

Towards a Provincial Strategy

Summary 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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<http://www.fasdontario.ca/groups/intervention.htm>



***Towards a Provincial Strategy:
Advancing Effective Respite Services in
Fetal Alcohol Spectrum Disorder (FASD)***
(Summary)

What we seek

A provincial strategy to address Fetal Alcohol Spectrum Disorder (FASD) developed in collaboration with FASD ONE, parents/caregivers, service providers, and other stakeholders. We invite the provincial government to become the leaders in Advancing Effective Practices, and to address the need for the life-long supports required by children, youth, and adults affected by FASD.

Why?

Ontario is one of the only provinces without a provincial strategy to address the disorder, yet FASD is considered to be the leading cause of developmental disability in Canada (Public Health Agency Canada, 2007). One percent or approximately 300,000 Canadians are currently FASD affected (Public Health Agency of Canada, 2007). In Ontario, that number translates into 30,439 children and youth under the age of 19 who would be affected by the disability.

In spite of this number, much remains unknown about FASD because it is most often an invisible disability. Most people with FASD do not have distinguishing facial characteristics; they appear normal, and are of average to above-average intelligence. In addition, Ontario currently has limited diagnostic capabilities.

The result of this ignorance is costly in terms of the secondary disabilities that people with FASD develop without proper support. These may include: mental health issues, poor academic or employment outcomes, addictions, and involvement with the child welfare system and/or the law.

The question is whether to pay now to put the necessary systems and safety nets in place or to pay later, when the costs to society in all these areas will be much higher. It is extremely likely that the costs of paying later will be many times the cost to the system of paying now. It is a question of funded interdependence versus the “bottomless pit” of high-cost failure for both the system and the adult with FASD. (Public Health Agency of Canada, 2007).

What exactly is FASD?

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.

Who We Are

FASD ONE (Ontario Network of Expertise, formerly known as the FASD Stakeholders for Ontario) is a group of stakeholders working together to address issues related to FASD in Ontario. Our membership includes experts and specialists in the following areas:

health	child welfare
children's mental health	research
addictions	justice
early learning and development	Aboriginal services
developmental services	

It also includes family members, who have an intimate knowledge of the practical needs of individuals living with this disability.

FASD ONE is an unincorporated collaboration of diverse provincial and local stakeholder groups. We work to promote, plan, facilitate, and support the coordination, enhancement, and expansion of services and initiatives. Our aim is 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 this range of disabilities, the Intervention and Support Working Group of FASD ONE commissioned three research papers in areas of critical importance: effective practices, education, and respite.

About Respite Services—Findings from the Research

Respondents to a 2008 survey of Ontario care and service providers identified respite support as one of the highest needs for families affected by FASD. This survey was followed up in 2009 with an in-depth investigation of respite for families of individuals with or suspected of having FASD.

The resulting study, *Towards a Provincial Strategy: Advancing Effective Respite Services in Fetal Alcohol Spectrum Disorder (FASD)* (Whyte, 2010), investigates the effectiveness of respite services presently available for families of individuals with FASD. The study also identifies barriers preventing families from accessing available respite services. This paper provides a summary of the findings from that study.

What is respite?

Respite is a support service providing family caregivers with a temporary break from the physical and emotional demands involved in caring for a family member who has a disability. Respite can be formal or informal, and is distinguished by purpose, duration, location, and service provider.

Benefits of Respite

Respite is beneficial: such was the overwhelming response in the 2010 study from those across the province of Ontario who were affected by FASD and were receiving respite. Ninety-five percent of the surveyed caregivers responded that respite was an effective way of reducing stress. Ninety-two percent of those respondents receiving respite agreed that respite is vital to maintaining permanent family relationships and unity—one of the strongest themes of why respite is so important that emerged in the study.

Other themes emerged from the qualitative data related to caregivers' use of respite time. These included doing activities that don't normally get done, either because of the hypervigilance required to keep children with FASD safe or the exhaustion of caring 24 hours a day/seven days a week for children with FASD.

Among these activities were the following:

- self care
- attending to daily, household tasks, such as groceries or laundry
- staying connected or reconnecting as a couple (which relates to maintaining the stability of long-term care for individuals with FASD)
- connecting with friends, family, and community to combat isolation—especially important for grandparent caregivers whose isolation can be compounded by a lack of familial and similar-aged peer supports
- utilizing respite time for one-on-one quality time or away time with siblings of the individual with FASD
- accessing continuing education and support through such resources as support groups or seminars on FASD

Barriers to Respite

Despite recognizing the importance of respite for their families, most caregivers who were receiving respite were struggling with very little support: sixty-five percent of these caregivers felt that they were *not* receiving enough respite time. The quantitative data showed that 51% of respondents were not receiving *any* form of respite at all, either informal or formal.

Caregivers in this study reported a number of reasons for not accessing respite, including:

- not knowing how to access respite, due to lack of information about support options as well as limited options among family or friends because of the difficulty of caring for children with FASD
- not being able to afford respite and/or not qualifying for funding or services
- believing that others cannot effectively care for their child, because of the need for caregivers with specialized training who understand the issues unique to FASD and who can effectively build a relationship with the child
- the individual with FASD not being open to being cared for by a different caregiver (either because of separation anxiety or lack of previous social experiences)
- suffering high emotional costs on the part of individuals with FASD and parents/caregivers due to the damage from ineffective respite

FASD, Respite, and the Child Welfare System

At present there is little or no government support for parents/caregivers of individuals with FASD. Due to program eligibility criteria, the vast majority of families are unable to access government support, such as Special Services at Home (SSAH) or Assistance for Children with Severe Disabilities (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 safety and 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. The risk is that families may not be able to withstand the stress and, as a result, break up, putting their child(ren) in care.

Applying the Ontario Association of Children's Aid Societies' cost figure of \$123 per day to care for a child or youth within the child welfare system in Ontario, the provincial government would spend **\$1,366,558,905** to care for the estimated 30,439 children and youth in the province affected by FASD. Compare that to the **\$109,580,400** the government would need in order to provide 24 hours a month of respite, at a rate of \$12.50 per hour, to the families of these children and youth.

Another way of putting it is: providing 12 families with 30 hours of respite per month for a year would cost less than the annual cost of caring for **one** child within the child welfare system in Ontario. From a cost benefit point of view, however, the savings inherent in supporting families affected by FASD through respite are largely immeasurable.

Recommendations

1. That the Ontario 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.
2. That legislators, policy makers, and public funders invest in respite for all families affected by FASD.
3. That legislators, policy makers, and public funders create inclusive and accessible programs for all families affected by FASD.
4. That legislators, policy makers, public funders, and service providers train, coordinate, and support respite workers for all families affected by FASD.
5. That legislators, policy makers, public funders, and service providers invest in research and knowledge-building regarding FASD in general, and, specifically, respite.