

# Towards a Provincial Strategy

Summary:  
Advancing Effective  
Educational Practices in  
Fetal Alcohol Spectrum  
Disorder (FASD)

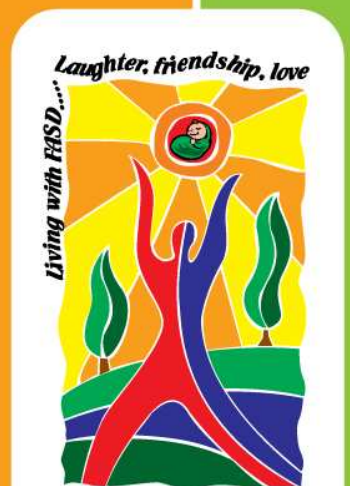
2010

**FASD | ONE**

Fetal Alcohol Spectrum Disorder  
Ontario Network of Expertise

Intervention and Support Working Group

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***Towards a Provincial Strategy:  
Advancing Effective Educational Practices 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 Education—Findings from the Research**

In March 2008 the results of a needs survey showed that the highest ranked needs for both caregivers and service providers were in education. In March 2009 the Intervention and Support Working Group of FASD ONE commissioned a study—*Towards a Provincial Strategy: Advancing Effective Educational Practices in Fetal Alcohol Spectrum Disorder (FASD)* (Duquette & Orders, 2010).

The purpose of this study was to examine the experiences of parents/caregivers and teachers/service providers in obtaining educational supports for children and adolescents with FASD in Ontario. Specifically, this research sought to identify the types of successful educational supports that are required, facilitators and barriers to obtaining them, as well as suggestions from the participants for parents/caregivers, service providers, schools, districts, and the Ministry of Education.

## **The Ontario Situation**

The Ministry of Education in Ontario currently does not recognize FASD under any of its five categories of exceptionalities. This makes it difficult for educational supports to be obtained. Additionally, unlike British Columbia, Alberta, Saskatchewan, and Manitoba, Ontario has not provided information about FASD to teachers to help them work effectively with students who are affected by the

disorder. The result is that as an invisible disability, FASD may be viewed by uninformed school personnel as wilful misbehaviour or academic laziness.

While congregated or specialized classes may be available for a few students, most students in Ontario with FASD are educated in inclusive classrooms. Currently, very limited literature exists on successfully educating these students within a collaborative or inclusive framework.

Three themes that emerged from the qualitative data gathered from parents/caregivers and teachers/service providers are described below.

### **Education**

Parents/caregivers reported that there is a general lack of knowledge about FASD at the Ministry of Education, and that this lack of knowledge extends to the schools. Respondents commented that the Ministry of Education does not acknowledge FASD, possibly because it has a low profile compared to the other exceptionalities (e.g., learning disabilities, intellectual disability, autism, giftedness).

The biggest challenge with schools for parents/caregivers is the lack of knowledge about FASD. This may explain why educators are inclined to perceive students with this disability as “normal” with behavioural problems instead of as permanently brain-damaged. Increased awareness of FASD is needed as is education about this disability for school board administrators, consultants, Special Education Advisory Committee (SEAC) members, trustees, educators, and the general public. Teachers/service providers reported that schools that know about FASD and educators who are willing to make accommodations facilitate the delivery of services and supports for students with this disability. Both groups of respondents indicated that when schools understood the needs of the students with FASD, they agreed to provide services and supports.

### **Funding and Services**

After lack of knowledge about FASD, teachers/service providers cited three additional barriers to the delivery of services and supports for students with FASD: lack of funding; the inability to obtain a diagnosis; and insufficient services, programs, and numbers of available Educational Assistants (EAs).

For parents/caregivers, the greatest challenges they face with school boards after lack of knowledge about FASD are the lack of funding for EAs and smaller classes. Parents/caregivers strongly supported hiring more EAs to provide as much one-on-one support in regular classrooms for children and youth affected by FASD. Teachers/service providers also called for more EAs and special placements for students with FASD, and recommended that early identification and intervention practices be implemented.

Other identified needs included educational supports for teachers in the form of a screening instrument, and a document created in collaboration with

parents/caregivers and service providers on how to work with students who have FASD. Teachers/service providers indicated the need for an increased capacity to identify students who may have symptoms of FASD and obtain a diagnosis.

Both groups of participants reported that when appropriate educational services and supports are not provided, the students with FASD usually experience academic difficulties, demonstrate behaviour problems, and are often suspended from school.

Without a diagnosis, early intervention, effective educational supports, knowledgeable teachers, and community services, youth with FASD fall into a negative downward spiral that begins with frustration and failure and ends in dropping out of school, involvement in criminal activities, and encounters with the law. This finding is also supported by the quantitative data from this study, which showed that parents/caregivers reported a lower proportion of students who had left school than teachers/service providers. With strong parent/caregiver support at home and the provision of appropriate educational supports and services at school, lowered incidences of withdrawal from school are possible.

### **Collaboration**

Teachers/service providers recommended that the boards of education collaborate with all stakeholders. Both groups of participants recommended that educators learn about FASD and work collaboratively as a team with parents/caregivers and service providers.

Teachers/service providers indicated that a team approach involving the teachers, parents, and service providers was necessary. Teachers/service providers also suggested that teachers, parents, and service providers should collaborate to work more effectively with students with FASD. Parents/caregivers, schools, service providers, and networks also need to collaborate to ensure that families across Ontario have access to psychologists and diagnostic facilities, particularly in the northern communities of the province.

### **Recommendations**

#### **Educating Teachers, Principals, and Educational Assistants about FASD**

- That the Ministry of Education and the members of FASD ONE prepare a comprehensive guide for educators on working in inclusive classrooms with students who have FASD. At least one hard copy should be provided to each school in Ontario and an electronic copy should be uploaded to the Ministry of Education website.
- That the Ministry of Education mandate training on FASD for administrators and educators across Ontario, which should be conducted in partnership with FASD ONE.

### **Making the Case with Schools and Districts**

- That schools provide a range of placements and programs for students with FASD including inclusive classrooms, congregated classrooms, vocational classes and programs, and alternative education programs. Districts should be encouraged to collaborate with service providers to develop specific programs for these students. The Ministry of Education, districts, and local schools should be urged to allocate funds to hire more EAs or re-assign them to students with FASD for as much of the school day as possible.
- That boards of education centrally designate at least one FASD special education consultant. This consultant would work with individual teachers and other school personnel in collaborating with others to provide effective educational programs for students with FASD.
- That boards of education provide workshops for parents on information about the Identification, Placement and Review Committee (IPRC) process and how to present the case for their children. Specific activities should be addressed, such as how to seek information, how to prepare for meetings, the role of education advocates, and how to collaborate with teachers and service providers.

### **Collaborating with Partners**

- That Ministries collaborate so that early diagnosis and intervention can be provided throughout the province and that children can develop critical language, math, and adaptive skills. Service providers and networks should collaborate with school boards to develop, field-test, and implement a screening instrument for FASD to be administered in kindergarten.
- That service providers encourage parents and caregivers to obtain a psycho-educational assessment if they suspect the child or adolescent may have FASD. Training should be provided for teachers and administrators on the process of obtaining a psycho-educational assessment and diagnosis. In addition, psycho-educational assessments should be readily available at the school level.
- That service providers, educators, and networks contact FASD support group(s) or parents and caregivers and give presentations on the services offered by their organization and the process followed to obtain a diagnosis.
- That service providers and community networks be prepared to collaborate with school personnel to meet the educational and adaptive functioning needs of children and adolescents with FASD when the parents are unable to do so.

### **Assess the Effectiveness of the Solutions**

- That the Ministry of Education and FASD ONE commission research in the following areas:
  - Effective screening; instructional, assessment, adaptive, and behavioural strategies used with all students who have FASD; and models of effective practices in Canada and beyond
  - Case studies on how parents/caregivers, educators, service providers, and networks can collaborate to meet the educational needs of students with FASD