

Towards a Provincial Strategy

Advancing Effective Respite Services in Fetal Alcohol Spectrum Disorder (FASD)

2010

FASD | ONE

Fetal Alcohol Spectrum Disorder
Ontario Network of Expertise

Intervention and Support Working Group



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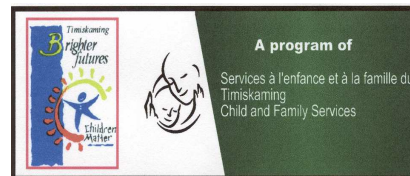
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FASD ONE (Ontario Network of Expertise, formerly known as the FASD Stakeholders for Ontario) is an unincorporated collaboration of diverse provincial and local stakeholder groups working to better serve children, youth, parents, pregnant women, and families affected by FASD in communities across Ontario. In order to better educate the public on issues facing people with FASD, the Intervention and Support Working Group of FASD ONE commissioned three research papers in 2009/2010 (of which this paper is one) on effective practices, education, and respite.

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Executive Summary

Fetal Alcohol Spectrum Disorder (FASD) is an umbrella term describing a range of disabilities that may affect people whose mothers consumed alcohol while pregnant. While there are different diagnoses included in the FASD spectrum, all individuals with FASD have brain damage. This brain damage can cause a range of disabilities including mild to severe delays in cognitive, physical, emotional, social and behavioural skills. Research with child welfare samples confirms that children and youth with FASD are likely to enter the child welfare system at an early age and remain in the system long term. Secondary disabilities are common for individuals with FASD and many require support throughout their lifetime. Caregivers of individuals affected by FASD are often not the biological parents. The purpose of this research was twofold: (a) Investigate the effectiveness of respite services presently available for families of individuals with FASD; (b) Identify barriers preventing families from accessing respite services.

In March and April 2009, 164 respondents representing 208 individuals affected by FASD in Ontario completed a survey about respite use. The findings are:

- Families face numerous barriers in accessing respite including exclusionary funding eligibility, the high level of care required by individuals with FASD, lack of suitable programs and trained workers and the emotional costs of using respite time.
- Respite is vital to families to combat burnout and fatigue, decrease isolation of the family as well as individual with FASD and maintain healthy family relationships.
- Respite is extremely effective in reducing caregiver stress.
- Respite is extremely effective in increasing family stability.
- Families affected by FASD are often in crisis.
- The cost of respite is a fraction of the cost of providing foster care for individuals with FASD.

Recommendations:

1. The Ministry of Children and Youth assume the lead for individuals and families affected by FASD.
2. Invest in respite for all families affected by FASD.
3. Create inclusive and accessible funding.
4. Train, coordinate and support respite workers.
5. Invest in research and knowledge building.

Case Study

James is nine-years-old, in grade four and has two older siblings. James looks like any other child. He reports that he hates school, likes sports, has lots of friends and is awesome on his Xbox. If prompted, he may explain that his brain works a little differently than others, because his mom drank alcohol when she was pregnant and now he has brain damage. He has been diagnosed with ARND.

For James, his brain damage means that he has a poor memory, is very impulsive, thinks slowly and is easily overwhelmed. His parents make every effort to minimize distraction and help James get through his day successfully. His dresser drawers have pictures on them to help him remember what is inside. There are pictures in his room and at the front door telling how to get dressed. Still, he is easily distracted and would never get through his morning routines without constant verbal reminders.

For safety, James' mother still walks him to school and waits until he goes in. James' brain damage means that he talks freely with strangers, cannot cross streets safely and if left alone would likely not reach school. School is very overwhelming for him. He hates the constant noise and cannot sit still. It's hard for him to read, do math and get organized. When things are difficult at school, James walks out of the classroom, sometimes out of the school. He just needs to get away. If someone gets in his way he may punch them or throw things. James says he has a lot of friends but yet is never invited to parties or even to hang out after school. His "friends" keep getting him into trouble. One tells him to take things from the teachers' desks. Others try to make him get frustrated to see him go into a rage and run away. James really wants friends but he cannot understand that this is not what real friends do.

James' parents are exhausted from attempting to stay one step ahead, avoid rages, meltdowns and conflicts. Most days it feels like everything is a fight, every step of the day, even with all the preplanning. There are many things that James loves to do and is good at, like sports, but the struggle to get him there is exhausting. Rewards and punishments have no effect and they are tired of repeating the same rules over and over again. They can never take their eyes off him.

Friends ask, "Why don't you just hire a babysitter and go out for dinner?" They tried this, when James was seven. In two short hours he ate two cartons of ice cream, jumped off the stair railing, tore apart his older brother's room looking for his "favourite car" and took off down the street running and screaming obscenities. Frantic, the "babysitter" called saying she couldn't get him to come back.

His parents need a break. His siblings are frustrated by James' constant demands on their parents' time and attention. As a couple they never go to parties together; choosing to go alone or not at all. James' parents know that their friends and family cannot really grasp what life is really like for them with him. They try to ignore the judgments - that they need to be better parents, or to discipline him more and set clearer limits. No one understands how exhausted they are; how heart-breaking it is to consider sending James to live somewhere else...no one understands how much they need a break.

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Introduction

In 2008, FASD ONE—Ontario Network of Expertise—(formerly the FASD Stakeholders for Ontario) conducted a needs assessment through an online survey of caregivers and service providers. The assessment was distributed among FASD e-lists, support groups, and agency clientele to determine the needs of people caring for someone affected by FASD. The resulting report, *Moving Forward and Supporting Families Affected by FASD* (Intervention and Support Working Group, 2008), served as the basis for the development of an evidence based-strategy to address the unmet needs of families caring for individuals with FASD.

FASD ONE is a group of service providers and parents/caregivers that work to address issues related to FASD in the province. There are five sub-committee working groups, of which the Intervention and Support Working Group is one. Its mandate is to “focus on building capacity within service sectors and systems and the general community to be able to respond appropriately to the unique and diverse needs of those living with FASD” (*Moving Forward* [2008], p. 2).

Respite support was identified by caregivers of individuals with FASD as one of their top three unmet needs (*Moving Forward* [2008]). Respite is defined as a family support service with the goal of providing primary caregivers a temporary break or refresher from the physical and emotional demands involved in caring for a family member who has a disability (Ministry of Children and Youth Services, 2008; Mullins, Aniol, Boyd, Page & Chaney, 2002).

Respite can be distinguished by purpose, duration, location, service provider and whether it is formal or informal (Pollack, Law, King and Rosenbaum, 2001). Purpose is understood as either primary service or secondary service. Primary services are those intended and designed solely for respite. Secondary services are developed for alternative reasons and respite results as a by-product. Examples of a secondary service are a summer day camp or a weekly swim program. Duration is the length of time that respite is provided. Respite can be on a short-term basis, such as a couple of hours each week, or longer term such as a weekend, week or month or longer. The location of the respite may also vary. Respite can be provided in the individuals' home, out of the home as a part of community-based recreational programming, in a different home of friends, relatives or neighbours, in a residential care facility or through short-term hospitalization. Consequently, the providers of respite can vary from trained professionals to personal and familial supports. Formal respite is often provided by professionals, in or out of home. Informal respite reflects cooperative models of respite, where there is more flexibility, often provided by family, foster parents or friends (Pollack et al., 2001).

In *Moving Forward* (2008), caregivers of those affected by FASD spoke of the inadequate support they receive in meeting the complex needs of their children with FASD, specifically for respite. The lack of support and respite contributes to high

levels of stress, frustration and exhaustion commonly experienced by caregivers of children and youth with FASD. The severity of this situation is further reflected in the words of a caregiver of an individual with FASD.

Families are in crisis and supports are difficult to find and challenging to fund. Many are forced to do without or to space respite too thin to be beneficial. Every day in our home there is potential for crisis – it is so far from what other families experience – there is little understanding...the experience of raising kids with FASD is ‘different’ in ways only other FASD caregivers can comprehend.

According to Health Canada (*Principles of Children and Youth Health*, 1993) for optimal development, “children need to grow up in a nurturing atmosphere of support, happiness, love and understanding”. Many children and youth affected by fetal alcohol are already at a disadvantage. For example, it is estimated that 80% of children and youth affected by FASD will be cared for by someone other than their biological families (Streissguth et al., 2004). As a result, many are or have been involved with the child welfare system. Numerous researchers have also stated that caring for an individual with FASD is extremely stressful, isolating and challenging (Fuchs, Burnside, Marchenski, & Mudry, 2007; Paley, O’Connor, Frankel & Marquardt, 2006). The single most important way that society can optimize the development of children and youth is through the support for the family (Health Canada, 1993). It is the principle of family support that informs FASD ONE’s assertion that adequate and appropriate respite is necessary not only for the optimal growth of children and youth affected by FASD, but also to aid all families in sustaining healthy, supportive and permanent relationships with their family members. Further, without support from government to community and grassroots organizations, families affected by FASD will break apart, ultimately costing tax payers billions of dollars.

FASD and Caregiving

FASD is an umbrella term describing a range of disabilities that may affect people whose mothers consumed alcohol while pregnant. Included under the FASD umbrella are the following diagnoses: FAS – Fetal Alcohol Syndrome,¹ pFAS – Partial Fetal Alcohol Syndrome, ARND – Alcohol Related Neurodevelopmental Disorder and ARBD – Alcohol Related Birth Defects (Public Health Agency of Canada, 2007).

¹ Confirmed alcohol consumption is not necessary for this diagnosis. (Chudley, A. E., Conry, J., Cook, J.L., Looock, C., Rosales, T. & LeBlanc, N., 2005)

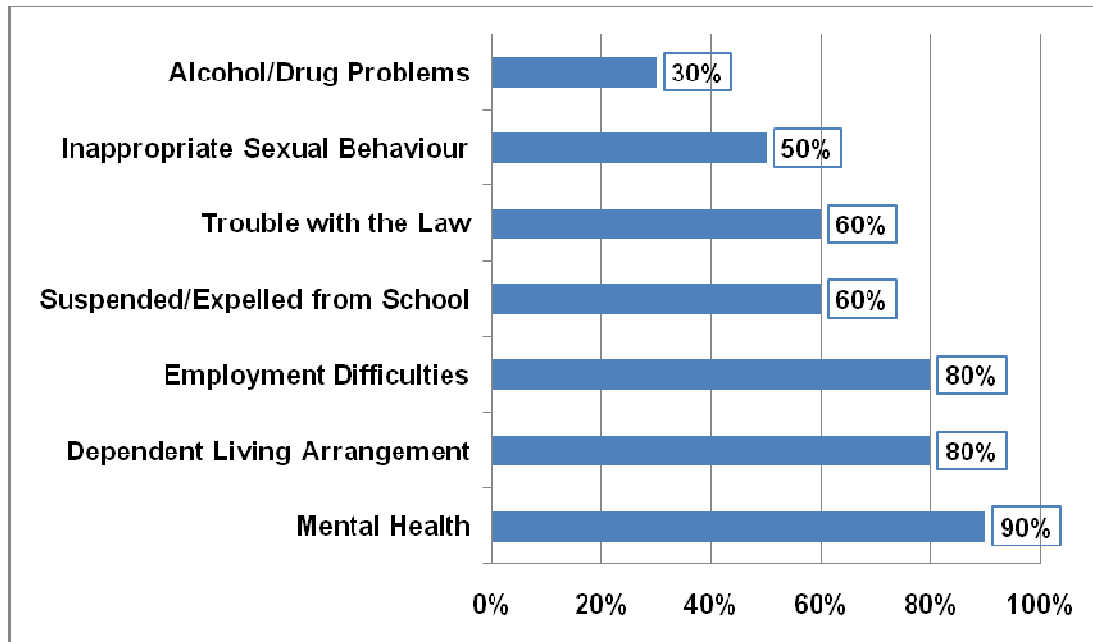
FASD is considered to be leading known cause of developmental delay in North America (Public Health Agency of Canada, 2007). According to the Public Health Agency of Canada, 1% or approximately 300 000 living Canadians of all ages are currently FASD-affected (Public Health Agency of Canada, 2007(b)). As the capacity to diagnose FASD increases in Canada, many researchers and FASD professionals expect the prevalence of alcohol-related affected individuals to reach 9.1 per 1000, nearly 1 in 100 births (Sampson, et al., 1997). It appears that there are a high percentage of children and youth with FASD in the child welfare system. Fuchs, Burnside, Marchenski, & Mudry of Manitoba (2005, p. 70) state that 17% of children in care were affected by diagnosed or suspected FASD.

The major difference between an individual diagnosed with FAS or pFAS and ARND is the lack of distinguishing facial features and growth impairments. Since the majority (approximately 95%) of individuals with FASD are diagnosed with ARND, this lack of identifying physical characteristics results in FASD usually being an invisible disability. Thus, many individuals are often misdiagnosed.

Of crucial importance is the permanent damage of the central nervous system domains such as brain structure, cognition, memory, executive functioning and abstract reasoning, attention deficit/hyperactivity, adaptive behaviour and social skills in ALL FASD diagnoses. Appendix A provides a comprehensive list of common characteristics of people diagnosed with FASD. Prenatal alcohol exposure affects each individual differently, presenting a variable level of disability for each person. These are lifelong disabilities that restrict an individual's ability to grow and mature into an independent and productive adult (Streissguth, Barr, Kogan & Bookstein, 1996). According to Connor, Sampson, Bookstein, Barr and Streissguth (2000) individuals with FASD will often require varying degrees of lifelong medical, social and educational support.

While the effects of FASD are permanent and lifelong, the development of secondary disabilities is variable. Streissguth et al. (1996) presented a detailed investigation of the various secondary disabilities associated with FASD including mental health issues, the inability to live independently as well as employment and education difficulties (Table 1).

Table 1: Secondary Effects of FASD (Adapted from Streissguth et al., 1996)



Streissguth, Barr, Kogan and Bookstein (1997) identified eight factors that were influential in decreasing the likelihood of secondary disabilities or secondary effects as presented in Table 1. The eight protective factors discussed by Streissguth et al. (1997, p. 35) were:

- Living in a stable and nurturant home for over 72% of life;
- Being diagnosed before the age of 6 years;
- Never having experienced violence against oneself;
- Staying in each living situation for an average of more than 2.8 years;
- Experiencing a good quality home (10 or more of 12 good qualities) from age 8 to 12 years;
- Being found eligible for DDD (Division of Developmental Disabilities) services;
- Having a diagnosis of FAS (rather than FAE);
- Having basic needs met for at least 13% of life.

Of these eight factors, half were directly related to a stable and nurturing home life during childhood. Many children and youth with FASD will lack stable, nurturing homes (Streissguth et al., 2004). As the experiences and needs of a child with FASD will vary considerably throughout their life course, caregivers encounter an ever changing array of challenges. Research has demonstrated that with early intervention, diagnosis and family stability the secondary disabilities of FASD can be

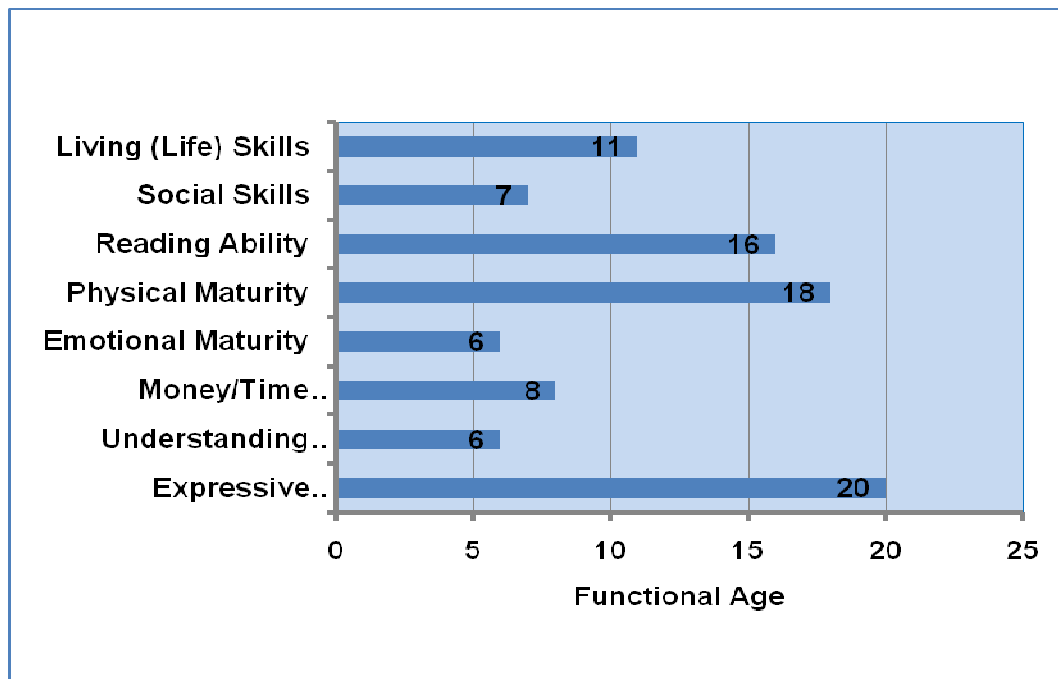
minimized and/or avoided and the impacts of this disorder can be greatly reduced (Public Health Agency of Canada, 2005; Streissguth et al., 2004).

Due in part to the invisible nature of FASD, the role of caring for those on the FASD spectrum is often very isolating for families. Brown and Bednar (2004) discussed how families felt that their children's behavioural issues were the only aspects seen by others. The families felt judged and dismissed. As a result of misunderstood behaviours "the children were at risk for school problems and the family, for social isolation" (p. 15).

Paley et al. (2006) determined that for parents of children with FASD, the strongest predictor of parent stress was the level of executive functioning of their child. Executive functioning refers to the set of cognitive skills needed for the planning, initiation, sequencing and monitoring of behaviour. Specifically there was a correlation between executive functioning and parental stress with low functioning creating high parental stress. Thus, for parents, regardless of their child's IQ, it was "the child's cognitive limitations in planning and organizing their behaviour in order to engage in effective problem solving and their ability to perform developmentally appropriate tasks in everyday life that were especially taxing to parents" (Paley et al., 2006 p.401). Paley et al. (2006) even suggested that children with FASD "are more challenging to parents (than other children) and thus can create significant stress to their parents" (p. 396).

Diane Malbin (2002) offers an explanation for caregivers' focus on executive functioning and perhaps the challenging nature of parenting individuals with FASD. In considering Table 2, an individual like James profiled earlier, would be able to converse at a level equivalent to his chronological age. However, due to dysmaturity skills related to daily activities and functioning, age discrepancies would be extremely apparent. For example, James' daily activities such as dressing, hygiene and organizing for school would be very difficult as he would be functioning at a developmental age of three years. Furthermore, James' social skills and emotional immaturity, likely at five years of age functionally, would further serve to isolate both James, as well as his family. As James grows older, gaps in money and time management skills would become more problematic. In the long term, the caregiving role for James' parents is uncertain and likely endless. An overwhelming number of individuals with FASD cannot live independently. The task of caring for and parenting a child with FASD is a substantial and often a lifelong commitment (Streissguth et al., 1996).

Table 2: Dymaturity—Fictional 18 Year Old with FASD (Malbin, 2002)



Given the ongoing research that has demonstrated the extreme stress on parents caring for children with FASD it is not surprising that *Moving Forward* (2008) concluded that respite support was one of the highest needs for families affected by FASD in Ontario. As a result of these findings, the Intervention and Support Working Group of FASD ONE conducted this in-depth investigation of respite for families of individuals with or suspected of having FASD. The purpose of this investigation was to research the effectiveness of respite services available to these families, and to identify the barriers preventing them from accessing respite services.

FASD and Caregiving

- 1 in 100 people have FASD
- All people with FASD have brain damage
- Secondary disabilities are minimized by supporting families
- Isolation of individuals and families is common
- Individuals with FASD have dymaturity
- Individuals with FASD often need life-long support
- Individuals with FASD can be very difficult to care for

Respite Survey Methodology

Instrument

The FASD Stakeholders Respite Study was conducted from March 20 to April 20 2009 using *Survey Monkey*, an online survey tool. The survey was emailed to known FASD parent support groups, e-lists and agencies. The email introduced the survey and explained that the survey was intended for caregivers of individuals diagnosed with or suspected of having FASD. The email directed possible respondents to an online link for the respite survey. A printable version of the survey was attached to the email to be distributed to families who were unable to connect electronically to the online survey. This method of recruitment yielded 164 respondents representing 208 individuals affected by fetal alcohol.

Data Analysis

The qualitative data were reviewed in detail to gain a general understanding of the respondents' experiences with respite in relation to their family member(s) affected by FASD. It should be noted that the perspective of biological parents with respect to respite may not be adequately captured here—only because the majority of responses came from adoptive parents, foster parents and grandparents. The researcher used a constant comparison approach to identify points of consensus across those who did respond to the survey, as well as differences in experiences. Through this process themes emerged and quotations were selected from the qualitative data to illustrate a range of experiences. Throughout this report quotations are included from caregivers of individuals from a wide range of ages and levels of functioning.

Results

Family Demographics

Table 3: Geographic Distribution of Respondents

Where in Ontario do you live? n=164	
Southwestern Ontario includes London, Sarnia, Windsor	31.1%
Kit/Wloo/Guelph/South to Lake Erie	17.1%
Grey-Bruce includes Owen Sound, Kincardine	11.0%
Southcentral Ontario includes Greater Toronto Area/Hamilton	9.8%
Central East includes Peterborough, Orillia, Barrie	9.8%
Eastern Ontario includes Ottawa and Kingston	7.9%
North West includes Thunder Bay, Kenora, Nipigon	6.7%
North East includes Sault Ste. Marie, Timmins, North Bay	6.7%

While the majority of respondents were living in the south-western region of Ontario, responses were distributed throughout Ontario including the northwest and eastern regions (Table 3).

Table 4: Caregiver Relationship to Individual with FASD

My relationship to this individual would be best described as: n=164	
Adoptive parent	59.5%
Other (please specify)	16.0%
Foster parent	10.4%
Grandparent	9.2%
Kin (sibling, aunt, etc)	2.5%
Biological parent	2.5%

As was found in existing research (Streissguth et al., 2004) the majority of children and youth with FASD were not being cared for by their biological parents. In this study, less than 3% of respondents were biological parents raising children affected by FASD (Table 4). Specifically, 60% of respondents were adoptive parents with foster parents and grandparents comprising the next largest groups of caregivers. The qualitative data included with the “other” category demonstrated that some caregivers did not know how best to classify themselves with regards to traditional family relationships. For example, due to multiple individuals being cared for (i.e. one kin and one fostered) respondents chose “other” to be inclusive of both children. Caregivers in the “other” category also described themselves as “step parent”, “girlfriend” and “cousin”.

Table 5: Age of Individual(s) With FASD

The person or persons I care for are in the following age groups.(Choose all that apply) n=164	
Infant (0–1 year)	2.5%
2–3 years old	8.0%
4–6 years old	20.2%
7–12 years old	45.4%
13–18 years old	37.4%
19–24 years old	10.4%
25 years old and over	9.2%

The ages of individuals being cared for ranged from infant to those over 25 years of age (Table 5). Within this sample from Ontario, 21% of families were caring for two individuals with FASD and 8% of families were caring for three or more individuals with FASD.

Barriers to Respite

The quantitative data showed that 51% of respondents were not receiving any form of respite, either informal or formal. Concurring with existing research (Murphy, Christian, Caplin & Young, 2006) caregivers in this study reported a number of reasons for not accessing respite. Since respondents were asked to choose all of the barriers that applied to their situation, multiple barriers were reported by the majority of the caregivers. For the purposes of this discussion, each barrier will be considered separately.

Table 6: Barriers to Respite

Why do you not use respite services? (choose all that apply)	n=81
Do not know how to access	36
Other (please specify)	36
Cannot afford it	27
Do not qualify for funding	24
Do not feel that others can care for child	21
Child will not stay/go with anyone else	19
Do not have time/energy to organize it	18
Do not need it	7

First, 36 of the 81 families not receiving respite who answered this question responded that they “do not know how to access” respite (TABLE 6). As one respondent explained,

I don't know where to access it, who to call, what services we would be entitled to, where to access funds, how to request, find someone reliable, willing, affordable that we would trust and would be good with our son.

This finding was consistent with those of Freedman and Boyer (2000) who reported that a lack of information about support options was a barrier experienced by many families. Ironically, caregivers commented that they do not know how to access respite because there is no respite available to their family. Many families had discovered that there were “no organizations willing to provide” formal respite in their area or that “most camps do not accept behaviour kids”.

In addition to limited or no formal respite services, due to family isolation, the possibility of using friends and family as respite providers was also not an option for many caregivers. Simply stated by one caregiver: “People don't want my kids over”. The behaviours that can be associated with FASD make it difficult for caregivers to rely on family and friends.

Our daughter's challenging behaviour make it hard for most people to deal with in a positive manner. Most people, including adult family members are not able to handle her behaviour and needs.

Two different adoptive parents described why they cannot rely on family members as respite caregivers:

My mother, as an example, can't cope with my daughter very well...She has said that we made a mistake adopting our daughter. It is true that it has made our family life very difficult. My daughter is a beautiful, joyful child.

It is too much to ask grandparents to take on FASD kids who may vanish without notice or apparent reason.

The second barrier identified by caregivers for not using respite was that they “cannot afford it” (n=27) and/or “do not qualify for funding” (n=24) (TABLE 6). There are two sources of continuous direct funding available to Ontario families of children and youth with disabilities. The Ministry of Children and Youth Services of Ontario provides qualifying families assistance through two programs Special Services at Home (SSAH) and Assistance for Children with Severe Disabilities (ASCD).

SSAH helps families who are caring for a child with a developmental or physical disability, as well as adults with a developmental disability (Ministry of Children and Youth Services, 2007). It provides families with a monthly allotment, to be used to assist with any support needed for personal development and growth and/or family relief and support. It requires a clinical diagnosis, and decisions are often dependent on IQ scores rather than the functioning level of individuals. Individuals with FASD are usually within the normal range for IQ. However, their level of functioning does not reflect their IQ scores due to dysmaturity (see TABLE 2). As a result, individuals affected by FASD are denied SSAH funding. This narrow criterion for accessing funds was one of the most significant barriers discussed by caregivers in the qualitative data addressing barriers to respite.

Our son is not ‘developmentally delayed enough’ to access respite.

Just because they [the children] have a high IQ does not mean that parents are coping well. Impulsivity, hyperactivity, poor judgment and many other things can be going on for children with high IQ. Mostly it is the behaviour that a parent needs a break from and the hypervigilance and not the child's poor cognitive skills.

I was told my child's IQ was too high in order to access respite services through the Ontario Government...her adaptive functions were not considered. This would have helped...my child's needs make her super difficult to care for and informal supports are not available because of this.

The need to broaden eligibility criteria of the SSAH program has been highlighted by many. The Ministry of Children and Youth Services, *Children's Respite Report – Best Practices and Best Delivery* (2006) recommended that to improve respite services there was a need for “greater flexibility of funding (e.g. broaden the eligibility criteria of SSAH, and flexibility in agency mandates)” (p.24). It should be noted that the proposed *Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, 2008* (Ministry of Community and Social Services, 2009b) offers some hope that the new definition of developmental disability will be more inclusive of FASD. However, the proposed changes will only apply to those 18-years-old and older (Ministry of Community and Social Services, 2009a).

The cost of respite and the inadequate level of assistance granted through the SSAH program were also discussed by caregivers. SSAH funding is not exclusively applied to respite. The flexibility in applying the funds is reflective of the diverse needs of all families with disabilities. However, recent consultations conducted across Ontario with regard to the transformation of developmental services have concluded that the financial support offered through SSAH is inadequate for meeting the costs deemed to be covered by SSAH (Parsons, 2006). Expenses such as transportation, materials, emergency respite, and long-term respite are not accounted for and restrict the ability of caregivers to maximize the use of funds. The reality of this shortfall is felt by families affected by FASD who are receiving SSAH funding. In fact, in this present study, the data shows that 53% of families receiving SSAH chose to supplement their respite with their own funds. Families, who have no discretionary income, are forced to make difficult decisions about whether to allocate SSAH funds to such things as life-skill training and tutoring, or respite. As explained by one parent,

It is so hard to find money to pay for respite as we also use the limited amount of SSAH funding for developmental purposes [tutoring] as he is so delayed in that area and it is a priority.

The situation with SSAH becomes even more problematic when one considers the seemingly unstable future of the SSAH program. The backlog and waiting lists that exist for funding are frustrating for parents. The program continues to experience difficulties in meeting demand; with a growing number of families needing access to the service outweighing the program's budget.

I have been, two years in a row, told that I was entitled to additional SSAH funding, but the money is not available.

The second funding option for families is Assistance for Children with Severe Disabilities (ACSD). ACSD is available to those with extraordinary costs of raising a child or children with a developmental and/or physical disability with severe functional loss. Similar to the SSAH, families are compensated monthly for

expenditures. Monetary allotment is dependent on clinical diagnoses, demonstrated severe functional loss and the financial circumstances of applicants. While the ACSD is available for extraordinary costs and can be utilized towards respite, the eligibility criteria often exclude most individuals with FASD. Furthermore, within this study, the data shows that 50% of families who received ACSD chose to supplement with private funds, again forcing them to make difficult decisions.

Although SSAH and ACSD offer a broad range of benefits and are open to a variety of individuals with disabilities; the allotment of funds is dependent on the nature and demands presented by a diagnosed disorder. However, the criteria for acceptance is done using a traditional understanding of physical, developmental and cognitive disability which does not align with the challenges found in raising a child or children with FASD. In particular the unique challenges of parenting a child with FASD centre on the individual's level of dysmaturity, low executive functioning combined with social, learning and behavioural challenges that most often require lifelong, one-to-one support. These challenges are not fully appreciated or properly assessed by the current SSAH and ACSD programs. As a result, most children with FASD do not qualify for ACSD and those receiving SSAH find their monthly allotment inappropriately assessed for the challenges presented in raising a child or children with FASD.

The lack of available funding sources means that many families do without a break or sacrifice other needs. As caregivers explain, they are forced to put themselves last, even with the knowledge that their family stability may be at risk.

Take it on the chin, suffer through even to the point where we are at risk of causing severe difficulty with family structure.

Challenging to budget for it [respite]...and we sometimes end up choosing between more learning activities for our child, and 'sanity time' for us, as funds won't cover both.

One adoptive parent explains how even though the individual with FASD is over 25 years old, the financial strain and need for support do not necessarily decrease.

Presently I am retired but have taken on a full time job. With the help we give our son, this is the only way we can make it.

The third barrier to respite is the belief that “others cannot care for child” (n=21) (see Table 6). For many caregivers, the process of having to find a competent respite worker is time consuming, frustrating and unsuccessful. Caregivers stated that their children were “too difficult for friends and family to manage” and that there were “not enough people that really get [actually understand] FASD in [their] community”. Murphy et al. (2006) found that the complexity of care needed by individuals with FASD required caregivers who are competent and compassionate.

Similarly respondents in this study felt that they did not have family or friends who were skilled and able provide regular respite.

Because individuals with FASD are very different than other disabled people, the care providers have to know what they are dealing with or they could cause more problems than they solve.

Difficulty in accessing suitable respite workers was also discussed in terms of “others cannot care for my/our child”. Some caregivers reported that they had “poor experiences with quality of care”. For example, one caregiver stated that her daughter “manipulated to get her way, and the list of instructions I left for her routine were not followed”. Many respondents stated that “trained people are scarce” and that they “struggle to find secure, safe and effective people” to care for their children. One caregiver of children 4–6 years old and 7–12 years old, both with FASD, explained,

I can't hire teenagers because my kids require adult supervision. I have to have someone who is available regularly because I can't have different people every time.

Another parent of a 5-year-old girl with FASD describes why it is difficult to have a break, even for a few hours.

I cannot even hire a babysitter of any age to handle my daughter for a couple of hours and pay out of pocket. No one is capable of handling her behaviours outside of my husband and myself.

Caregivers expressed the need for respite workers who have received training about FASD, have an understanding of issues that are specific to FASD and appreciate the unique needs of the individual child. Although not specific to FASD, other research has also identified lack of qualified staff as a key barrier to families accessing support (Freedman & Boyer, 2000; Pollock et al., 2001). Families of individuals affected by FASD explained that their need is for respite workers who would “build a relationship”, establish a “kind of trust” and ease transitions to and from respite and home. Caregivers spoke of the wanting to establish “seamless care” that would be committed to following the routines because

These children need consistency...change in one thing is enough to throw their entire world into a tailspin, this is not an exaggeration.

The need for experienced and trained respite workers was even more of a challenge for caregivers of older individuals with FASD. A foster parent describes this situation in terms of her teenage sons,

It is very, very, very difficult to find respite as my sons get older and their behaviours are more risky. Fewer and fewer people are willing to provide the care, often because of the level of supervision required and the need to keep negative influences away. Many people or situations are unsuitable as it could expose my children to influences which [could cause difficult behaviours] due to them being easily led.

The need for specialized training was noted in the recommendations in the *Children's Respite Report – Best Practices and Best Delivery* (Ministry of Children and Youth Services, 2006). Specifically, "special attention should be given to recruitment and training of respite workers for children who are medically fragile and children with mental health needs." (p. 40). Given the high probability of individuals with FASD having mental health issues (Table 1), it seems prudent to include training on FASD for respite workers as a priority.

The frustration of finding an informed and skilled respite worker is further exacerbated by the inability to retain respite workers. It is best if respite workers can develop a relationship with the children. Parents and caregivers know that children with FASD need familiarity, structure and routine, and do not respond well to change. However, inadequate compensation, little job stability and burnout cause a high turnover rate of relief workers serving families with developmental disabilities (Freedman & Boyer, 2000; Parsons, 2006). Furthermore, many have recommended a centralized agency responsible for supervising and coordinating respite workers (Ministry of Children and Youth Services, 2006; Pollock et al., 2001). While www.respiteservices.com has the potential to offer this service, the majority of families affected by FASD are ineligible due to the strict criteria for the SSAH program.

The fourth barrier was related to the openness of the individual with FASD to be cared for by a different caregiver. Some families (n=19) (TABLE 6) were struggling with multiple issues tied to the child being unwilling to be with anyone other than their primary caregiver.

Our adopted children with FASD also struggle routinely with attachment, trauma and abandonment issues.

My children have some of the mental health issues associated with FASD and it is a bit frightening to think about leaving them with strangers. They also have some attachment and behavioural issues that make it difficult as well. They need to be supervised constantly.

For many families, the need for in-home respite was discussed because of separation anxiety and lack of previous social experiences. For example, one grandparent stated that her "granddaughter will not stay ANYWHERE overnight

without us, she has separation anxiety” while another caregiver explained that her “daughter has never been to another home”.

The fifth barrier to using respite emerged from comments included in the “other” category (n=36) (TABLE 6). When examining the qualitative data for this category the theme of emotional costs of respite for both parents and individuals with FASD emerged. One caregiver summarized the dilemma faced by many when weighing the options of respite for individuals with FASD.

The job of getting everyone back on track after respite can be more work than keeping the consistency of the routine, even if it means giving up the chance for some down time.

Murphy et al. (2006) reported similar findings with parents explaining that respite was almost not worth it given the amount of energy, time and effort needed to prepare for it. One of the most common concerns discussed by families reflected the need for continual structure, supervision and support. A high level of care must be present during respite time to minimize disruptions for the individual with FASD. One caregiver was concerned that respite would not be an alternative for them because “too many people coming in and out of the house is disruptive as the consistency is now strongly implemented.” Families felt “guilty for asking for help”. Some adoptive, foster or kin caregivers may feel that they do not have the right to ask for assistance or a break. Some caregivers believe that since they choose to adopt or foster, they must accept all the challenges and problems on their own. Other caregivers were “scared to try (respite) due to my son not accepting the authority of that person.” Others expressed fear of being judged or criticized.

People do not understand the total issue to do with FASD. There are assumptions that go with every worker, which do not usually fit with FASD...one of the worst [assumption] is that there are no problems, just parenting issues.

Caregivers recognize that it is difficult to understand FASD unless you are “living it”. As Brown and Bednar (2004) stated many caregivers would like to be acknowledged, valued and respected for their experience. Or as one of the current study respondents stated, how “extremely difficult it is for the caregivers of a FASD individual because you have to provide care 24/7.”

Respondents' Barriers to Respite

- **Funding eligibility based on IQ**
- **No suitable programs**
- **Lack of information about options**
- **Lack of knowledgeable, consistent respite workers**
- **High level of care required by individuals with FASD**
- **Emotional costs of respite**

There are multiple barriers to respite reported by the 51% of families affected by FASD not receiving respite. Many indicated through quantitative data that they did not know if there were respite services available or how to access any services that were open to their children. A significant source of frustration for many caregivers was the restrictive guidelines to provincial funding programs for children and youth with disabilities which prevented their children from qualifying. The need for trained, skilled and consistent respite workers was discussed in relation to the need for structure and routine for persons with FASD.

Characteristics of Respite Use

The data demonstrated 85 of the 164 respondents reported using formal and/or informal respite (Table 7). As in other studies of respite for families affected by FASD (Beatty, Goodman, Anderson, & Lwin, 2009), the caregivers in this study reported overwhelmingly that the goal for their respite time was to “reduce stress” (n=50), “improve the stability of . . . [their] home” (n=41) and access personal time (n=36) (Table 7). It should be noted that respondents were asked to “choose all that apply” for this question and thus multiple uses for respite were reported. Analysis of the qualitative data connected to the “other” category demonstrated that respondents also used their respite time to allow them to “do community work”, “cover overtime functions at work” and address unfinished school or work commitments.

Table 7: Type of Respite Service Used

What type of respite services do you use? Choose all that apply.	n=85
Formal	40
Informal	61

Table 8: Caregiver Use of Respite Time

I use respite (choose all that apply)	n=68
To reduce stress	50
To improve the stability of my home	41
To have more personal time	36
To have more time with family/friends	32
To have more time to care for myself	29
To run errands	26
To allow for extracurricular activities	25
Other (please specify)	21
To allow me time to take FASD training	19

A number of clear themes emerged from the qualitative data related to the question on caregivers' use of respite time. The predominant goals of respite, to reduce stress and improve stability of their home were pursued by caregivers by using their respite time in a variety of ways. Caregivers engaged in activities of self-care, tried to connect with their other children without FASD, spent time with partners and friends or attended to household duties. Within the following analysis of the use of respite time, it is assumed that caregivers' uses of respite time are interrelated. For example, to improve the stability of the home, one must reduce the stress, possibly by having more personal time and taking time for extracurricular activities. These themes have been isolated purely for the purpose of discussion and the reader should not consider them to be in order of importance.

The first theme that emerged for caregivers' use of respite time was self-care. Self-care was often described in terms of going to personal appointments and commitments that are impossible or difficult to do with their child(ren) who has/have FASD, such as being able to "read, walk the dog...garden, have a long hot bath with candles." Common language used in the self-care category was the need to

“relax”, “take a nap”, “reenergize”, “recoup”, “distress” and “recharge”. Similar to other studies (Owens-Kane, 2007) the majority of parents were exhausted and, in an attempt to avoid burnout, were seeking self-care time to rest. As one commented,

Occasionally we may go to a movie or out to dinner...[twice in the past 6 months] but most of the time we are so exhausted that we watch an old movie...and we generally crash by 11 p.m. or sooner.

Others spoke to the need for a break from the emotional drain and exhaustion associated with the 24/7 supervision that is necessary to care for most children and adolescents with FASD. “I always feel like I am on full alert all the time.” Other comments from different caregivers demonstrated the caregivers’ need for a break from the vigilant care and attention needed to keep individuals with FASD safe. For example, one caregiver described how respite time was used to do “nothing, nothing, nothing...[or] anything uninterrupted” and another caregiver “takes time to just not have responsibilities, not to have to be on call”. The importance of this time was highlighted by the following comments from caregivers:

We stay home to get rest and relaxation, recoup, get ready for the next series of sessions of fixations, outbursts, etc.

It is critical to have respite – for the health and well being of the whole family. Caring for a child with FASD is constant – emotionally, mentally and physically. There is not one moment when you can relax.

These qualitative results are similar to the conclusions of Brown and his colleagues from a series of studies conducted on families caring for those with FASD. Brown and Bednar (2004) stated that it takes “high energy and good self-care strategies” (p. 11) to constantly meet the challenge of the “internal and external demand of parenting” (p.11) an individual affected by FASD. In another study, the effects of burnout and fatigue were investigated in relation to the causes of placement breakdown for foster children affected by FASD (Brown, Bednar & Sigvaldason, 2007). It was concluded that the challenge of maintaining personal health for caregivers, specifically in the areas of fatigue and burnout affected foster parents willingness and ability to continue to offer quality care to their child(ren) (Brown et al., 2007).

The second theme that emerged in caregivers’ use of respite time was attending to daily, household tasks. The impact of caring for an individual with FASD is evident when parents choose to spend their limited respite time on “regular, ordinary, day to day life things [such as] groceries, chores, taxes, bills and laundry”. For many, the hypervigilance that is required to keep their children safe makes the completion of these daily activities very difficult.

We get the house organized, get caught up on paperwork that requires quiet and concentration...cleaning, planning for activities...do errands that are more time consuming or in busier environment not suitable for the child with FASD.

For families coping with FASD some simple tasks, such as grocery shopping, become very challenging due to the behaviours associated with their child's inability to cope with overstimulation, lack of structure and unpredictability. Many caregivers spoke of using their respite time to "shop in peace". Others tackled household maintenance and repairs of damage "caused during their rampages".

The third theme in the respondents' use of respite time reflected the need for couples to stay connected or reconnect given the high level of stress inherent in caring for individuals with FASD. Respondents commented on the need to have some "quiet time with my husband [wife, partner], just to catch up". The need for couples to connect is directly related to maintaining the stability of long-term care for individuals with FASD. A number of respondents pointedly and eloquently illustrated the vital role that respite plays in maintaining their family's health.

Without respite we would be unable to continue to parent these children. Doing so would cause our family to crumble under the pressure and stress of explosions, emotions, lies and oppositional defiant disorder...Respite recharges us all and allows us to do it all over again.

Without having the respite that we have now our family would not be whole, it would have broken down ages ago and we could not have gone on being their parents.

The fourth theme related to use of respite time was the need to connect with friends, family and community in an attempt to combat isolation. One mother of several children, one with FASD, described what it was like for her when her son was younger.

When he was in preschool, I think I was chronically depressed because I couldn't take him anywhere and I didn't have respite. I remember crying almost every day because I couldn't do anything or take him anywhere and he was constantly all over me and having meltdowns and upsetting everybody.

Brown and Bednar (2004) stated that caregivers of children with FASD felt that their children's behaviour issues limited what or how others saw of them. As a result of behaviours common with FASD, parents and their children are at risk for social isolation. One caregiver provided an effective description of the cycle of judgment and isolation that many others experience.

Typical family events, social settings and functions which most people take for granted are not an option for us without respite...we can never sit and watch our older son's hockey game...or sit in church services...We are constantly judged in every social situation. The worry over what he might do when we are out in public situations is non-stop...most people look at him and do not see that his behaviour is a result of an invisible disability.

Thus, it is not surprising that Doumer, Dekker and Koot (2006) concluded that families dealing with both emotional and behavioural needs were most in need of support.

For grandparents who are raising children affected by FASD this isolation is compounded by a lack of familial and similar aged peer supports. As one grandmother explained:

We are grandparents raising a seven-year-old. Our friends are no longer in the loop of parenting, our extended family is now quite an age or deceased. When we raised our birth sons we had those resource networks available to us.

Isolation may also be more of an issue for grandparents due to the incredible amount of energy it takes to care for someone with FASD. As one grandparent suggested “we are of an age where we don't have the stamina to manage two young children they way we could have in our twenties or thirties.”

The fifth theme was utilizing respite time for one-on-one time with siblings of the individual with FASD. The choice to “spend time with my other children and have a peaceful quality family time during supper” was echoed by many. The importance of this time was highlighted by a caregiver, whose children are older, when discussing the importance of respite.

Even now some of my adult children carry the scars of what happened relationally in our home because of one child. It would have been so valuable to have blocks, when we could be without that child, so that the others could have their space and time.

One parent explained that the “other children have become resentful towards them [those with FASD] because of their behaviours.” It is vital that siblings of children with FASD have time away. This description of what respite time is like for siblings and other family members provides a glimpse into the level of stress and disruption which can be brought on by an individual with FASD.

When they [family members with FASD] are away, the family enjoys `normalcy' and everyone lets down their guard. We all have more relaxed, unguarded time together. Tensions are gone, lots of `normal' communication and it is thoroughly enjoyable.

The sixth theme in respite use was related to continuing education and support. Many caregivers explained that they used their respite time to “attend support groups and seminars on FASD and child rearing with disabilities”. The role of support groups was mentioned by many. Some respondents were connected with various support groups such as adoptive parents and grandparents in addition to being parents of someone affected by fetal alcohol. According to Murphy et al. (2006) membership in support groups is beneficial for a variety of reasons. First, caregivers experience a reduction in negative emotions related to the individual with a disability. Further, “the shared caregiving experience appeared to strengthen endurance and resolve of caregivers” (p. 184).

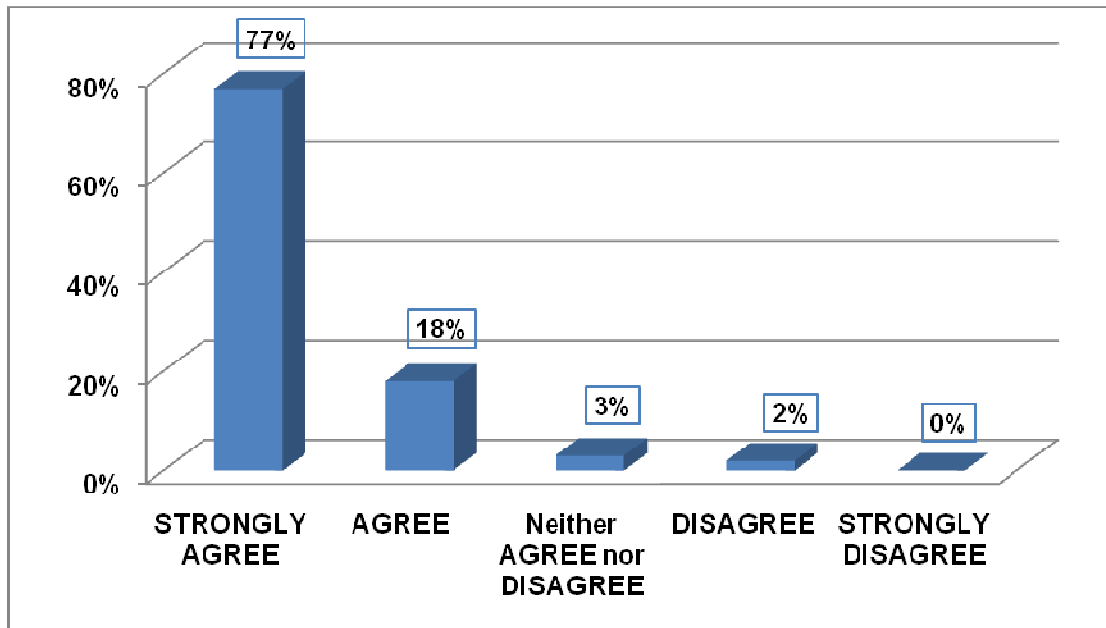
Themes in Respondents' Use of Respite
Goals: Decrease Stress, Increase Family Permanency

- **Combat burnout and fatigue with self-care activities**
- **Complete routine chores and household repairs**
- **Maintain relationship with spouse/partner**
- **Combat isolation – connect with friends and family**
- **One-on-one time with sibling**
- **Support groups and education**

Benefits of Respite

Respondents from across the province of Ontario affected by FASD who were receiving respite reported overwhelmingly that it is beneficial. When asked if respite helps reduce their stress level 95% (77% strongly agree, 18% agree) of caregivers responded that respite was an effective way of reducing stress (Table 9).

Table 9: Respite Helps Reduce My Stress Level



Numerous respondents explained how respite helped decrease their level of stress:

My husband and I struggle almost daily to keep our marriage together. The stresses we feel in raising two teenage boys with ARND are unbelievable. No one understands and no one seems to care.

I find my stress level decreases when I have time for myself and then I am much more effective and patient with my daughters and their needs.

Our stress level is so greatly reduced even with a couple of hours.

These findings are consistent with existing research which has determined that respite is an effective method of reducing stress in families affected by FASD (Beatty et al., 2009). Owens-Kane (2007) examined respite care for kinship, foster and adoptive caregivers of children with special needs and determined that 93% of caregivers reported reduced stress as a definite benefit of respite. Research also suggests that the decrease in stress from respite could positively affect the physical and mental health of caregivers. Murphy et al. (2006) determined that the majority of caregivers of children with disabilities “reported adverse physical and mental health impacts and trace this to a combination of the concrete tasks of caregiving and the pervasive anxiety about their child’s health and future” (p. 184). However, despite recognition of the negative influences on their health, caregivers cited lack of time

and lack of respite hours as two of the barriers to promoting their own health (Murphy et.al., 2006). Within the present study, caregivers provided examples of how respite time eases the physical and mental strain of caring for someone with FASD.

The burnout caused by parenting someone with FASD is unbelievable.

These wonderful, caring, damaged children can unknowingly cause all kinds of stress and reactions that are dangerous to every one's mental health. We all need time out from each other to calm down and cool off.

Looking after a child with FASD is emotionally and physically draining. The caregiver is of no use to anyone else if they are not stable.

The Murphy et al. (2006) investigation of caregivers of children with disabilities concluded that “virtually all (of the caregivers) had experienced chronic fatigue and sleep deprivation” (p.183). There is some evidence that exhaustion and burnout may be worse for caregivers of individuals with both emotional and behaviour problems such as many of those with FASD. For example, in their investigation of supports for parents of youths with intellectual disabilities, Doumer et al. (2006) concluded that those who perceived that their children had both emotional and behavioural problems were the families that required the most support. Given that many individuals with FASD exhibit both emotional and behavioural symptoms it may be assumed that caregivers will require high levels of support. Brown et al. (2007) provide some evidence to support this assumption from their investigation of causes of placement breakdown for foster children affected by FASD. In their study, foster parents identified “exhaustion” and the “challenge of maintaining personal health” as two of the six factors affecting placement stability (p.328). The following statement from a caregiver summarizes the importance of respite in reducing the stress of caring for someone with FASD.

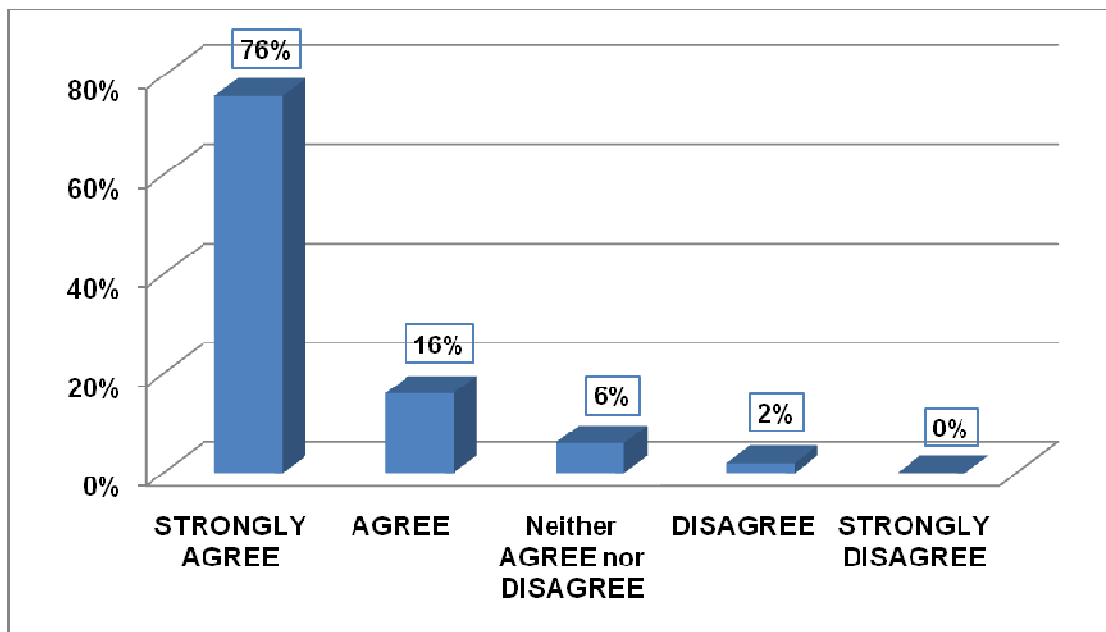
FASD is the hidden disability and therefore the time and effort put into our children, the exhaustion and mental fatigue is hidden. And there is stress in hiding the results of stress and relationships fail which is simply not OK for our children or the families of our children. We need the time away, to regenerate, to know there is something else in the world, to see the sunshine...

Of those respondents receiving respite, 76% strongly agreed and 16% agreed that respite is vital in maintaining permanent family relationships for individuals affected by FASD (TABLE 10).

The respite is the only thing that allows us to regroup so we can be there in a positive, calm, loving manner to help and meet our children's' needs.

Respite provides time for one to take care of one's self. It relieves stress, physically and mentally. It also allows one to recharge their ability to cope.

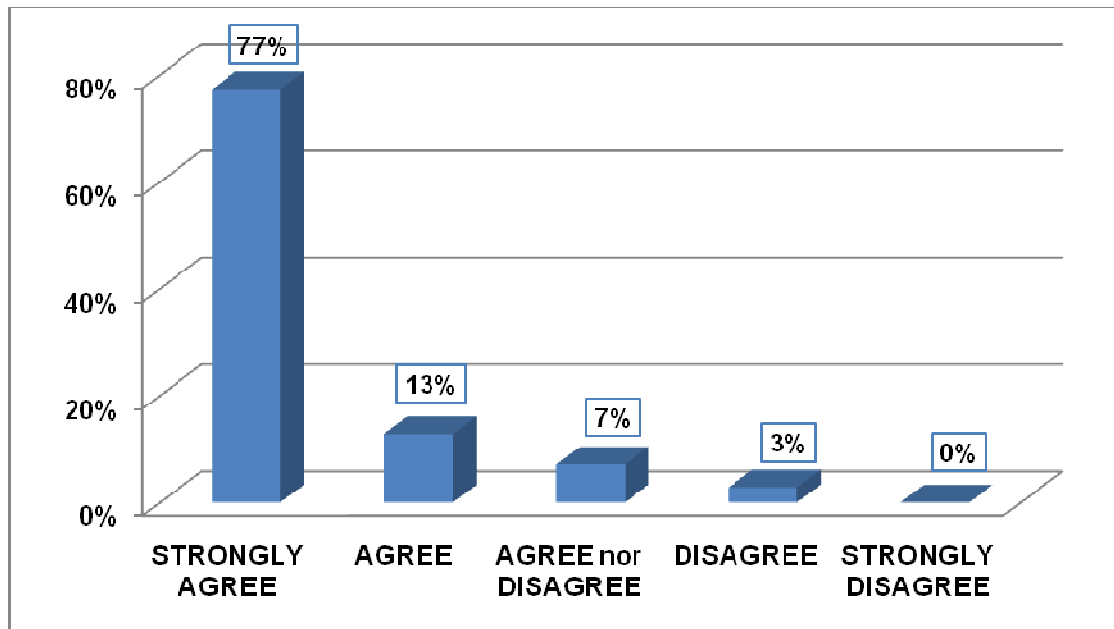
Table 10: Respite Contributes To My Ability to Provide Long-Term Care



Goodman and Anderson (2007) provide some insight into respite enabling families to provide long-term care. Prior to respite being implemented 83% of caregiver's relationships with family members had been strained due to caring for someone with FASD. In a post respite questionnaire, 92% of caregivers stated that their relationships with family members had improved with respite (Goodman & Anderson, 2007). Similarly, following a period of respite, Owens-Kane (2007) reported a statistically significant number of caregivers felt more pleased and less strained with their relationship with the child with a disability.

Caregivers in this study recognize that respite is a vital service, even though the majority were not receiving adequate amounts of respite. When asked if respite was important to their family 90% of caregivers either agreed (13%) or strongly agreed (77%) with the statement (Table 11).

Table 11: Respite Is Important to My Family



While caregivers recognize the importance of respite time for many reasons, one of the strongest themes which emerged was related to family breakdown. The comments below illustrate the strong link between respite and family permanency.

Without respite we would be unable to continue to parent these children. Doing so would cause our family to crumble under the pressure and stress of explosions, emotions, lies...

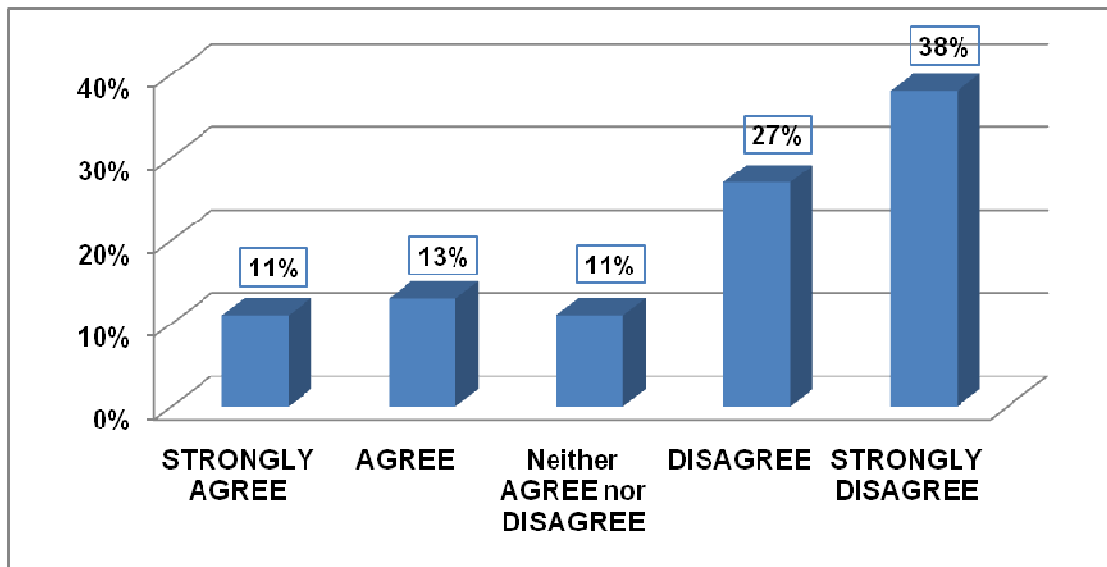
Despite recognizing the importance of respite for their families, most caregivers who were receiving respite were struggling along with very little support. When asked if they were receiving enough respite 65% of these caregivers felt that they were *not* receiving enough respite time (Table 12). A comment from one parent who did not have access to respite provides a startling example of what lack of support may look like.

When my kid was 12, he started to go off the rails...he was oppositional, assaultive and generally exhausting. This was when I was most aggressively seeking assistance. Eventually I was able to place him in a residential treatment centre, but by that point I was so worn down that I had my own crash. I ended up on disability, in treatment myself, and didn't return to work for three years.

Another caregiver described how her daughter’s adolescent years were particularly challenging for her family. While this quote is dramatic, it is representative of the extreme pressures that some families affected by FASD face every day.

During the difficult years, the emotional strain hour by hour was almost unbearable. I ended up eventually on three years of medical leave. At one point, my partner and other child had to leave the house nightly, while our daughter raged, and wait for a signal to return. At one point I felt my choice was to abandon her at a mental health clinic, rather than inflict her one more time on the rest of the family, or drive us both off a cliff.

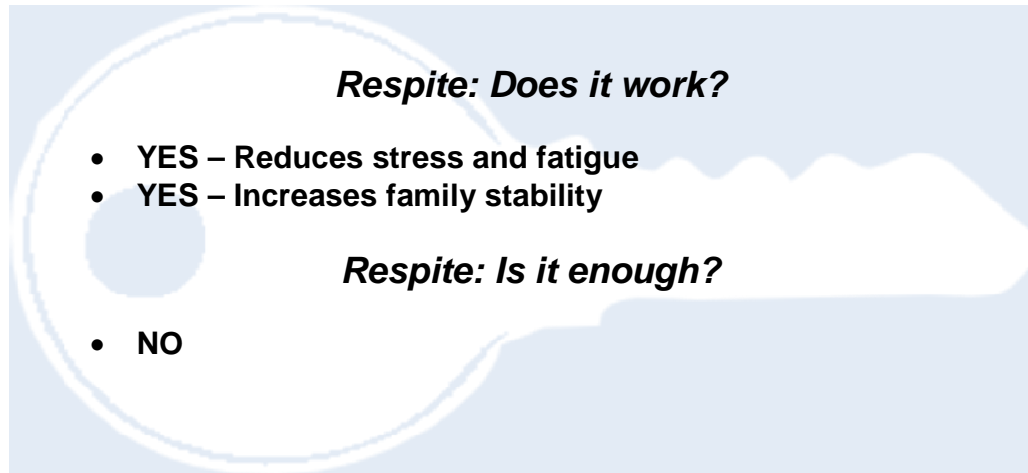
Table 12: We Receive Enough Respite



The quantitative data shows that families of this study believe that respite is a vital resource to enable them to not just manage everyday demands but emerge strengthened and whole. Unfortunately, for most of these families they are receiving little or none of this vital resource. The caregivers reported a number of barriers to accessing respite including a lack of programs and information as well as qualified respite workers. A source of frustration for many was also the strict eligibility requirements for government funding programs. These barriers to respite seemed to increase the families’ isolation and stress. The result for many is living in a state of constant hypervigilance and anxiety.

For those who were lucky to receive some respite, the benefits were exceptionally clear. Lower stress levels and increased ability to care long term were cited. Respite time was often used for personal care, connecting with friends and family as well as completing day to day duties. All of these helped reduce the extreme levels of fatigue and burnout which are common in caregivers of those with FASD. The goal

of increasing family permanency is especially poignant given that the majority of individuals with FASD have been or still are involved with the child welfare system. Lack of respite for the birth family could perhaps be the deciding factor in children going into foster care and/or adoption.



FASD, Respite and the Child Welfare System

Similar to other studies, less than three per cent of children in the present study were being cared for by their biological parents. Many caregivers discussed their experiences and feelings toward the child welfare system in the qualitative responses throughout the study.

Adoptive parents feel left high and dry, with no guidance as to diagnosis, care, etc. for parents or community. Adoptive parents are left to struggle through for their kids and the fair treatment of their kids throughout their life.

I have a lot of comments and concerns about FASD...and the amount of [non] support available for adoptive parents.

Owens-Kane (2007) addressed the importance of respite care in ensuring positive outcomes for kin, foster and adoptive families. She also stated that the use and evaluation of respite care should be part of the support services provided to children and families involved in the child welfare systems. If current kinship, foster and adoptive caregivers were unable to provide a stable home and much needed services to children, these children would be at risk for additional out-of-home placements (p. 98).

There is very little current research on the economics of the child welfare system, specifically addressing the costs of foster care and adoption. One study, completed

in North Carolina (Barth, Lee, Wildfire, & Guo, 2006), offers some useful information in considering the cost of supporting adoptive parents through ongoing subsidies for the use of respite. While the child welfare system in the United States is administered and funded with different models than Ontario, the data is pertinent given that the costs of caring for a child, regardless of disability, are similar.

Bart et al. (2006) conducted an investigation of the governmental costs of long-term foster care and adoption in North Carolina after two major pieces of federal foster care legislation were passed in the United States. The intent of these two laws was to make the placement of children in adoptive homes a priority across the United States. In response, a number of federal and state programs were developed in an attempt to increase the percentage of children adopted from foster care. Adoption subsidies and tax credits for adoptive families are examples of such programs. In their examination of the costs of long-term foster care Barth et al. included the costs of adoption subsidies within their analysis. Barth et al. (2006) commented that “although subsidies underwrite some of the cost of care for children, such subsidies are likely to cover only a small fraction of the lifetime investment made by adoptive parents and extended family” (p.154). In relation to the comparative cost of supporting adoptive parents through subsidies versus the cost of long-term foster care, Barth et al. (2006) state that “the costs of adoption could increase considerably before they equal those of foster care” (p. 150). In fact, they determined that the overall cost advantage of adoption over foster care from admission until age 18 is a savings of \$65,422 per child.

Therefore, the findings of Barth et al. (2006) confirm that in the short term, costs of adoption are substantially greater than those of foster care. However, in the long term, adoption has substantial value to children and governments. Barth et al. (2006, p.154) offer two recommendations for governments:

1. Find considerable resources to invest in adoptions today in order to save foster care funds tomorrow.
2. Cuts in subsidy amounts could reduce the likelihood of adoption and ultimately increase costs for foster care.

From a Canadian perspective, in Manitoba Fuchs et al. have conducted a series of studies on children and youth in the child welfare system in Manitoba. Originally Fuchs et al. investigated all children in the system but recently the research team has concentrated on children and youth affected by FASD. This series of reports offers a glimpse of the unique challenges that FASD present to the families and individuals child welfare system in Manitoba.

In their study of the characteristics of children and youth receiving services from the child welfare system in Manitoba, the authors estimate that 17% of children in care in Manitoba were affected by diagnosed or suspected FASD (Fuchs et al., 2005). In their 2007 report, Fuchs and his colleagues conducted their investigation on children

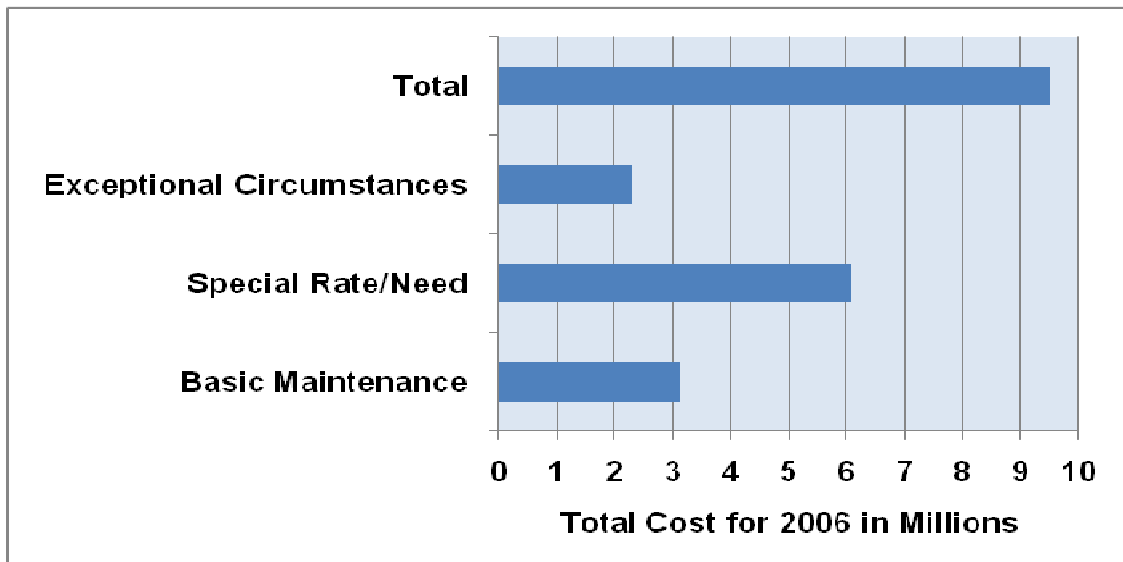
with FASD in the Manitoba child welfare system. They determined that children with FASD come into care at an age that was at least one year younger than any other group of children. The children with FASD also became permanent wards more quickly. The mean age of children with FASD when they became permanent wards was two years younger than children without disabilities and three years younger than children with other disabilities (Fuchs et al., 2007). Therefore, research with child welfare samples confirms that children and youth with FASD are likely to enter the child welfare system at an early age; they are also likely to remain in the system long term.

Fuchs, Burnside, Marchenski, Mudry, & De Riviere (2008) utilized three main categories of costs to examine the economic impact of children with FASD. The three categories, which were predetermined by the child welfare agencies in Manitoba were:

1. Basic maintenance
2. Special rate/needs
3. Exceptional circumstances

Table 13 illustrates the total costs of these three categories for the “400 children in the random sample, for 2006. The overall total cost of care for the 400 children was \$9,504,094” (Fuchs et al., 2008, p. 13-14). This figure breaks down to \$65 per day for a child in care with FASD in Manitoba in 2006.

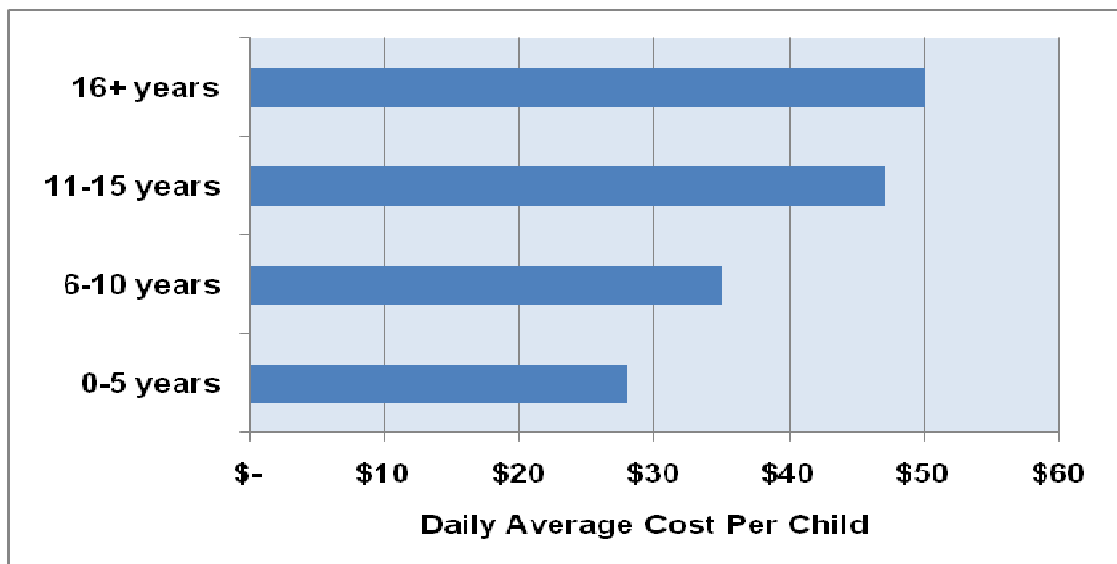
Table 13: Total Financial Cost for 2006 In Canadian Dollars (Fuchs D., Burnside, Marchenski, Mudry, & De Riviere, 2008, p.14)



Fuchs and his colleagues examined each of the three main categories of costs separately. Relevant to this discussion of respite, is the special rate/needs category.

Within the special rate/needs category, 97.3% of the 400 children had some costs recorded, with an average of \$15,617 for 2006 or \$43 per day per child (Fuchs et al., p. 15). Table 14 illustrates that when examined by age groups, the average special rate/need costs increased as age increased. The authors suggest that this increase may be because “the demands on parents would increase as children enter their teen years and this is reflected in the increase in the average of special rates as children age” (p. 22). When compared to the special rate/need costs for all children in care over the same time period, Fuchs et al. determined that the average cost per child was higher for those with FASD. At an average of \$43 per day, children with FASD who were permanent wards and who have FASD cost more than the average of \$35 per day for the total number of children in care.

Table 14: Average Daily Special Rate/Needs Costs By Age Group in Canadian Dollars (Fuchs D., Burnside, Marchenski, Mudry, & De Riviere, 2008, p.16)



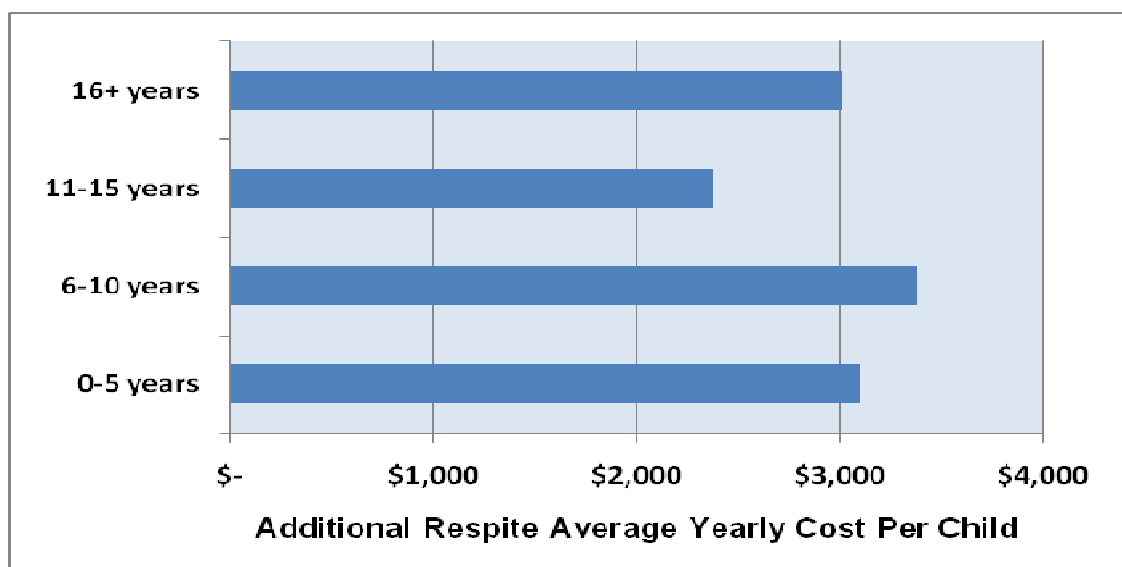
Further detailed investigation of the special rate/needs category was conducted by dividing the cost based on four subcategories:

1. Respite
2. Fee for service
3. Therapy
4. Medical costs

Respite funds, under the special rate/needs category, are the funding provided in addition to funds allotted under the basic maintenance rate. Fuchs and colleagues (2008) determined that additional funding for respite was provided for 243 (60.8%) children for a total amount cost of \$679,795. The range of costs for respite ranged from \$48 to \$25,342 per child for 2006. When examining respite use for different age

groups, Fuchs and colleagues stated that while the proportion of caregivers receiving respite was comparable across the age groups, the costs of respite for those 11–15 years old were less than other ages (Table 15). The reason for this difference is unclear, however, the authors speculate that it may be because of frequent placement breakdowns resulting in teens being placed in shelters or short-term placements where respite is not needed. Another reason may be that it is “the challenge of finding respite workers for this age group” (Fuchs et al., 2008, p.22)

Table 15: Additional Respite—Average Yearly Cost per Child (Fuchs D., Burnside, Marchenski, Mudry, & De Riviere, 2008, p. 17)

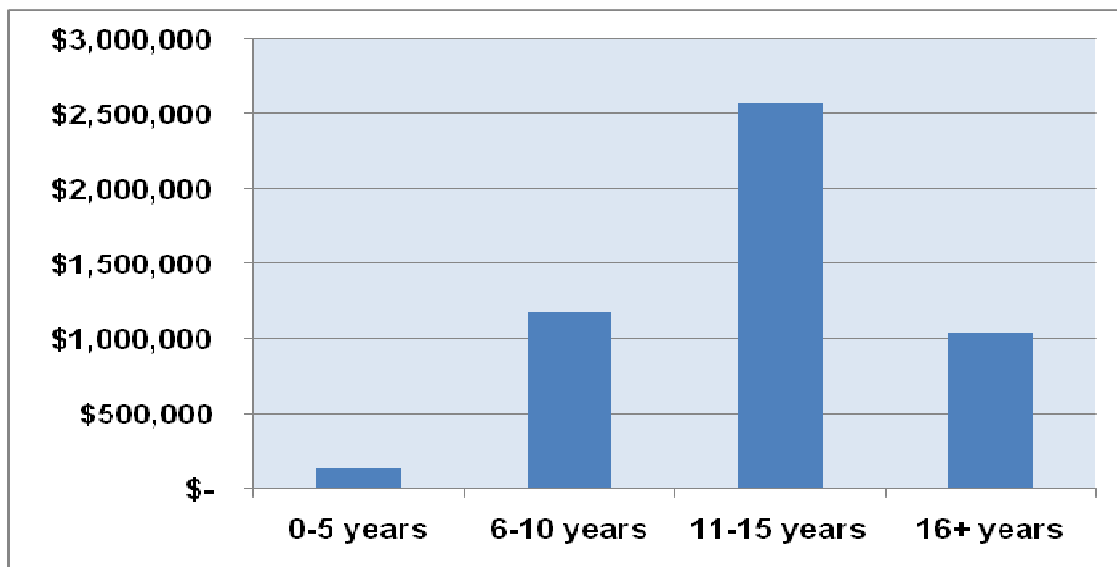


Fee for Service was a second subcategory included in the special rate/need cost category which is relevant to this discussion. Fee for service was defined as the additional compensation paid to a foster parent to acknowledge extra time and services which were provided based on the needs of the child and the skills of the care provider (Fuchs et al., 2008, p. 16). Additional funding was provided to caregivers of 371 (95.4%) of the children in this sample. The average yearly cost was \$13,273 per child for a total of \$4,924,163 for 2006 (p.16). Furthermore, Fuchs and colleagues (2008) determined that as the age of the child increased the fee for service also increased (Table 16). The authors stated that “the high fee for service, compared to other groups of children, suggests that caring for children with FASD is a particular challenge for foster parents” (p. 21).

A comment from a foster parent in the present study eloquently supports the need for greater respite and fee for service funding and explains what happens when those are not available.

Not enough people understand the amount of energy one FASD child needs to function on a daily basis. The child I had needed constant 24/7 visual and physical supervision. I feel it is extremely important to provide relief for these kinds of kids and for people to know the amount of work and stress each child causes. Due to the seriousness of this child's needs, this child no longer lives with me in my foster home and has been moved to a group home.

Table 16: Total Fee For Service Costs By Age Group (Fuchs D., Burnside, Marchenski, Mudry, & De Riviere, 2008, p.17)



In summary, Fuchs and his colleagues determined that children with FASD enter the child welfare system earlier than other children, stay in the system longer and require a higher level of funding to support them and their caregivers. At \$65 per day, the cost to care for a child or youth with FASD is greater than other children in care, both with or without disabilities. The increased costs of care for individuals with FASD appeared to be related to the higher special rate/needs funding which includes additional respite funds and fee for service. This increase of cost in the areas of respite and fees for service account for the reimbursements paid to caregivers for the extra stress and skills needed to care for individuals with FASD.

The results of the group of studies by Fuchs and his colleagues as well as those by Barth et al., (2006) are likely of no surprise to caregivers of children and youth affected by FASD in Ontario.

I believe that respite should be automatic for parents of FASD children. If this adoption placement is unsuccessful the cost for

care for these children will be hugely more expensive than the amount we receive each month. I am angry that I had to fight for and threaten legal action in order to get it [from Children's Aid Society].

The plague of FASD is more common than most professionals realize and the amount of caregiving provided by families and friends saves society millions every year. It's time that we had a break now and then.

The above quote from a caregiver succinctly summarizes the present economic reality of FASD and respite in Ontario. The majority of individuals affected by FASD in Ontario are being cared for with no government assistance or support given to their families. The vast majority of families are unable to access government support programs such as SSAH or ACSD to help with the day to day costs of caring for an individual with FASD. Many families have been forced to alter their employment situation, cutting back or ceasing to work entirely, in order to provide the structured, supportive and supervised environment necessary to foster the development of the individual with FASD. The result is that families are sacrificing financial well being, accumulating financial debt and thus incurring more stress and anxiety.

FASD is never going away. It is there 24/7 and so are the 24/7 stresses. The caregivers need to look after themselves, and this can only be done with a break. To get a break one has to have financial ability to pay for respite. As retired seniors this is very hard and adds additional stress.

I had to quit my full time job and my husband takes unpaid leaves to help. We also have two [other] sons in university and no government support structures take all those expenses into account. We live in a house that is falling down and are in more debt than ever [before adoption we had our house paid for] and never have any money for ourselves. It would cost the Province a fortune to provide the care we give in a residential setting – and would ultimately do more damage to our son – but we get no help, no subsidies, no respite – nothing...the financial and emotional burden is taking its toll!

Given the evidence of the effectiveness of respite in decreasing stress and increasing family stability, one adoptive parent of a four- to six-year-old child with FASD pleads the case that many caregivers are pondering about the Ontario government.

To government, policy makers, researchers and advocates: Wake up and help support the children and families...If you do not do it now, you will have to do it later, when secondary

disabilities and placement breakdown arise. Please recognize and support caregivers and children affected by Fetal Alcohol Syndrome. It will decrease chances of placement breakdown, secondary disabilities and strengthen the families who work very hard every day to overcome daily challenges. Do not neglect them again by ignoring their needs and the needs of those who they depend on. They need the help and deserve the help. Just because they have an invisible disability does not mean they should be invisible. FASD is a disability and should be recognized and supported as one, just like other disabilities. Please help.

Caregivers in this study were acutely aware of the importance of providing funding for respite to increase the stability of their homes.

It is critical that the government and social services agencies understand that the best chance for FASD kids is in their own homes, but the parents must have sufficient support to make this possible.

FASD, Respite and Child Welfare System

- **Children and youth with FASD are likely being cared for by someone other than their biological parent**
- **Children with FASD enter the child welfare system early**
- **Children and youth with FASD often remain in the child welfare system**
- **Costs of care for children and youth with FASD are higher than others with disabilities**
- **Ontario families affected by FASD are saving government billions of dollars every year**
- **Ontario families affected by FASD are in crisis**

Failing Families Affected by FASD

There are a number of documents published by the Ontario Ministry of Child and Youth Services which endorse the theory that support of families to enable optimal child development is important. For example, family permanency has been one focus of the Ministry of Children and Youth Services Child Welfare Transformation agenda (Ministry of Children and Youth Services, 2005). The guiding principles of this Transformation Agenda include:

- Outcome Focused: Program, policy, funding and legislative directions will achieve better child welfare outcomes in the areas of child safety, permanency and child well-being
- Balanced Service Approach: Change to policy and practice will maintain a strong emphasis on child safety, build on family and community strengths, encourage prevention and early intervention and achieve continuity of care and relationships for children and youth.

(Ministry of Children and Youth Services, 2005, p. 6)

Another example, again concerning child welfare, details a number of expectations which could result in an improvement of child outcomes in terms of safety, well being and permanence. Within the draft report *Linking Child Welfare and the Children's Service System in Ontario: A Policy Framework for Communities* (Ministry of Children and Youth Services, 2005b, p. 11) the following expectations were outlined:

- Prevent or reduce the need for initial and repeat referrals to societies
- Prevent admission to care or permit children to return safely to the care of their birth family
- Significantly enhance the stability of current placements considered to be at risk of disruption and decrease moves of children in care
- Permit children or youth to move from group homes to family based care

There is direct link between respite and each of these expectations. For example, for the third expectation, the data from this present study and other research (Beatty et al., 2009; Owens-Kane, 2007) clearly prove that respite reduces stress and increases caregivers ability to maintain permanent homes for children. In the case of the fourth expectation, for many individuals to move into family based care respite should be a mandatory service offered to caregivers and, according to Fuchs et al. (2007), additional respite time should be arranged for caregivers of children and youth with FASD.

Finally, Ministry of Children and Youth Services, *Children's Respite Report – Best Practices and Best Delivery* (2006) stated that respite services should be provided when families “need it as a prevention measure and not only as a response to a

crisis” (p. 6). It is clear that the Ontario government is not providing support to families affected by FASD.

At times we just want to throw in the towel and hand them back to Children’s Aid Society because we can’t get any help...no one in the community understands our frustration.

Families of children and youth affected by FASD are in crisis. Most are not receiving any respite, preventative or crisis related. As a result, some have been forced to make very difficult decisions to protect themselves and the rest of their family.

My 13-year-old is in a group home...My 6-year-old is on a wait list for funding...Our community doesn’t support us and the system will probably fail him as well. The boys will both need a lifetime of support.

When families need to place their children in inappropriate residential placements because appropriate situations don’t exist, it is criminal.

Failing Families Affected by FASD

- **Family permanency and support are key principles for Ontario’s MCYS**
- **Families affected by FASD are not receiving critical respite and support**
- **MCYS is failing families affected by FASD**

Cost of Supporting Respite for Families

To determine a financial cost figure to utilize in a cost benefit analysis the Ontario Association for Children's Aids Societies (OACAS) provided information based on the cost of caring for children and youth in care in 2007–2008 (see Table 17). While this calculation excludes overhead and some expenses, the resulting comparison illustrates the overwhelming cost benefits of providing respite to families affected by FASD.

Table 17: Costs Per Child in Care (2007–2008)

Average Boarding Costs	\$34,746
Average Support Services Cost	\$6,257
Average Residential Client Services Cost	\$3,827
Total Average Cost per Child per Year	\$44,830
Total Average Cost per Child per Day	\$123

The OACAS defined Support Services Costs as the cost of staffing associated with children in care. Residential Client Services are made up of 3 components: (a) client personal needs (recreational, education-related, any other out-of-pocket expenses); (b) health and related needs (prescription medications, etc.) and (c) professional services to client (cost of psychologists, medical practitioners, legal assistance).

Assuming the Public Health Agency of Canada estimate that 1% of people in Canada have FASD, then Ontario would have 30,439 children and youth under the age of 19 with FASD. Assuming that these 30,439 children and youth lived with separate families, it would cost the Ontario Government a total of **\$109,580,400** to provide 24 hours a month of respite, at \$12.50 per hour. By applying the OACAS figure cost figure of \$123 per day to care for a child or youth, it would cost the Ontario Government **\$1,366,558,905** to care for these 30,439 children and youth within the child welfare system in Ontario (see Table 18).

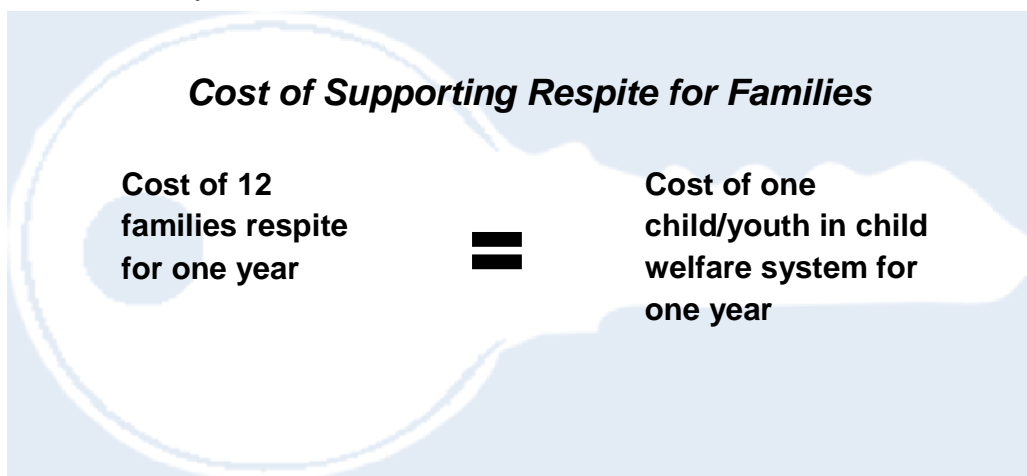
Table 18: Cost of Respite Care vs. Foster Care

Estimated Ontario FASD population under 19 years of age	Cost of care per day	Days per year	Total Cost For one year of care
30,439 x	\$123 x	365 =	\$1,366,558,905

Estimated Ontario FASD population under 19 years of age	Cost of 24 hours of respite per month	Months per year	Total Cost For one year of care
30,439 x	\$300 x	12 =	\$109,580,400

While these figures may be exaggerated it is important to note that 92% of respondents in this study who were receiving respite agreed that respite is vital in maintaining permanent family relationships for individuals affected by FASD (TABLE 10). The development of a respite program for families affected by FASD would allow the Ontario Government to address the goals of increasing permanency and supporting families to minimize initial and repeat referrals to the child welfare system.

From a cost benefit point of view, the savings inherent in supporting families affected by FASD through respite are largely immeasurable. It is difficult to quantify the benefits to children and youth of stable homes and nurturing lifelong relationships. However, given the costs provided by OACAS, providing 12 families with 30 hours of respite per month for a year would cost less than caring for *one* child or youth within the child welfare system in Ontario.



Recommendations from FASD ONE

- 1. The Ministry of Children and Youth assume the lead, collaborating with other legislators, policy makers and public funders to develop a provincial strategy for respite for individuals and families affected by FASD.**

Individuals and families affected by FASD need a government ministry to take responsibility for their issues, especially respite. Given the importance of early diagnosis and support combined with the high percentage of children and youth with FASD who are/were involved with the child welfare system it is logical that the Ministry of Children and Youth take the lead for a provincial respite strategy.

- 2. Legislators, policy makers and public funders invest in respite for all families affected by FASD.**

Respite is a cost effective strategy to assist families affected by FASD decrease caregiver stress, fatigue and burnout while also increase family stability and permanency.

Provide funding for respite per child or youth with FASD or suspected FASD, accounting for short-term out-of-home care, continuous in-home care, and recreational programming. Allow families choice to maximize the benefit of respite to themselves and their family.

- 3. Legislators, policy makers and public funders create inclusive and accessible funding programs for all families affected by FASD.**

Eliminate traditional criterion from provincial funding programs based on deficit and intelligence based standards which exclude many individuals with FASD. Criterion based on functioning level and needs, as well as adaptive skills, are more appropriate for those affected by FASD. It is vital to recognize that IQ is not a measure of functionality for individuals with FASD.

- 4. Legislators, policy makers, public funders and service providers train, coordinate and support respite workers for all families affected by FASD.**

Respite workers must be trained to understand the unique needs of individuals and families affected by FASD. Access to respite workers must be easy for families to recruit. Respite workers should be supported to create environments to address families' need for consistency, skill development and caregiver relief.

- 5. Legislators, policy makers, public funders and service providers invest in research and knowledge building regarding FASD, in general, and in specific respite.**

Research specific to those with FASD is limited, particularly evaluating the benefits and outcomes of respite care. Government and service providers should support the evaluation of respite services to ensure their efficacy and cost benefits. Future research should also look at ways to recruit biological parents whose children have prenatal alcohol exposure for their perspectives on respite.

Conclusion

As we gain an understanding of FASD, we begin to understand that we've been setting these kids up for failure because we haven't appreciated or understood their disability. We've also not been helpful to the parents and care providers because we haven't provided them with the education and support they need and so they also end up feeling like failures as well. As the service providers we feel like we've failed these kids and their families so when you think about it we all end up feeling like failures with these kids...so who's left to help?

There is a vital need for respite for the families of individuals with FASD in Ontario to increase family stability. This study of caregivers of individuals with or suspected of having FASD clearly demonstrates that many caregivers have a sense of failure, isolation, helplessness and anger. The powerful qualitative data combined with quantitative results provide a synopsis of the experiences of Ontario families affected by FASD with respite. Most families cannot access provincial funding programs due to exclusive criterion which focuses on IQ level rather than functioning and adaptive skills. These exclusive criterion, combined with lack of appropriate programs, qualified respite workers and the emotional costs of using respite time emerged as consistent barriers for families in accessing respite.

Families who were able to access respite reported that it was an effective coping strategy which helped combat burnout and fatigue, allowing caregivers to feel able to care for individuals with FASD on a permanent basis. Many caregivers reported using respite time to maintain relationships with spouse/partner and/or other siblings. Isolation felt by caregivers was also decreased by the use of respite enabling them to connect with friends and family and attend support groups.

Respite is beneficial for families affected by FASD. It is viewed as an important service by caregivers. Respite decreases caregiver stress and increases caregivers' ability to provide permanent homes for individuals affected by FASD.

The cost of caring for a child or youth with FASD is higher than caring for other children. The majority of children with or suspected of having FASD have had contact with the child welfare system. Research with child welfare samples confirms that children and youth with FASD are likely to enter the child welfare system at an

early age and remain in the system long term. The best care alternative for all children is permanent placement in a family home. To enable successful placements resulting in permanency, families require support in caring for individuals with FASD. The cost benefit analysis of providing respite for Ontario families affected by FASD is striking. It is prudent that The Ontario Ministry of Children and Youth Services take the lead in developing a provincial strategy for respite for families affected by FASD. It makes sense financially, socially and morally.

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Appendix A: Common characteristics of people diagnosed with FASD

Research shows that people with a diagnosis on the FASD spectrum can show any of the following characteristics. A minority of people have many of these characteristics and qualify for a diagnosis of FAS or pFAS. The majority (95%) of people have fewer characteristics and qualify for the diagnosis of ARND on the FASD spectrum. These represent the “invisible majority” of people who have FASD. All people with FASD are individuals. No two persons with FASD are exactly the same.

Characteristics at birth can include:	<ul style="list-style-type: none"> • Abnormally small head circumference • Underdeveloped or damaged brain – (fMRI detectable) • Low muscle tone • Less fatty tissue • Identifiable facial features (philtrum, palpebral fissures, upper lip) • Major organ malformations • Vision problems • Hearing problems, repeated ear & respiratory infections • Seizure disorder and/or Tremors • Infantile Irritability
Cognitive characteristics can include:	<ul style="list-style-type: none"> • Mild to moderate developmental delays • Speech and language disorders • Expressive and receptive language deficiencies • Mathematical deficiencies • Difficulty with abstraction and comprehension • Problems generalizing one situation to another • Poor attention\concentration skills • Memory deficits • Impaired judgment
Motor characteristics can include:	<ul style="list-style-type: none"> • Motor delays • Poor coordination/Clumsiness • Fine motor impairment • Poor core strength
Behavioural characteristics can include:	<ul style="list-style-type: none"> • Hyperactivity with or without Attention Deficit Disorder • Impulsivity • Lying • Stealing • Stubbornness & Oppositional behaviour
Psychosocial characteristics can include:	<ul style="list-style-type: none"> • Delayed socialization and communication skills • Show inability to consider consequences of actions • Inability to interpret social cues, sullenness • Lack of reciprocal friendships • Socially withdrawn • Mood lability • Display teasing or bullying behaviours • Periods of high anxiety and/or excessive unhappiness • Mental illness

(Adapted from: *Knowledge and attitudes of health professionals about Fetal Alcohol Syndrome: Results of a national survey*. Public Health Agency of Canada, 2004, p. 25, Retrieved from the Internet on July 16, 2009)

Appendix B: Survey Instrument

Respite for Families Affected by Fetal Alcohol Spectrum Disorder

This survey is only for residents on Ontario who are caring for someone with or suspected of having Fetal Alcohol Spectrum Disorder.

The purpose of the survey is twofold. First, to investigate the effectiveness of respite services presently available for families of individuals with a Fetal Alcohol Spectrum Disorder or FASD. Second, to identify the barriers preventing families from accessing respite services.

Respite refers to any informal or formal arrangement that offers you, the caregiver, relief while facilitating a positive and rewarding experience for the individual in your care. There are many forms of respite which you may refer to more as babysitting, a break or relief for any amount of time.

Please mail completed survey to:

**1. The person or persons I care for are in the following age groups.
(Choose all that apply)**

- Infant (0-1 year)
- 2-3 years old
- 4-6 years old
- 7-12 years old
- 13-18 years old
- 19-24 years old
- 25 years old and over

2. My relationship to this individual would be best described as:

- Biological parent
- Grandparent/Kin (sibling, aunt, etc)
- Adoptive parent
- Foster parent
- Other (please specify)

3. Where in Ontario do you live?

- Central East (includes Peterborough, Orillia, Barrie)
- Eastern Ontario (includes Ottawa and Kingston)
- Grey-Bruce (includes Owen Sound, Kincardine)
- Kitchener/Waterloo/Guelph and areas south to Lake Erie
- North East (includes Sault Ste. Marie, Timmins, North Bay)
- North West (includes Thunder Bay, Kenora, Nipigon)
- Southcentral Ontario (includes GTA/Golden Horseshoe)
- Southwestern Ontario (includes London, Sarnia, Windsor)

4. What type of respite services do you use? (Choose all that apply)

- Formal
- Informal
- None

**** If you answered NONE to the above question please skip to Question 14 ****

5. How do you pay the person/people doing the respite for you? Choose all that apply.

- Special Services at Home (SSAH)Funds
- Assistance for Children with Severe Disabilities (ACSD)Funds
- Children's Aid Society Funds
- Private funds
- I don't pay

6. I use respite (choose all that apply)

- To have more personal time
- To have more time to care for myself
- To have more time with family/friends
- To improve the stability of my home
- To all me time to take FASD training
- To allow for extracurricular activities
- To run errands
- To reduce stress
- Other (please specify)

7. Please describe what the individual with a FASD does during respite time. (e.g. stays home, goes out in community to movies or park, attends camp/groups, does home work, time of day/evening/overnight)

8. Please describe who provides your respite time. Choose all that apply.

- Agency (residence, groups, camp)
- Family, paid
- Family, unpaid
- Friends, paid
- Friends, unpaid
- People Agency has found
- People I have found

9. Describe any challenges that you had/have accessing respite.

10. Please provide names of agencies involved in your family's respite so that we may contact them for further information about their programs.

Agency who provided respite worker(s) _____

Agency who provided programming _____

11. How often do you have respite? (e.g. once a week, once a month, twice a month)

12. Please respond to the following statements:

a) Respite contributes to my ability to provide long term care for this individual

- Strongly Agree
- Agree
- Neither Agree nor Disagree
- Disagree
- Strongly Disagree

b) Respite helps reduce my stress level

- Strongly Agree
- Agree
- Neither Agree nor Disagree
- Disagree
- Strongly Disagree

c) We receive enough respite.

- Strongly Agree
- Agree
- Neither Agree nor Disagree
- Disagree
- Strongly Disagree

13. Please describe what you do during respite time? List all activities.

*****Please skip to Question 15*****

14. Why do you not use respite services? Choose all that apply.

- cannot afford it
- child will not stay/go with anyone else
- do not feel that others can care for child
- do not have time/energy to organize it
- do not know how to access
- do not need it
- do not qualify for funding
- Other (please specify) _____

15. Describe strategies that you feel would allow you to access respite.

16. Describe what types of respite you would prefer (e.g. in home, short term, overnight, residential, camps, flexible)

17. Respite is important to my family.

- Strongly Agree
- Agree
- Neither Agree nor Disagree
- Disagree
- Strongly Disagree

18. Please tell us more about your response to the above question.

19. Do you have any other comments about FASD and respite?
