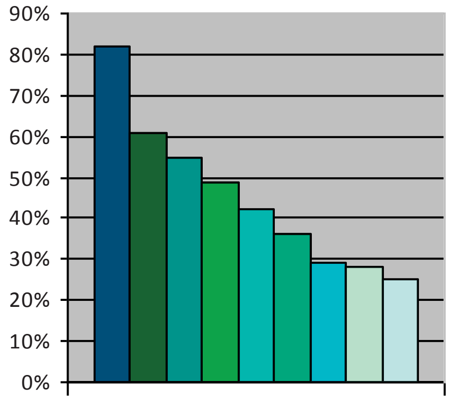
On the other hand, 19% of parent-carers report that they very often or always find it difficult to concentrate or fulfill work responsibilities because of their family responsibilities.

22% of 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.

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.

> *“ I have taken sick days to avoid burn-out, and a leave of absence from work, twice now, when [my son’s] medical needs called for it”*

To keep their family life running (that is, to free up time, increase family resources, or reduce demands) :



- 82% Reduced participation in sports and leisure
- 61% Called on extended family for support
- 55% Called on friends for support
- 49% Decided to have fewer children
- 42% Quit work altogether
- 36% Turned down a promotion or job
- 29% Became self-employed
- 28% Employed a nanny or housekeeper
- 25% Moved to be closer to support

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Thank you for Participating

The purpose of the FDSI is to promote the participation, health and wellbeing of people with disabilities and their families across all areas of life. We aim to forge new research collaborations, fuel innovation, and build systems capacity to support persons with disabilities and their families, by bringing people together from different disciplines and sectors (university, government, community) and by working in partnership with individuals with disabilities and their families.

The Family and Disability Studies Initiative is dedicated to promoting dissemination of new knowledge into policy and practice. We are committed to promoting the rights of persons with a disability and their families to engage in decision making processes that affect their lives, and to equal opportunities for health and wellbeing across the lifespan.

Join the Online Forum

Please take a moment to visit our online discussion forum.

The Sustainable Family Care Forum is a place on the internet for families of children with disabilities (including adult children) to enter into an open discussion about juggling the demands of parenting, employment, dealing with government and private support agencies, and a variety of other life challenges.

The purpose of this part of the study is to help us achieve a deeper understanding of family life for parent-carers of children with disabilities, and the resources they need to keep their family life running. We want to know what families are thinking about balancing life's other demands with parenting a child with a disability.

You can log-on and join the discussion whenever it is convenient for you to do so by visiting the forum at www.supportedparenting.ca

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