

Towards a Provincial Strategy

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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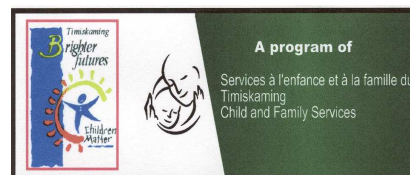
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FASD ONE (Ontario Network of Expertise, formerly known as the FASD Stakeholders for Ontario) is an unincorporated collaboration of diverse provincial and local stakeholder groups working to better serve children, youth, parents, pregnant women, and 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 that refers to a range of outcomes including mild to severe disturbances of cognitive, behavioural, physical, emotional, and/or social functioning that have been observed among individuals with prenatal alcohol exposure (Streissguth & O'Malley, 2000). Each year, it affects 1 in 100 babies and their families in Canada (Public Health Agency of Canada, 2007) and the cost burden of FASD in Canada is profound (Stade, Unger, Stevens, Beyenne, & Koren, 2006). Students with FASD experience a myriad of academic and behavioural problems in school that put them at risk of not graduating. The purpose of this research was to examine the experiences of parents, caregivers, teachers, and service providers in the area of obtaining educational services and supports for children and adolescents with FASD in Ontario.

The Intervention and Support Working Group of FASD ONE—Ontario Network of Expertise—(formerly FASD Stakeholders for Ontario) commissioned this study that was conducted in March and April 2009, in which 110 parents and caregivers and 98 teachers and service providers participated in an electronic survey and responded to demographic and open-ended questions about their experiences. The major findings were as follows:

- There is a lack of awareness of FASD among the general public, administrators, and teachers.
- There is a need for educators, parents/caregivers, and service providers to work together to ensure that educational services, programs, and supports for students with FASD are available to them.
- There is a need for further research on a screening instrument, evidence-based practices, and how communities and schools can collaborate.

Major Recommendations

1. The Ministry of Education, boards of education, and local schools should work in partnership with the community to provide specific programs for students with FASD and increase in-class support for them.
2. The Ministry of Education and FASD ONE should collaborate to develop a screening instrument, commission research on effective educational practices for students with FASD who are placed in regular classrooms, and investigate models of school/community collaboration.
3. The Ministry of Education and FASD ONE should work together to prepare a document outlining how to teach students who have FASD in inclusive classrooms and how to collaborate with parents/caregivers and service providers. Training of all educators and administrators should follow.
4. FASD ONE should collaborate with parents, service providers and networks to improve awareness about FASD.

Case Study

Ms. Lloyd's¹ classroom is distinctive from the other classrooms that line the hallways of this Toronto area high school. For example, couches, bean bag chairs and exercise balls are positioned around the room. The students, who range in age from 13 to 18, arrive half an hour later than the other students in the school, and finish their school day a half hour earlier. Each student in this self-contained classroom has an individualized program and works at his or her own pace. The student to adult ratio is high, sometimes with as many as five or six adults supporting the seven students in the class. And although these students may not look dissimilar from the students down the hall, their academic and social needs are considerably different. All of Ms. Lloyd's students have been diagnosed with FASD. These students have been suspended and/or expelled from their previous schools as a result of behavioural difficulties often associated with FASD. As Steve Catney, Executive Director of Toronto's Alliance Youth Services states, "These kids are tough; they are significantly hard to serve".

Catney received his first referral for a client with FASD over four and a half years ago. In his efforts to find an appropriate educational placement for that initial client and a number of other FASD affected clients, Catney found that the unique needs of students with this disability were not being met in the regular classroom. He explains, "I'd been in touch with the school board to discuss the fact that our kids were having a very difficult time fitting into the regular school structure out here and had made the recommendation to them that they [students with FASD] would probably be better served in a classroom that was sensitive to their needs."

When the Peel District School Board secured the funding to expand their Section 23 programs, specialized school programs funded by the province for "hard to serve" students, they contacted Catney to help set up a class for adolescents affected by FASD. Section 23 classes are collaborative educational programs designed to provide services to students who have exhausted the resources of their home schools and "are unable to attend regular or special education classes within a community school" (Associated Youth Services of Peel website). The Peel District School Board provided the physical classroom space, a teacher, and Educational Assistant (EA). Alliance Youth Services provided a full-time Child Youth Worker, as well as FASD training for the classroom teacher and EA.

Under the direction of the classroom teacher, the students participate in academic programming from 9:30 a.m. to 1:30 p.m. There is an understanding and acceptance that individual capabilities will vary; sometimes on a day-to-day basis. Catney explains, "So if students are supposed to be doing math but they are not having a good day, they can work on an art project, or they can work on the computer, or they can do other things in the classroom as well. Accommodations are made in the classroom based on the client's abilities on a specific day." Students progress at their own pace, often working towards one or two credits per semester depending on their individual capabilities. From 1:30 until 3 p.m. the students work on what Catney refers to as "functional life skills" (e.g., social skills, practical skills such as budgeting).

¹ Not her real name

In Catney's opinion, the biggest challenge in setting up the program has been "to educate the adults, to educate the school administration and to educate the other teachers in the school about FASD and what the needs of our clients are." Catney notes that he experienced some "reluctance and resistance" on the part of the local school administration in setting up the program. He attributes this tension to a lack of understanding about FASD, coupled with a degree of skepticism; "they know the [students'] history, and they know that things haven't worked in the past and they're not so sure that things are going to work going forward."

Although the Section 23 class for students with FASD has only been in operation since October 2008, there is evidence to suggest that the program is working. For example, by June no behavioural incidents involving the students had been reported. All of the students earned at least one academic credit, which is significant given that they had been unable to attain a credit in the past two or three years. Of the seven students who finished the year, at least five will be returning to the class. Resistance from the staff and administration is lessening; something Catney attributes to education (he conducted a workshop on FASD for a staff PA day) and regular communication. While he is pleased with these outcomes, Catney is quick to point out that he is "still learning" and is hoping to build on the initial successes. A goal for the upcoming year is to begin to integrate the Section 23 students with support, perhaps starting with design and technology classes. Catney's longer term goal is to collaborate with other service agencies (i.e., Metro CAS, Metro Catholic CAS and Native Family and Child services) and school boards to increase the number of Section 23 classes offered for students affected by FASD. He states confidently, "where there is a need, we can set them up, no problem". He adds, "the kids are great. They aren't that tough when you handle them the right way; when you give them . . . good support."

Although it could be argued that Section 23 classes are for the hardest to serve, lessons from this initiative may be applied to regular and special education classrooms: provide students with appropriate support, accommodations and modifications and give teachers training on how to work with students with FASD. This case study illustrates what can be achieved when service providers and school boards collaborate to provide creative and flexible programming that is sensitive to the needs of students affected by FASD.

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Introduction

FASD ONE—Ontario Network of Expertise—(formerly the FASD Stakeholders for Ontario) 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 and Supporting Families Affected by FASD* [Intervention and Support Working Group, 2008], p. 2). In March 2008 the results of a needs survey showed that the highest ranked needs for both caregivers and service providers were in the area of education. In March 2009 the Intervention and Support Working Group commissioned a study on the educational needs and barriers to obtaining these needs with the purpose of providing recommendations for actions to address the gaps in the system.

Fetal Alcohol Spectrum Disorder

Fetal Alcohol Spectrum Disorder is an umbrella term that refers to a constellation of physical and mental birth defects that may develop in individuals whose birth mothers consumed alcohol during pregnancy. (See Appendix A for a list of common characteristics.) Individuals with FASD are usually diagnosed as having Fetal Alcohol Syndrome (FAS), Partial Fetal Alcohol Syndrome (pFAS), or Alcohol Related Neurodevelopmental Disorder (ARND). Confirmed alcohol consumption by the birth mother is an element of two of these diagnoses (pFAS and ARND) (Chudley, A. E., Conry, J., Cook, J.L., Looock, C., Rosales, T. & LeBlanc, N., 2005). Those with FAS have characteristic physical (diminutive stature and small head circumference) and facial features (small eye slits, short nose, long and flat philtrum, thin upper lip, and underdeveloped chin). With a diagnosis of pFAS individuals show some of the physical and facial characteristics accompanying FAS. They also have learning and behavioural difficulties which implies central nervous system damage. Individuals diagnosed with ARND do not exhibit the characteristic features, but demonstrate central nervous system damage (learning difficulties, poor impulse control, poor social skills, and problems with memory, attention and judgment) (Alberta Learning, 2004). Fetal Alcohol Effects (FAE) is a term that was previously used to describe the symptoms of alcohol-affected individuals who did not have a diagnosis of FAS. Regardless of the presence of the characteristic physical and facial features, *all* of the above affected individuals have permanent brain damage that may have serious implications for academic and vocational success, social inclusion, and emotional well being (Burgess & Streissguth, 1992; Graefe, 1998; Ryan & Ferguson, 2006).

FASD affects approximately 1 in 100 people living in Canada (Public Health Agency of Canada, 2007), which means that there may be about 300,000 individuals living with this disability. However, this is a rough estimate as a diagnosis falling under the FASD

spectrum may be delayed or missed entirely (Sokol, Delaney-Black, & Nordstrom, 2003).

The economic impact of FASD was examined by Ontario researchers who studied the social and individual costs of FASD in Canada (Stade, Ungar, Stevens, Beyene, & Koren, 2006). They found that the annual cost of a person with FASD was \$14,342 and national annual costs were \$344 million, with education being the largest single component of the cost. (A 2009 study by Stade et al. puts the total adjusted annual costs associated with FASD at the individual level at \$21, 642 [95% CI, \$19, 842; \$24, 041]; the same study totals the cost of FASD annually to Canada of those from day of birth to 53 years old at \$5.3 billion [95% CI, \$4.12 billion; \$6.4 billion].) Determinants of cost were found to be severity of the disability and age of the child. Children with severe cognitive and behavioural disabilities due to prenatal alcohol exposure require more specialized education and health services. The costs for children aged 6–15 years were higher than the costs of all other groups, and peaked in early adolescence. The researchers emphasized the need for decision-makers to be aware of the substantial long-term economic impact of FASD.

Over a lifetime, individuals with FASD share certain primary and secondary disabilities. The *primary* disabilities result from the damage done to the brain by alcohol and reflect differences in brain structure and function. Primary disabilities for people affected by prenatal alcohol exposure include physical and health conditions (e.g., issues with oral palate, kidneys, spine, heart, and sensory systems); delays in meeting developmental milestones, difficulties in memory, comprehension of language (oral and written) and social cues, cognitive functioning (slow mental processing, difficulty with abstract thinking, and reasoning); poor fine and gross motor skills, and poor behaviour regulation; trouble maintaining appropriate attention and focus; and problems with adaptive skills (Goldschmidt, Richardson, Stoffer, Geva, & Day, 1996; Kerns, Don, Mateer, & Streissguth, 1997; Mattson & Riley, 1998; Streissguth, Aase, Clarren, Randels, LaDue, & Smith, 1991; Streissguth, Barr, Kogan, & Bookstein, 1996).

For the most part, FASD is an invisible disability because it involves central nervous system dysfunction and people with it are often misunderstood. They do not appear to have a disability and are assumed to meet the expectations of classrooms, social groups, jobs, and communities. When they do not, they are frustrated and punished and are often thought of as lazy and willfully noncompliant. It has been noted that adolescents and adults with FASD often experience *secondary* disabilities (Streissguth & Kanter, 1997) that arise when there is a discrepancy between expectations and the person's ability to perform. One such example is school disruption. Research has also identified other secondary disabilities among individuals with FASD: social isolation, depression, anxiety, suicidal thoughts and attempts, delinquency, unplanned pregnancies, homelessness, and victimization (Steinhausen, Willms, & Spohr, 1993). Streissguth and her colleagues (1996) reported that those individuals without the characteristic facial and physical features had higher rates on all secondary disabilities than those diagnosed with FAS.

Educational Experiences

Prenatal alcohol exposure is cited as the most common single cause of intellectual disability (Winzer, 2008), however many individuals with FASD have IQ scores that are within the normal range but below what would be expected for the child's environment and background (Mattson & Riley, 1998). While in school, children with FASD have a range of needs and demonstrate significant cognitive deficits in attention, memory, and executive function that are beyond those predicted on the basis of their IQ scores (Kerns, et al., 1997; Streissguth, 1997). It has also been found that individuals with FASD are even more in deficit in their adaptive functioning in the areas of communication, daily living, and socialization skills as measured on the Vineland Adaptive Behavior Scale. Moreover, these individuals often lag further behind their peers as adolescents and adults than they did as children (Clarren, 1995; Streissguth, et al., 1996). There are very few studies in the area of the educational experiences and outcomes of students with FASD. Research conducted in the US has shown poor educational outcomes for these students who eventually dropped out of high school after disruptions that included suspensions and expulsions (Gorman, 1995; Streissguth, et al., 1996).

In Canada, the research done by Duquette and Stodel (2005) involving adoptive parents and adolescents with FASD clearly showed that supportive and knowledgeable teachers and principals can facilitate successful school experiences. However, in a study involving adoptive parents in Canada and the US, it was also reported that not all school personnel understand FASD, and do not always provide the accommodations listed on the child's Individual Education Plan (IEP) (Duquette, Stodel, Fullarton, & Hagglund, 2007). In these cases, parents are forced to advocate on behalf of their children for services and accommodations they feel are required to obtain positive education outcomes. Parental advocacy, therefore, acts as a protective factor that mediates the risk factor of FASD (Duquette, Stodel, Fullarton, & Hagglund, 2006a). The findings also demonstrate that with appropriate accommodations, it is possible for students with FASD to graduate from high school (Duquette, Stodel, Fullarton, & Hagglund, 2006b).

The Ontario Situation

In the province of Ontario five categories of exceptionality are laid out in the definition of an exceptional pupil found in the Education Act (1990). The categories are: behaviour, communication (autism, deaf and hard-of-hearing, language impairment, speech impairment, and learning disability), intellectual (giftedness, mild intellectual disability, and developmental disability), physical (physical disability and blind and low vision), and multiple (multiple exceptionalities) (Ontario Ministry of Education, 2001). Ontario presently does not recognize FASD as an exceptionality that falls under any of the five categories, which sometimes can make it difficult for educational supports to be obtained. Additionally, unlike British Columbia, Alberta, Saskatchewan, and Manitoba, Ontario has not provided information about FASD for teachers on how to work effectively with students who are affected by it. The effect is that as an invisible

disability, FASD may be viewed by uninformed school personnel as willful misbehaviour and academic laziness.

To address the educational needs of students with FASD, some districts choose to provide congregated or self-contained classrooms. Although not in Ontario, one such example is the program at the elementary level at David Livingstone School in Winnipeg. The Section 23 class housed in a secondary school in Toronto described earlier in this report is another example of how students with FASD may be educated with positive outcomes. What is notable about this model is the collaborative approach between educators and service providers. While congregated classes may be available for a few students, most students in Ontario with FASD are educated in inclusive classrooms and there is currently no literature on educating these students within a collaborative framework.

The Purpose of this Research

The purpose of this study was to examine the experiences of parents/caregivers, teachers, and service providers in obtaining educational supports for children and adolescents with FASD in Ontario. Specifically, this research sought to identify the types of 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.

Methodology

This research is using a qualitative approach in order to understand the experiences of the participants from their perspectives (Creswell, 1998).

Instrument

Data were collected using two questionnaires consisting mostly of open-ended questions that were designed for a) parents and caregivers and b) teachers and service providers. The items for the questionnaires were field-tested with the FASD Group of Ottawa on March 3 and revised. Using Survey Monkey, they were then formatted so that the questionnaires would be accessible electronically. The items for both questionnaires were sent to the members of the Intervention and Support Working Group who were involved in the education committee for their input. The items were further revised and a recruitment notice with links to the questionnaires was prepared (see Appendix B). A paper version of the parents/caregivers survey was also developed to be mailed to a group of parents who participated in the FASD camps held two and three years ago (see Appendix C).

Both surveys consist of a few demographic items followed by open-ended questions related to required supports for their children, students, or clients; how those supports were obtained; and recommendations for teachers and principals, boards, and the Ministry of Education.

Data Collection Procedures

On 17 March 2009, the recruitment notice was sent electronically to the email contact lists for the 27 FASD support groups and 20 FASD committees in Ontario that were accessed through the FASD ONE website (www.fasdontario.ca). It was also distributed through electronic mailing lists: FASDnews, FASD_Canadian_link, FASlink, FASDO, FASDAY, AdoptionCanada, and others. On the following day it was sent to friendship centres and to people with Children's Mental Health Ontario. On March 19, the survey was sent as a Word document to the chair of the Intervention and Support Working Group to be mailed to the parents who participated in the family camp experiences held in Orillia in 2006 and 2007. On March 27, the recruitment notice was sent to the members of FASD ONE. Additionally, all recipients of the recruitment notice were asked to forward it to others so that the number of respondents could be increased.

The survey was accessible until April 13, 2009. Two reminder notices were sent (on April 1 and April 8) via email to encourage participation. As of March 30 there were 111 survey responses. By April 18, 110 parents and caregivers, and 98 teachers and service providers had responded to the survey request. All participants were thanked for their participation.

Data Analysis

Quantitative data were analyzed descriptively to provide a clear picture of the participants and the children and adolescents. The analysis of the demographic items was done via Survey Monkey and tables were generated showing the number of responses to specific questions and the breakdown of those responses. The tables are presented in the next section.

The qualitative data were read repeatedly to ensure understanding. The data from the parents/caregivers and teachers/service providers were analyzed similarly and separately. Specifically, the start codes were knowledge/awareness, funding, and collaboration. Each response was coded and categories were developed (Miles & Huberman, 1994). Quotes from the qualitative data were selected to demonstrate the range of responses according to the code. In some cases, a single message was very clear, such as more funding is required. For other codes there was a marked variation in the responses. From the data, themes emerged (Creswell, 1998). The findings of the qualitative data are presented in the next section along with representative quotes from the parents/caregivers and teachers/service providers.

Trustworthiness

The data were analyzed by the first researcher and checked by the second researcher to ensure that the findings could be traced to the original data (Mertens, 2005).

Results and Findings²

Demographic Data

1. The Respondents

Table 1: Relationship with the child—Parents/Caregivers (n=106)

What is your relationship to your child (children) with FASD or suspected FASD?		
	<i>answered question</i>	106
	<i>skipped question</i>	4
	Response Percent	Response Count
Adoptive mother	58.5%	62
Foster mother	12.3%	13
Birth mother	2.8%	3
Adoptive father	0.9%	1
Foster father	0.0%	0
Birth father	0.0%	0
Kinship family (e.g. grandparent, other family member)	13.2%	14
Other (please specify)	12.3%	13

All but two of the respondents identified themselves as females. The table above shows one adoptive father and under “other” one participant identified themselves as an “adoptive mother and a foster father”; however, we do not know if one or both foster parents completed the survey.

Those identifying themselves as “other” stated their relationship to the child with FASD as follows: grandparent (2), educator (2), youth worker (1), health care provider (1), caregiver (1), stepmother (2), legal guardian (1), and adoptive mother and foster father (1). One person indicated having no relationship with the child with FASD.

² Summaries of data on the children and quantitative findings can be found on pages 16–17 and 21–22.

Table 2: Living with a partner or spouse—Parents/Caregivers (n=85)

Are you living with a partner or spouse?		
	Response Percent	Response Count
Yes <input type="checkbox"/>	80.2%	85
No <input type="checkbox"/>	19.8%	21

The table above shows that most of the participants share a residence with their spouse or partner.

Teachers/Service Providers (n= 76)

What is your position?	
<i>answered question</i>	76
<i>skipped question</i>	17

- 34 (44.7%) were service providers (community/family support worker, social workers, service coordinator/manager)
- 27 (35.5%) were classroom teachers, special education teachers, early childhood educators, school administrators
- 8 (10.5%) were public health nurses
- 6 (7.9%) were other professionals (medical, speech language pathologist, psychologist, occupational therapist)
- 1 (1.3%) was a foster parent

2. The Families and Case Loads

Table 3: Number of children in your family—Parents/Caregivers (n=103)

How many children are in your family?		
<i>answered question</i>		103
<i>skipped question</i>		7
	Response Percent	Response Count
1 <input type="checkbox"/>	16.5%	17
2 <input type="checkbox"/>	35.0%	36
3 <input type="checkbox"/>	24.3%	25

How many children are in your family?			
	4	7.8%	8
	5	9.7%	10
	More than 5	6.8%	7

Slightly more than half of the families have 1 or 2 children.

Table 4: Number of children currently working with—Teachers/Service Providers (n=80)

How many children with FASD or suspected FASD are you currently working with?										
									<i>answered question</i>	80
									<i>skipped question</i>	13
1.	0	2.	3	3.	0	4.	5	5.	1	
6.	2	7.	5	8.	2	9.	0	10.	1	
11.	10	12.	2	13.	4	14.	2	15.	0	
16.	0	17.	0	18.	2	19.	1	20.	0	
21.	0	22.	6	23.	4	24.	4	25.	4	
26.	0	27.	1	28.	2	29.	1	30.	6	
31.	0	32.	12	33.	10	34.	3	35.	9	
36.	5	37.	7	38.	6	39.	25	40.	3	
41.	0	42.	2	43.	25	44.	0	45.	10	
46.	2	47.	3	48.	0	49.	3	50.	3	
51.	5	52.	3	53.	15	54.	3	55.	1	
56.	3	57.	5	58.	8	59.	2	60.	0	
61.	0	62.	0	63.	10	64.	1	65.	3	
66.	1	67.	2	68.	0	69.	1	70.	1	
71.	8	72.	0	73.	1	74.	2	75.	0	
76.	0	77.	0	78.	1	79.	5	80.	8	

Number of children = 232 among 80 respondents

1–5 children	42
6–10 children	9
11–15 children	6
16–20 children	0
21–25 children	2
None	21

Approximately 4 children per respondent and 22 had more (11 educators, 7 service providers, 1 pediatrician, 1 trainer, 2 others)

3. The Children

Table 5: Age, sex, and grade in school of child (children)—Parents/Caregivers (n=104)

What is the age, sex, and grade in school of your child (children) with FASD or suspected FASD?									
								<i>answered question</i>	104
								<i>skipped question</i>	6
Age	0 - 3	4 - 5	6 - 8	9 - 12	13 - 14	15 - 19	20+	Response Count	
Child 1	1.0% (1)	6.7% (7)	23.1% (24)	30.8% (32)	11.5% (12)	21.2% (22)	5.8% (6)	104	
Child 2	16.7% (6)	2.8% (1)	25.0% (9)	19.4% (7)	16.7% (6)	19.4% (7)	0.0% (0)	36	
Child 3	8.3% (1)	8.3% (1)	16.7% (2)	33.3% (4)	0.0% (0)	25.0% (3)	8.3% (1)	12	
Child 4	16.7% (1)	16.7% (1)	33.3% (2)	0.0% (0)	33.3% (2)	0.0% (0)	0.0% (0)	6	
Child 5	0.0% (0)	0.0% (0)	33.3% (1)	0.0% (0)	0.0% (0)	66.7% (2)	0.0% (0)	3	

The table above shows the age distribution of 161 children. Most children are in the age 9–12 range (43) and the fewest in the 20+ years range (7)

Table 6: Sex of child (children)—Parents/Caregivers

Sex	Female	Male	Response Count
	Child 1	44.7% (46)	
Child 2	38.9% (14)	61.1% (22)	36
Child 3	50.0% (6)	50.0% (6)	12
Child 4	33.3% (2)	66.7% (4)	6
Child 5	33.3% (1)	66.7% (2)	3

160 children are accounted for in the above table, which shows 91 males and 69 females.

Among Child 2, 4, and 5 boys outnumber girls two to one.

Among Child 3 there are equal numbers of boys and girls.

Table 7: Grade in school—Parents/Caregivers

Grade in school									
	Not in school yet	Preschool/ Kindergarten	Grade 1 - 3	Grade 4 - 6	Grade 7 - 8	High school	Post secondary	No longer in school	Response Count
Child 1	2.9% (3)	5.9% (6)	25.5% (26)	22.5% (23)	13.7% (14)	23.5% (24)	1.0% (1)	4.9% (5)	102
Child 2	13.9% (5)	8.3% (3)	19.4% (7)	16.7% (6)	16.7% (6)	22.2% (8)	0.0% (0)	2.8% (1)	36
Child 3	8.3% (1)	8.3% (1)	25.0% (3)	8.3% (1)	16.7% (2)	25.0% (3)	0.0% (0)	8.3% (1)	12
Child 4	0.0% (0)	33.3% (2)	16.7% (1)	16.7% (1)	16.7% (1)	16.7% (1)	0.0% (0)	0.0% (0)	6
Child 5	0.0% (0)	0.0% (0)	33.3% (1)	0.0% (0)	0.0% (0)	66.7% (2)	0.0% (0)	0.0% (0)	3

Grade in School

- 9 are not in school yet
- 12 are in preschool or kindergarten
- 38 are in grades 1–3
- 31 are in grades 4–6
- 23 are in grades 7 & 8
- 38 are in high school
- 1 is in post secondary
- 7 are not in school
- (159 children in total)

Table 8: Failed a grade (grades)—Parents/Caregivers (n=147)

Has this child failed a grade or grades?				Response Count
	Yes	No	I don't know	
Child 1	23.0% (23)	74.0% (74)	3.0% (3)	100
Child 2	22.6% (7)	71.0% (22)	6.5% (2)	31
Child 3	33.3% (3)	66.7% (6)	0.0% (0)	9
Child 4	0.0% (0)	100.0% (5)	0.0% (0)	5
Child 5	50.0% (1)	50.0% (1)	0.0% (0)	2

Failed Grades

No grades failed = 108 (73.5%)

Yes grade/s failed = 34 (23%)

Don't know = 5 (3.5%)

Table 9: Received a “social pass”³—Parents/Caregivers (n=143)

Has this child had a "social" pass to the next grade?				Response Count
	Yes	No	I don't know	
Child 1	45.9% (45)	41.8% (41)	12.2% (12)	98
Child 2	20.7% (6)	69.0% (20)	10.3% (3)	29
Child 3	55.6% (5)	44.4% (4)	0.0% (0)	9
Child 4	40.0% (2)	60.0% (3)	0.0% (0)	5
Child 5	0.0% (0)	100.0% (2)	0.0% (0)	2

Social Pass

Yes, a social pass/passes = 58 (41%)

No social passes = 68 (48.5%)

Don't know 15 (10.7%)

³ A pass to the next grade even though the student does not meet academic requirements.

Table 10: Age of child (children)—Teachers/Service Providers (n=59)

What are their ages, sex, and grade in school of the children with FASD or suspected FASD you are currently working with?								
							<i>answered question</i>	59
							<i>skipped question</i>	34
Age	0 - 3	4 - 5	6 - 8	9 - 12	13 - 14	15 - 19	20+	Response Count
Child 1	6.8% (4)	18.6% (11)	27.1% (16)	22.0% (13)	8.5% (5)	15.3% (9)	1.7% (1)	59
Child 2	8.7% (4)	13.0% (6)	17.4% (8)	23.9% (11)	13.0% (6)	19.6% (9)	4.3% (2)	46
Child 3	5.9% (2)	5.9% (2)	20.6% (7)	29.4% (10)	5.9% (2)	29.4% (10)	2.9% (1)	34
Child 4	12.0% (3)	8.0% (2)	12.0% (3)	32.0% (8)	12.0% (3)	24.0% (6)	0.0% (0)	25
Child 5	5.0% (1)	5.0% (1)	15.0% (3)	55.0% (11)	5.0% (1)	10.0% (2)	5.0% (1)	20
Child 6	7.7% (1)	15.4% (2)	7.7% (1)	38.5% (5)	15.4% (2)	15.4% (2)	0.0% (0)	13
Child 7	0.0% (0)	0.0% (0)	18.2% (2)	18.2% (2)	36.4% (4)	18.2% (2)	9.1% (1)	11
Child 8	0.0% (0)	0.0% (0)	10.0% (1)	50.0% (5)	20.0% (2)	10.0% (1)	10.0% (1)	10
Child 9	0.0% (0)	14.3% (1)	28.6% (2)	14.3% (1)	14.3% (1)	28.6% (2)	0.0% (0)	7
Child 10	0.0% (0)	0.0% (0)	28.6% (2)	0.0% (0)	28.6% (2)	28.6% (2)	14.3% (1)	7

Most children are in the 9–12 range (66) and the fewest are in the 20+ range (8).

Table 11: Sex of child (children)—Teachers/Service Providers

Sex			Response Count
	Female	Male	
Child 1	39.0% (23)	61.0% (36)	59
Child 2	45.7% (21)	54.3% (25)	46
Child 3	29.4% (10)	70.6% (24)	34
Child 4	28.0% (7)	72.0% (18)	25
Child 5	40.0% (8)	60.0% (12)	20
Child 6	46.2% (6)	53.8% (7)	13
Child 7	18.2% (2)	81.8% (9)	11
Child 8	50.0% (5)	50.0% (5)	10
Child 9	28.6% (2)	71.4% (5)	7
Child 10	42.9% (3)	57.1% (4)	7

The above table shows 145 males (62.5%) and 87 females (37.5%).

Table 12: Grade in school—Teachers/Service Providers

Grade in school									
	Not in school yet	Preschool/ Kindergarten	Grade 1 - 3	Grade 4 - 6	Grade 7 - 8	High school	Post secondary	Not in school	Response Count
Child 1	6.8% (4)	16.9% (10)	25.4% (15)	15.3% (9)	11.9% (7)	10.2% (6)	0.0% (0)	13.6% (8)	59
Child 2	8.7% (4)	13.0% (6)	23.9% (11)	10.9% (5)	19.6% (9)	13.0% (6)	0.0% (0)	10.9% (5)	46
Child 3	5.9% (2)	8.8% (3)	20.6% (7)	20.6% (7)	8.8% (3)	26.5% (9)	0.0% (0)	8.8% (3)	34
Child 4	12.0% (3)	8.0% (2)	12.0% (3)	28.0% (7)	16.0% (4)	16.0% (4)	0.0% (0)	8.0% (2)	25
Child 5	5.3% (1)	5.3% (1)	10.5% (2)	47.4% (9)	15.8% (3)	5.3% (1)	0.0% (0)	10.5% (2)	19
Child 6	0.0% (0)	23.1% (3)	7.7% (1)	38.5% (5)	7.7% (1)	15.4% (2)	0.0% (0)	7.7% (1)	13
Child 7	0.0% (0)	0.0% (0)	9.1% (1)	18.2% (2)	36.4% (4)	9.1% (1)	0.0% (0)	27.3% (3)	11
Child 8	0.0% (0)	0.0% (0)	10.0% (1)	40.0% (4)	20.0% (2)	0.0% (0)	0.0% (0)	30.0% (3)	10
Child 9	0.0% (0)	14.3% (1)	14.3% (1)	28.6% (2)	14.3% (1)	0.0% (0)	0.0% (0)	28.6% (2)	7
Child 10	0.0% (0)	0.0% (0)	28.6% (2)	0.0% (0)	14.3% (1)	28.6% (2)	0.0% (0)	28.6% (2)	7

Grade in School

14 are not in school yet
 26 are in pre-school and kindergarten
 44 are in grades 1–3
 50 in grades 4–6
 35 are in grades 7–8
 31 are in grades 9–12
 0 are in postsecondary school
 31 are not in school
 (231 children in total)

Table 13: Failed a grade (grades)—Teachers/Service Providers

Has this child failed a grade or grades?				Response Count
	Yes	No	I don't know	
Child 1	20.0% (11)	58.2% (32)	21.8% (12)	55
Child 2	33.3% (14)	50.0% (21)	16.7% (7)	42
Child 3	22.6% (7)	58.1% (18)	19.4% (6)	31
Child 4	18.2% (4)	68.2% (15)	13.6% (3)	22
Child 5	27.8% (5)	44.4% (8)	27.8% (5)	18
Child 6	25.0% (3)	66.7% (8)	8.3% (1)	12
Child 7	36.4% (4)	54.5% (6)	9.1% (1)	11
Child 8	50.0% (5)	30.0% (3)	20.0% (2)	10
Child 9	57.1% (4)	14.3% (1)	28.6% (2)	7
Child 10	28.6% (2)	42.9% (3)	28.6% (2)	7

Failed Grade

No failed grades = 115 (53.5%)

Yes failed a grade(s) = 59 (27.4%)

Don't know = 41 (20.1%)

Table 14: Received a “social pass”—Teachers/Service Providers

Has this child had a "social" pass to the next grade?				Response Count
	Yes	No	I don't know	
Child 1	28.3% (15)	30.2% (16)	41.5% (22)	53
Child 2	48.8% (20)	17.1% (7)	34.1% (14)	41
Child 3	37.5% (12)	28.1% (9)	34.4% (11)	32
Child 4	52.2% (12)	21.7% (5)	26.1% (6)	23
Child 5	42.1% (8)	26.3% (5)	31.6% (6)	19
Child 6	66.7% (8)	25.0% (3)	8.3% (1)	12
Child 7	54.5% (6)	9.1% (1)	36.4% (4)	11
Child 8	50.0% (5)	20.0% (2)	30.0% (3)	10
Child 9	71.4% (5)	0.0% (0)	28.6% (2)	7
Child 10	57.1% (4)	28.6% (2)	14.3% (1)	7

Social Pass

No social passes = 50 (23.2%)

Yes a social pass/passes = 95 (44.1%)

Don't know = 70 (32.6%)

The data show that social passes were given more often than a fail (44.1% compared to 27.4%).

Summary of Data on the Children

For both sets of respondents, most of the children were in the 9–12 year range (43/104 for parents/caregivers and 66/231 for teachers/service providers). The participants indicated that the age category with the fewest children was the 20 years of age or older (7/161 for parents/caregivers and 8/231 for teachers/service providers). The data showed that boys outnumbered girls (91 boys and 69 girls for parents/caregivers; 145 boys and 87 girls for teachers/service providers).

For both sets of respondents, most children were in grades 1–6 (43.4% for parents/caregivers and 40.7% for teachers/service providers). The percentage of children in high school for both groups was similar (15.1% for parents/caregivers and 13.4% for teachers/service providers). However, parents/caregivers reported that only 7 of the 159 children were no longer in school, whereas the teachers/service providers indicated that 31 of the 231 children were no longer in school. [Continued]

For both sets of respondents, more children have not failed a grade than have failed a grade (108/142 for parents/caregivers; 115/164 for teachers/service providers). Parents/caregivers indicated that more children had not received a social pass (68/126) than had received one (58/126). However, teachers/service providers reported roughly two to one that their children had received a social pass (95/145). The data also suggest that there is a group of students with FASD who have had neither a failed grade nor have been granted a social pass. Presumably, these students are performing academically at or close to grade level.

4. Category for Identification Purposes

Table 15: Identification, Placement, and Review Committee (IPRC) category—
Parents/Caregivers (n=85)

If your child with FASD was identified by an IPRC, what was the category?						
<i>answered question</i>						85
<i>skipped question</i>						25
Exceptionality						
	Behaviour	Communication	Intellectual	Physical	Multiple	Response Count
Child 1	25.9% (21)	17.3% (14)	23.5% (19)	3.7% (3)	29.6% (24)	81
Child 2	23.8% (5)	14.3% (3)	19.0% (4)	4.8% (1)	38.1% (8)	21
Child 3	25.0% (2)	0.0% (0)	12.5% (1)	0.0% (0)	62.5% (5)	8
Child 4	25.0% (1)	0.0% (0)	0.0% (0)	0.0% (0)	75.0% (3)	4
Child 5	33.3% (1)	0.0% (0)	0.0% (0)	0.0% (0)	66.7% (2)	3

Category

Multiple is the most popular category (23.8% overall)

Child 1 is almost equally identified as multiple, behaviour or intellectual

Child 2 – multiple at 38.1% and behaviour at 23.8%

As the number of children in the family increased, the number of children categorized as “multiple” also increased.

Table 16: IPRC Category—Teachers/Service Providers (n=39)

If the child with FASD was identified by an IPRC, what was the category?						
<i>answered question</i>						39
<i>skipped question</i>						54
Exceptionality						
	Behaviour	Communication	Intellectual	Physical	Multiple	Response Count
Child 1	45.2% (14)	9.7% (3)	9.7% (3)	3.2% (1)	32.3% (10)	31
Child 2	50.0% (10)	10.0% (2)	15.0% (3)	0.0% (0)	25.0% (5)	20
Child 3	56.3% (9)	6.3% (1)	12.5% (2)	0.0% (0)	25.0% (4)	16
Child 4	23.1% (3)	15.4% (2)	7.7% (1)	7.7% (1)	46.2% (6)	13
Child 5	33.3% (4)	16.7% (2)	16.7% (2)	0.0% (0)	33.3% (4)	12
Child 6	50.0% (2)	50.0% (2)	0.0% (0)	0.0% (0)	0.0% (0)	4
Child 7	50.0% (3)	33.3% (2)	0.0% (0)	0.0% (0)	16.7% (1)	6
Child 8	40.0% (2)	20.0% (1)	20.0% (1)	0.0% (0)	20.0% (1)	5
Child 9	66.7% (2)	33.3% (1)	0.0% (0)	0.0% (0)	0.0% (0)	3
Child 10	50.0% (2)	25.0% (1)	0.0% (0)	0.0% (0)	25.0% (1)	4

Category (across all children)

Behaviour	51 (44.7%)
Multiple	32 (28.1%)
Communication	17 (14.9%)
Intellectual	12 (10.5%)
Physical	2 (1.8%)

More children are identified in the behaviour category than any other which may be indicative that some of the children/adolescents have been involved with social workers, youth workers, principals, and the justice system. It may also reflect parents having advocated to get their children identified in this category, or that “behaviour” may be the category in which the most appropriate placement and services are provided by some boards of education.

5. Region

Table 17: Region in which the family lives—Parents/Caregivers (n=108)

In what region of Ontario do you live?		
	<i>answered question</i>	108
	<i>skipped question</i>	2
	Response Percent	Response Count
NW Ontario (includes Kenora, Thunder Bay, Longlac, and Marathon) <input type="checkbox"/>	12.0%	13
NE Ontario (includes Sault Ste Marie, Sudbury, Timmins, Kirkland Lake, and North Bay) <input type="checkbox"/>	14.8%	16
SE Ontario (includes Kingston and Ottawa) <input type="checkbox"/>	22.2%	24
SW Ontario (includes Waterloo, Guelph, London, and Windsor) <input type="checkbox"/>	25.9%	28
GTA (Greater Toronto Area) <input type="checkbox"/>	20.4%	22
Golden Horseshoe (includes Hamilton, St. Catharines, and Niagara) <input type="checkbox"/>	4.6%	5

Almost three-quarters of the parent/caregiver participants were from southern Ontario.

Among the “camp” parents (n=14), 9 were from southern Ontario and 5 were from northern Ontario.

NE 4
 NW 1
 SE 2
 SW 3
 GTA 4
 GH 0

Table 18: Region in which you work—Teachers/ Service Providers (n=92)

In what region of Ontario do you work?		
	<i>answered question</i>	92
	<i>skipped question</i>	1
	Response Percent	Response Count
NW Ontario (includes Kenora, Thunder Bay, Longlac, and Marathon)	23.9%	22
NE Ontario (includes Sault Ste Marie, Sudbury, Timmins, Kirkland Lake, and North Bay)	18.5%	17
SE Ontario (includes Kingston and Ottawa)	13.0%	12
SW Ontario (includes Waterloo, Guelph, London, and Windsor)	26.1%	24
GTA (Greater Toronto Area)	14.1%	13
Golden Horseshoe (includes Hamilton, St. Catharines, and Niagara)	4.3%	4

Almost 60% of the respondents were from southern Ontario. The SW and NW regions have the greatest number of participants with 46, which is half the total number of respondents.

6. School Board

Table 19: Area served by school board—Parents/Caregivers (n=108)

Does your school board mostly serve an urban or rural area?		
	<i>answered question</i>	108
	<i>skipped question</i>	2
	Response Percent	Response Count
Rural	23.1%	25
Urban	34.3%	37
Rural and Urban	42.6%	46

Table 20: Area served by school board—Teachers/Service Providers (n=92)

Do you mostly work in an urban or rural area?			
<i>answered question</i>			92
<i>skipped question</i>			1
		Response Percent	Response Count
	Rural <input type="checkbox"/>	29.3%	27
	Urban <input type="checkbox"/>	39.1%	36
	Rural and Urban <input type="checkbox"/>	31.5%	29

Over 40% of the parents/caregivers described their board as rural and urban, whereas about 40% of the teachers/service providers were involved with boards they described as being urban.

Summary of Quantitative Data

The parent/caregiver data show that most of these respondents were adoptive mothers (62/106) living in southern Ontario with a partner or spouse (85/106) and who had 1 to 2 children with FASD. Among the teachers/service providers, teachers made up 35.5% (27/76) of the group and service providers another 44.7% (34/76). Most of these participants were working with 1 to 5 children with FASD in southern Ontario.

For both groups of respondents, the largest proportion of the children was between 9 and 12 years of age and in the elementary grades. The participants indicated that they cared for or worked with more boys than girls. Additionally, both groups reported that more children had not failed a grade than had failed one.

However, there were four differences in the data for the two groups.

- Parents/caregivers were more likely to be with a rural/urban school board and teachers/service providers indicated that they were most often employed by or work with an urban board of education.
- Parents/caregivers reported that their children's exceptionality had been categorized as multiple, behaviour, or intellectual, with multiple occurring most frequently. However, teachers/service providers stated that the children they worked with were more likely classified as behaviour or multiple than the other categories, with behaviour leading at 44.7% (51/114).
- Parents/caregivers indicated more frequently that their children had not received a social pass, whereas teachers/service providers reported social passes at the rate of two to one. [*Continued*]

- Parents/caregivers reported that only 0.04% (7/160) of their children were no longer in school, whereas teachers/service providers indicated that 13% (31/231) of their children were no longer in school.

Qualitative Data

1. In school, what educational accommodations, supports, services, or programs have worked for your child/children?

Parents/Caregivers (n=98)

Placements

- Regular classroom with as much one-to-one time with an EA as possible (36)
- Special education class (16)
- Resource room withdrawal (4)
- Small group within the classroom (2)
- Private school (2)
- Home schooling (4)

Curriculum modifications

- Language/English, math, science

Instructional accommodations

- Assistive technology (laptop with software), highly structured classroom, predictable routines, fidget toys, photocopied notes, visual supports, one instruction at a time, chunking information

Assessment accommodations

- Has test questions read to them, extra time for tests and exams, oral testing

Other

- Quiet spot in the classroom or school, few distractions (visual, auditory), permission to leave the classroom when overstimulated or overwhelmed, speech language pathologist, occupational therapist, socialization groups, constant supervision, help with organization

What educational accommodations, supports, services, or programs have worked for the children and adolescents with FASD or suspected FASD that you work with?

Teachers/Service Providers (n=61)

Placements

- Regular classroom with as much one-to-one time with an EA as possible (25)

- Special education class (2)
- Resource room withdrawal (6)

Curriculum modifications (7)

- Language

Instructional accommodations

- Hands-on, proximity, scribe answers, test questions read, move to a quiet place when overstimulated, music while working, chunking information into smaller segments, visual aids, fewer questions, more freedom of movement, choice activities with required activities, short blocks of work time followed by breaks, pre-teach and re-teach, more time, manipulatives, preferential seating, timetable with pictures instead of words, cooperative learning, reduced amount of homework

Structured setting

- Consistency with routine, structured groupings, structured time blocks

Other programs

- *Roots of Empathy*, self-regulation, social skills, behaviour program, sensory integration therapy, adaptive behaviour training, life skills

Specialists

- Behaviour consultant, social worker, CAS, FASD/ECE worker

Special equipment

- Laptop with writing support software

Summary

Both groups indicated that students with FASD are most likely to be placed in regular classrooms with as much one-to-one time with an EA as possible, in a special education class, or in a regular classroom with resource room withdrawal. Language is the area in which curriculum modifications are most likely to be made. A range of accommodations were reported in the classroom environment, instructional process, assignments, and assessment methods. Both groups also stated that laptops with appropriate software were used by students with FASD. A difference in the responses of the two groups of respondents was that the teachers/service providers reported that their students were receiving the support of a behaviour consultant, social worker, the CAS, or an FASD/ECE worker.

2. Did the school board initially agree to provide these services and supports?

Parents/Caregivers (n=101)

Yes	40	39.6%
No	61	60.4%

Of those who responded “yes”:

Participant: adoptive mother (29) and kinship family (9)

Age group: highest for children aged 9–12 years, lowest for children aged 6–8 years

Type of board: urban/rural (18), urban (14), rural (8)

Sex: males (33), females (19)

Category: multiple (15), behaviour (11), intellectual (9), communication (7), physical (0)

Region: NW (1), NE (40), SW (12), SE (9), GTA (11), GH (3)

Teachers/ Service Providers (n=61)

Yes 29 47.5%

No 32 52.5%

Of those who responded “yes”:

Age group: highest for children aged 9–12 years, lowest for children aged 13–14

Type of board: urban (13), rural (8), rural/urban (8)

Sex: males (67), females (32)

Category: behaviour (17), multiple (15), communication (11), intellectual (8), physical (1)

Region: NW (11), NE (2), SW (3), SE (10), GTA (3), GH (0)

Summary

Boards of education were more likely not to agree initially to provide services and supports for students with FASD than to agree. However, teachers/service providers were more likely to meet with success when asking for assistance for students with FASD than parents/caregivers (29/61 and 40/101, respectively). Parents/caregivers reported more success with boards in the northeast than in other parts of the province, whereas teachers/service providers were able to convince boards in the northwest and southeastern parts of Ontario more often than in other regions.

3. To those who responded “yes” to #2: Why do you think the board agreed to provide them?

Parents/Caregivers (39/40)

Parents/caregivers had a psycho-educational assessment and other documents (9)

- *“Overwhelming data – behavioral observations, recommendations from other schools, first-hand experience”*
- *“He has had a psycho-educational assessment done and also there is a diagnosis from CHEO [Children’s Hospital of Eastern Ontario] on file as well as I constantly supply FASD information to them”*
- *“All the appropriate documentation has been provided”*

The school understood the needs and were agreeable (9)

- *“The administration and support staff (CYW [Child and Youth Worker]) had a good understanding of what an invisible disability can be like. We communicated a lot.”*
- *“Because that is what was suggested from the IPRC review – their own staff”*
- *“Support and understanding of our son’s situation”*

Parents/caregivers advocated for the child’s needs (7)

- *“Because I was a very proactive parent and knew that my daughter would have difficulty coping in all areas of her education”*
- *“Due to the strong advocates that my husband and myself are and through our community partners e.g., children’s rehab centre”*
- *“To placate parent”*

Teachers/Service providers (28/29)

The school understood the needs and were agreeable (16)

- *“Our board’s philosophy is inclusive education and they provide us with the supports that we need to help our students move forward”*
- *“These are basic accommodations for all identified students”*
- *“They recognized the needs of the students”*
- *“The students are entitled to the supports in order to achieve success”*

There were concerns about behaviour (4)

- *“School was willing to do anything to help the child due to his disruptive behaviour and outbursts which were having negative effects on his peers”*

Summary

Both groups of respondents indicated that when schools understood the needs of the students with FASD, they agreed to provide services and supports. However, parents/caregivers had to validate their claims with a psycho-educational assessment and other documents and advocate for the services and supports required by their children.

4. To those who responded “no” to #2: How did you obtain the services and support for your child/children?

Parents/Caregivers (59/61)

Parents/caregivers advocated for the child’s needs (30)

- *“A lot of work – going to the school board, principal, letters, police involvement”*
- *“Fighting with the school board and having many, many meetings, bringing in community players to the meetings to back us up, e.g., psychological reports and other reports”*
- *“Persistence and advocacy ... constantly being present at the school”*
- *“Medical letters from doctor, and persistence from social worker, as well as therapist”*

- *“Educational advocate has helped by coaching me and attending IPRCs”*
- *“Went to newspapers and school board, finally directly to Ministry of Education”*
- *“Pushing for my child’s rights. Always being after the school. Fighting to get testing done.”*
- *“Relentless queries ... bringing anything in to the principal I could lay my hands on to enlighten the school around FASD. Made my case daily when necessary. IPRC attendance and did not leave until I received what I thought was necessary for my child.”*
- *“By continually meeting with the school and vice-principal, principal, admin staff etc. and constantly talking/advocating, bringing advocates, providing info I have managed to somewhat educate them.”*

Having a psycho-educational assessment done (7)

- *“Got my daughter tested through Sick Kids”*
- *“Psycho-educational assessment, speech and language assessment, occupational therapy assessment, meetings with FASD professional”*
- *“Because the children are under CAS care, the school board is held accountable. CAS also pays for all the tests which otherwise would have put the children on a waiting list to receive.”*
- *“For the oldest, it took 3 psych-ed evaluations starting at age 7 and ending at age 12 for his score to be ‘low enough’ for the spec. ed services”*

Decided on a private school (3)

- *“I have chosen to send my son to a small private school (at great cost to me) in order to meet his needs. My son ‘falls through the cracks’ of the public system due to the fact that he is high functioning cognitively; but of course he has the social/emotional/behavioural challenges common to FASD.”*

Found a school willing to work with the child (3)

- *“We are fortunate to have received a change in principal this year, which yielded us the new principal who is supportive”*
- *“Changed schools and found someone who was willing to listen and try working with us”*

However, there were parents/caregivers who expressed that they had still not received services (5), that the school does not recognize FASD (1), and that the school will not implement the IEP (6)

Teachers/Service Providers (29/32)

Parents and others advocated for the child (8)

- *“Advocacy from parents, special education teachers”*
- *“My service provides most and/or advocates strongly for the child with the school board. Provides assistance for parents to advocate for their child to get their needs met.”*
- *“Parents advocated heavily with the school board”*

Service provider gives support to the family and school (7)

- *“I work for SSAH [Special Services at Home] and Respite for sibling/family. No direct services/dollars are provided for this girl. I am working in the family for the sibling, and often work with both children.”*
- *“I provided services and/or support for the adults who care/teach these children”*
- *“My role as AHBHC [Aboriginal Healthy Babies Healthy Children] worker is to refer and connect family with services in the community”*

Working with the school and showing a need (5)

- *“Meeting and coordinating with parents and have administrative support”*
- *Show evidence of need through development of behaviour plan, observations, ongoing records of behaviour”*
- *“Continued education and training of all staff and eventually one school co-operated and then could use that as an example”*

No educational services were obtained (3)

Funding was obtained (2)

- *“Access to funds/support through Coordinated Access”*
- *“Funding in place from INAC [Indian and Northern Affairs Canada] through the tuition agreement”*

Summary

Participants reported that in order to obtain services and supports for the children, parents/caregivers and teachers/service providers had to advocate for them. Parents/caregivers also stated that they required a psycho-educational assessment to bolster their claims. The role of the service provider appears to involve providing support for the family, connecting the family to services, assisting the parents to advocate for the child, and finding funding for programs for the child. However, it is troubling that some parents reported that they had to send their children to private schools and others stated that they still had no services or support for their children.

5. What facilitates the delivery of educational services and supports for children and adolescents with FASD?

Teachers/Service Providers Only (n=58)

Having a diagnosis (12)

- *“Timely and specific diagnosis so funding can be accessed”*
- *“We need a diagnosis to provide supports, we have no diagnostic services in northern Ontario”*
- *“A diagnosis, good understanding of the children’s needs, resources available”*

Schools that know about FASD (15)

- *“Knowledgeable, experienced staff from teachers to superintendents”*
- *“Awareness and experience with FASD across the school board. One does not feel the need to address FASD until they themselves are faced with it or have to deal with a child with FASD”*

Schools that are willing to make accommodations (9)

- *“There would need to be a great deal of flexibility on general programming as well as intensive supports”*
- *“Energy and support to implement the changes to teaching style and classroom”*
- *“A belief that all students can learn, given sufficient time and support”*

Parents advocating for their children (9)

- *“Families having assistance with advocating for the special supports required for their child”*
- *“Insistent parents”*

Team approach (7)

- *“Having a Resource team and the support of all staff and admin staff (i.e., principal on board)”*
- *“Knowledgeable teachers and developing a good relationship with the parents”*
- *“Invested principals, involvement of children’s mental health agency”*
- *“Need ongoing support from Special Ed department/guidance/administration/parents/ board officials/community”*

Summary

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. They also stated that parents/caregivers, who obtained a diagnosis for their child(ren) and advocate, contribute to increased services and supports for students with FASD. Additionally, teachers/service providers indicated that a team approach involving the teachers, parents, and service providers facilitated service delivery.

6. What are the barriers to obtaining educational services and supports for children and adolescents with FASD?

Teachers/Service Providers Only (n=63)

Lack of knowledge about FASD by educators (30)

- *“Lack of understanding and awareness of FASD within the educational system including the school boards and with individual teachers themselves. Educators do not know how to recognize FASD symptoms, signs, behaviours or how to deal with them”*

- *“Failure of personnel to understand how these deficits affect the child in the classroom”*
- *“Lack of knowledge as to what is available”*
- *“School staff who are not aware of the difficulties of these youth, are untrained and closed minded to alternatives in working with these youth”*

General lack of funding (21)

- *“Inadequate funding”*

Inability to obtain a diagnosis (18)

- *“In the Northern community [there is] a long waiting list to be seen by a specialist”*
- *“The main problem is receiving a diagnosis. Most parents don’t want to admit that they drank during pregnancy”*
- *“Next to impossible to get a diagnosis which excludes the student from funding”*

Insufficient services, programs, and EAs (11)

- *“Lack of comprehensive services”*
- *“No current programming for FASD youth”*
- *“Limited resources available (few EAs in the board) – given to students who are medically fragile, physically disabled etc. first”*

Summary

Teachers/service providers cited four main barriers to the delivery of services and supports for students with FASD: (1) lack of knowledge about FASD; (2) lack of funding; (3) inability to obtain a diagnosis; and (4) insufficient services, programs, and EAs.

7. What happens when your child does not receive the educational services or supports that are needed?

Parents/Caregivers (n=93)

Behaviour problems occur at school (42)

- *“He has emotional breakdowns where he rages and becomes extremely upset causing a danger to other children and staff”*
- *“He gets very stressed out and angry and acts out violently at school and at home. Can’t learn, can’t behave, is totally miserable and makes everyone miserable.”*

Academic problems occur (22)

- *“Academically, if he is not being engaged appropriately, he drifts, loses attention. Fortunately, he does not act out.”*
- *“She doesn’t learn, gets distracted, bothers other kids”*
- *“He does not succeed”*
- *“Fails to progress, gets frustrated, does not learn”*
- *“Academic failure, low self-esteem, lack of self-confidence needing a lot of therapy and counseling services”*

Suspensions from school (6)

- *“Usually suspensions for one to two days because he doesn’t think through the consequences of his actions”*
- *“He gets suspended as he needs EA assistance to keep him focused and on track”*

Parents/caregivers are asked to take the child home (5)

- *“We will be called to pick her up”*

The long-term outcomes of consistent unmet needs may result in the adolescent with FASD dropping out of school. One parent wrote, *“She was unable to keep up with classmates, was humiliated, disinterested, boy-crazy and dropped out.”*

What happens when children and adolescents with FASD do not receive the educational services or supports that are needed?

Teachers/Service Providers (n=64)

- They become frustrated (13)
- Experience failure (18)
- Act out (13)
- Suspended from school (8)
- “Slip through the cracks” (7)
- Drop out (8)
- Develop secondary disabilities (5)
- Become involved in criminal activities (6)
- End up in the criminal justice system (10)

Summary

Both groups of participants reported that when appropriate educational services and supports are not provided, the students with FASD experience academic difficulties, demonstrate behaviour problems, and are suspended from school. Parents indicated that they are also asked to take their child home from school. However, teachers/service providers reported more severe consequences. These students may eventually “slip through the cracks”, develop secondary disabilities, drop out of school, become involved in criminal activities, and end up in the criminal justice system.

8. What challenges do you face with your child’s/children’s teachers and principal with regard to FASD?

Parents/Caregivers Only (n=96)

Lack of knowledge about FASD, need to educate (34)

- *“THEY NEVER HEARD OF IT”*
- *“They don’t know what it is! They’ve never dealt with this sort of thing before.”*

- *“Educating the educators”*
- *“I face the challenge of routinely educating them on her disability. I need to also constantly advocate for her and make them understand that while she appears to be a typically developing child, she has a diagnosis of FASD which means her brain works differently and many days she needs more support and help with transitions and one-on-one attention and understanding that she is not behaving in a willful way when she destroys something or hits or crashes into people or screams etc.”*

“Know-it-all” attitude (12)

- *“They are aware that he has FASD, and they feel that they already know enough about FASD, that they do not need any insight on dealing with it. They know it all and have been working with ‘kids like this for years’. When an inservice was done ...no teachers attended. He is a nuisance and mom (me) is an even larger nuisance and bothers them.”*
- *“The biggest obstacle was ignorance and lack of acceptance and willingness to learn about FASD so that my son could be educated”*

The students look “normal” and are perceived as having behavioural problems (11)

- *“They see FASD as a behaviour and nothing else”*
- *“Because he is so high functioning, I have to often remind them of his FASD, so they remember to look at his behaviours as symptoms of an underlying issue, rather than assuming that he can’t control himself”*

No challenges at this time (9)

- *“Almost none now – positive advocating with the school has meant they now advocate on my child’s behalf as well.”*
- *“No challenges currently, but we felt many before. The school principal has been amazingly supportive of our child’s needs and has brought in outside FASD supports to educate staff.”*
- *“The teachers we have currently fully understand that this child must be treated with patience and given lessons repetitively”*

Summary

Parents/caregivers indicated that the biggest challenge with the schools is the lack of knowledge about FASD, which may explain why educators are inclined to perceive students with this disability as “normal” and having behavioural problems. Parents also cited the “know-it-all” attitude of some educators as a challenge. However, it should be noted that some parents/caregivers (9/96) reported no problems with the school due to their advocacy and the knowledge level about FASD shown by the educators.

9. What recommendations do you have for your child’s/children’s teachers and principal with regard to FASD?

Parents/Caregivers Only (n=96)

Learn about FASD (55)

- *“Learn that it is a disability and that behaviours are a reaction to an event that has set them off. Learn that they communicate in a different way. Be patient with both the parents and children. Listen to the parents. ... they know and understand their child. Know that FASD is not the result of a dysfunctional family in most cases.”*
- *“It is invisible and just because a child is doing well today does not mean the disability has disappeared and that supports should be removed. Supports for FASD should not have a behaviour label on them.”*
- *“More education is needed by the school board around the issues and best practices”*

Follow the IEP and use specific instructional methods (22)

- *“Formulate an appropriate IEP and honour it. – it is a contract after all”*
- *“One-on-one assistance throughout the day”*
- *“Treat them with respect and understanding. Don’t overly discipline. Give social situation training. Give a quiet place to work. Get their peers to accept and help them.”*

Listen to parents and work with them (19)

- *“Be as supportive of the family as humanly possible – they NEED it”*
- *“Keep us informed of all untoward behaviours, let us help with the child’s program and let us know if the meds are working”*
- *“Assume for the sake of argument that the primary caregiver is also part of the child’s education team and include them in the process and listen to their input... We could all work better as a team for the child if we did not have to deal with power struggles between school and home.”*
- *“Listen to parents – we are not idiots who are overprotective – we are realists who live with FASD daily and the residual effects of non-understanding professionals”*

What recommendations to overcome the barriers do you have for teachers and principals?

Teachers/Service Providers (n=62)

Learn about FASD (20)

- *“Increased understanding of the realities of FASD and acknowledgement that it is an invisible and inaudible disorder that is deserving of accommodations for students”*
- *“Training for teachers and principals on FASD”*
- *“Provide extensive training in FASD from a brain damage perspective, suggesting various resources available from BC, Alberta, ... after all there are NO provincial resources in Ontario”*
- *“Education on FASD for the whole community”*

- *“I think just providing the information to the school board. There is a large overlap with FASD and other disabilities, at least in the way that they are accommodated, but it’s always good to know the basic facts of a disability”*

Increase capacity to provide a diagnosis (9)

- *“Better funding for assessment teams to ensure appropriate professional support”*
- *“Work with health on Dx [diagnosis]. As a member of the Health community I can say I am not well supported by the Ministry, hospital or local health unit. I work in isolation to Dx and treat which is a very poor use of resources. We need physicians, agencies, psychologist, OT [occupational therapy], speech and school staff to work with families and their affected children. This means more clinicians and therapists, earlier assessments and a team approach.”*

Develop a team approach

- *Listen to families and work with parents (2)*
- *Work with the medical community (2)*
- *Work with outside agencies (3)*

Summary

Both groups of participants recommended that educators learn about FASD and work collaboratively as a team with parents/caregivers and service providers. Parents/caregivers also recommended that teachers follow the IEP and teachers/service providers suggested that there needs to be an increased capacity to identify students who may have symptoms of FASD and obtain a diagnosis.

10. What challenges do you face with your board of education with regard to your child/children with FASD?

Parents/Caregivers Only (n=86)

Lack of knowledge about FASD (21)

- *“Unawareness, indifference, lack of empathy/sympathy, frustration”*
- *“They don’t recognize the disorder – so haven’t done any training for staff”*
- *“There are no specialists in the board that deal with FASD. There is no one to go out to the school and work with the teachers on strategies and ideas.”*

Funding: EAs (10), small classes (2)

- *“The funding model does not harness an [EA] to a child – the school can place support where they want”*
- *“Not enough support in the class or in the yard. My child should have an EA with him at all times. The EA could be shared with a couple of other kids, but it would be more direct supervision.”*
- *“Lack of funding for EAs, small classes, lack of understanding in regards to FASD”*

No problems with the board (8)

- *“So far the staff and the board have been supportive”*
- *“None now – we took her out and sent her to private school”*

Policies: identification (5)

- *“The board tells me that FASD is not a recognized disability so therefore it does not have to be acknowledged. Unless the child has severe behaviour, it is ignored.”*
- *“Try to place them into a certain designation when more than one is necessary – i.e., behaviour and intellectual disability”*
- *“Exceptionality/identification I think it should be physical/intellectual”*
- *“FASD is not recognized as a learning disability. You still have to fit them into the allowed categories”*

Policies: computers (3), grade retention (2)

- *“These kids need computers to LEARN. Don’t deny them computers with bureaucracy that says they have to have a certain level of literacy to get one in the first place. What nonsense! You can’t have a computer unless you have already learned what you need to learn without the computer that you need in order to learn!”*
- *“Initially they refused to hold my child back a year. After fighting this, it was then allowed.”*

Need to advocate constantly (6)

- *“Need to advocate and educate each year as the staff involved always change”*
- *“If my child is not a behaviour problem, then he gets no EA support; one has to fight continually to get resource issues addressed”*

Summary

Parents/caregivers stated that the greatest challenge they face with school boards is the lack of knowledge about FASD. This was followed by lack of funding for EAs, smaller classes, and Ministry of Education and school board policies (identification, computers, and grade retention). It should be noted that a small number of parents/caregivers (8/86) reported having no problems at this time with their local board of education.

11. What recommendations do you have for your board of education with regard to students with FASD?

Parents/Caregivers (n=86)

Education of staff (48)

- *“I feel that teachers need to be better informed about the traits of FASD. I gave a presentation to the teachers of our school and it opened a lot of eyes and increased sensitivity and awareness. Hopefully this helps the ‘they won’t’ attitude and change it to ‘they can’t.’”*

- *“More education about FASD spread to ALL their staff – including secretaries who we had to teach about FASD”*
- *“To have the teachers take special education courses. All educators should have this course.”*

Provide special classrooms and program options (12)

- *“I would like to see special classrooms for children with FASD similar to those in Winnipeg. Children would have their own computers with appropriate software; classrooms would be simple and uncluttered. Teachers would be trained in special techniques appropriate to children with FASD.”*
- *“Smaller class size is a must”*
- *“Offer more tech type programs at local schools, or allow students to go to another school for certain courses”*

Hire more EAs (11)

- *“Keep them in regular classes with an EA, as students with FASD learn to copy the positive behaviours, and keep them with their peers. It’s important for teachers to recognize that students with any disability want to be treated like so called ‘normal’ students.”*
- *“EA support is essential”*

What recommendations do you have for boards of education?

Teachers/Service Providers (n=59)

Education of staff (20)

- *“Have your teachers more aware of FASD and how to manage additional children in the classroom along with children with FASD”*
- *“Provide specialized training for resource teachers, administrators and education assistants regarding FASD and the services required and needs of students”*

Increase funding

- General funding (7)
- To hire educational EAs (6)
- To provide different placements (e.g., alternate placements for students who can’t be educated in regular classrooms) (3)

Increase awareness, assessment, and intervention at an early age (10)

- *“To become more aware of the need for intervention at earliest age possible”*
- *“Early detection and intervention are key for these students. Boards need to develop an easy to use behaviour observation tool so that behaviour incidences can be recorded and corrected early.”*
- *“Lobby for FAS/FASD funding/diagnosis”*

Work with all stakeholders (10)

- *“Families are not an important member of the school team”*

- *“Get to know the parent and their hurdles in life before passing judgment on them”*
- *“When a child is suspected of having FASD, it would be very, very, very helpful if the school could work with a properly trained neuropsychologist AND Sick Kids/St. Mike’s to coordinate their efforts for a diagnosis. This is starting to happen in the north but it takes a lot of effort by individual teachers and not enough people are aware of the process.”*
- *“Permit sharing of resources SLP [Speech-Language Pathology], Psychology etc. for students in the school system at the level of the specialized FASD diagnostic team level.”*
- *“Allow the resources from the community to come in and provide education to the teachers”*

Summary

Education of staff about FASD was the recommendation with the highest priority for both groups of respondents. Both groups also called for more EAs and special placements for students with FASD. Teachers/service providers recommended early identification and intervention practices be implemented and that the boards of education collaborate with all stakeholders.

12. What challenges, if any, have you faced with the Ministry of Education with regard to you child/children with FASD?

Parents/Caregivers Only (n=82)

Provide more funding (16)

- For assessment and diagnosis (6)
- To hire more EAs (5)
- Generally provide more funding for services and programs (5)

No challenges with the Ministry of Education (18)

- *“None so far”*

Education of teachers and principals (11)

- *“Not knowing about FASD!”*

FASD is not acknowledged by the Ministry of Education (8)

- *“They do not acknowledge FASD as a disability”*

Identification categories (5)

- *“No FASD designation”*
- *“Accept another IPRC designation for students with a wide range of cognitive/communication/emotional/behavioural challenges and ‘invisible disabilities’... The LD [Learning Disability] IPRC designation does not reflect the*

complexity of my son's needs but he does not 'fit' other existing ones, MID [Mild Intellectual Disability], DD [Developmentally Delayed] or Physical."

Summary

Parents/caregivers reported that there is a general lack of knowledge about FASD at the Ministry of Education that trickles down to the schools. They also identified the lack of funding and identification category for FASD as challenges at the provincial level. However, it should also be noted that 18/82 parents/caregivers have faced no challenges with the Ministry of Education.

13. What recommendations do you have for the Ministry of Education with regard to students with FASD?

Parents/Caregivers (n=87)

Training on FASD for educators (37)

- *"Train and educate your educators to understand this disability and provide supports for these children. Have only the staff that do understand this disability working with these children. It is horrific to watch what can happen to these children if the adults around them do not understand their disorder and assume they are misbehaving on purpose and are willfully making the 'wrong' choices."*
- *"Adopt documents from BC, Yukon (or other jurisdictions) to provide training for current teachers on supportive measures for affected students"*
- *"Train people about FASD in supports, education and most of all – prevention!!!!!!"*

Increase funding (25, see breakdown below)

Hire more educational EAs (9/25)

- *"Make more funds available for good EAs"*

Provide special classes (6/25)

- *"These kids can learn in the right environment. Put money into developing FASD classrooms."*

Provide small classes and specialized courses (5/25)

- *"More money for individual teachers or smaller three- or four-to-one ratio"*
- *"More hands-on life skills classes"*
- *"Courses that will help him to join the work force in the future. Farming, shop, auto mechanics and any specialty that he could do."*

General funding for supports (5/25)

- *"Give them the supports that they need to succeed"*
- *"This group exists and they need to face it and educate now or Corrections will pick up the cost later"*

Acknowledgement that FASD exists (10)

- *“FASD is a real disability that must be recognized”*
- *“I feel that the Ministry is currently all about ADHD and Autism, and FASD is nowhere to be seen in their documents”*
- *“Find out about it and understand how prevalent it is – more prevalent than many conditions which receive more attention”*

Teachers/Service Providers (n=55)

Increase general funding for services and supports (19)

- *“Find better ways to provide funding for these needy students”*
- *“More funding and help for services and support for families that have children with FASD”*
- *“Fund special education appropriately, more one-to-one support needed at the high school level”*
- *“...amend the system to allow for more EAs support”*
- *“Provide funding and make psychologists available”*
- *“You require a developmental pediatrician who understands these kids to also be involved. You need to hit on health now.”*

Provide funding for training on FASD (18)

- *“Ministry needs to focus on increasing awareness with monies for additional support staff and training”*
- *“Add information on FASD to Ministry of Education website, funding for Professional Development related to FASD, increase awareness of invisible disabilities like FASD”*
- *“Educate staff with bare bones of FASD, how to recognize it, NOT just by the facial features but other traits and provide them with support for strategies!! Help the educators provide more structure and routine in their classrooms to help all children as these things will help all children not just the ones with FASD. Help educators so the educators can help our children.”*
- *“Provide courses in teachers’ college re: children with special needs and how to manage behaviour within a classroom. It is inevitable that teachers will need to deal with children struggling with mental health issues and they should be educated on how to do so.”*

Summary

The recommendations for the Ministry of Education put forward by both sets of respondents was to increase training about FASD for all administrators and educators and to increase funding for services and supports for students with this disability.

14. What would help you advocate for educational services and supports for your child/children with FASD?

Parents/Caregivers Only (n=90)

Educational advocates (10)

- *“We need some FASD advocates in our community to advocate for funding, help us find services, sit in on IPRC meetings, educate teachers with FASD students”*

A source of information (10)

- *“Central information that is offered so everyone knows where to access it”*
- *“Contact numbers of qualified people to refer to”*
- *“More workshops for myself, groups to join to help band together (the voice of 100 vs. the voice of 1). A better understanding of the red tape within the school system.”*
- *“Training for myself on how to go about advocating for my children in a positive way”*
- *“A centralized body that has parents’ voices and knowledgeable professionals advocating for change in the education system at the ministry level”*

Other

Public awareness of FASD (3)

- *“Education of the vast public via newspaper, television and schools”*

Political action (2)

- *“We need every SEAC [Special Education Advisory Committee] in the province to have a parent who is dealing with a child with FASD”*
- *“Sit on school council, receive minutes from the [SEAC] with school board”*

Summary

Parents/caregivers indicated that having access to the services of educational advocates, more information about advocacy, and the assistance of knowledgeable professionals would help them make a strong case for their sons and daughters. Additionally, they recommended increased public awareness and political action as facilitating their fight for services and supports.

15. What could your own organization do differently to better serve the educational needs of children and adolescents with FASD?

Teachers/Service Providers Only (n=55)

Educate teachers/administrators and the community (18)

- *“I think we do well, but everyone should be trained to listen well to issues from parents we come in contact with and to support the adults in our community with FASD”*
- *“Keep training people in FASD, recognizing that there are many children already in our system who are suffering and we are wasting money and time on as we are not correctly identifying the problems. We tend to set these children up for failure even with the best of intentions to assist them when we do not understand the basic*

precept of FASD – Prenatal BRAIN DAMAGE which results in a lifelong neurodevelopmental disorder.”

- *“Provide education and support to the community (schools, families, etc.) regarding FASD”*

Work with all stakeholders (11)

- *“Continue to provide families with information to assist with advocating”*
- *“Collaborate between organizations/agencies”*
- *“Schools need support from agencies (health and CAS), medical providers and families”*
- *“I live in a very small community. The school and the community are linked together so tightly that it would be impossible to change the school without also affecting change on the community. All of us (staff and local people) could begin the conversation about FASD and the healing that needs to take place before we are able to better serve the educational needs of students with FASD.”*
- *“In my community the agencies are on board, but there is no opportunity for health at the table. You require a developmental pediatrician who understands these kids to also be involved. You need to hit on health now.”*

Provide flexible programming (6)

- *“Be flexible in adapting existing programming”*
- *“Provide the student with an alternate school day schedule”*
- *“Consider a Section 23/day treatment class specifically for FASD children”*
- *“Have more space and room available, so that when children are getting suspended instead of having a free day at home, they could come here, work on their school work one-on-one with myself at the same time get suggestions for coping at/with school as well as other things like life skills and social behaviour etc.”*

Summary

Teachers/service providers recommended that administrators, teachers, and the public be educated about FASD. They also suggested that teachers, parents, and service providers collaborate to work more effectively with students with FASD. The need for more flexible programming was another recommendation.

Themes

There were three themes that emerged from the qualitative data gathered from parents/caregivers and teachers/service providers. They are described below.

1. There is a need to *increase awareness* of FASD and provide education for administrators, educators and the general public about this disability. Respondents commented that the Ministry of Education does not acknowledge FASD, possibly because it has a low profile compared to other exceptionalities (e.g., learning disabilities, intellectual disability, autism, giftedness). Participants also indicated that educators need to be aware of the symptoms, diagnostic

procedures, effective instructional and adaptive strategies, and how to manage the behaviour of children and adolescents with FASD. Moreover, school board administrators, consultants, SEAC members, and trustees need to be informed about FASD. It was also reported that the general public also needs to know about the potential challenges and outcomes for individuals affected by FASD and their families. The importance of prevention education was expressed by several survey respondents.

2. There is a need to *increase funding* for educational services and supports for students with FASD who are educated in regular classrooms so that they experience more success and graduate from high school. Parents and caregivers strongly supported hiring more EAs to provide as much one-on-one support in regular classrooms for children and youth affected by FASD. Educational supports for teachers, in the form of a screening instrument and a document on working with students who have FASD, in collaboration with parents/caregivers and service providers should also be prepared. These items might be developed jointly by the Ministry of Education and FASD ONE and be available electronically and in hard copy.
3. There is a need for parents/caregivers, schools, service providers, and networks *to collaborate in order to ensure that families have access to psychologists and diagnostic facilities across Ontario*, particularly in the northern communities of the province. Without a diagnosis, early intervention, effective educational supports, knowledgeable teachers, and community services, individuals with FASD fall into a negative downward spiral that begins with frustration and failure and could end in dropping out of school, involvement in criminal activities, and encounters with the law. It should be noted that Streissguth and her colleagues (1996) reported similar secondary disabilities associated with FASD. This finding is also supported by the quantitative data from this study that showed that parents and caregivers reported a lower proportion of students who had left school than teachers/service providers. Parent/caregiver support at home and the provision of appropriate educational supports and services at school contribute to a lowered incidence of withdrawal from school.

Assumptions

The following assumptions and findings guided the recommendations presented in this section of the report.

1. Ontario will continue to follow an inclusive model of education in which most children are educated in the regular classroom.
2. The Ministry of Education will not add more categories of exceptionalities to the five that currently exist.

3. The categories under which individuals with FASD are classified in the IEP document are not directly linked to the quantity or quality of service provided to students with FASD.
4. Students with FASD present a broad range of strengths and needs. To facilitate access to the range of supports offered by boards of education, it is necessary to identify a student under one of the Ministry's five categories. Strict adherence to a single category for all students who have FASD will not result in the provision of supports that will meet the individual needs of child or adolescent.
5. In the area of special education, the Ministry of Education provides funding, the regulatory framework under which boards and schools operate, and documents intended for professional development. Boards of education determine how the funds are allocated across the board (e.g., congregated classrooms, number of EAs per school) and principals decide how the school will meet the needs of its students (e.g., how EAs will be deployed).

Recommendations

Identify Solutions

Educating Teachers, Principals, and EAs about FASD

Some parents/caregivers expressed that their children's educational needs were being met by knowledgeable and caring teachers and principals. However, the data clearly demonstrated that most participants perceive that educators, administrators, and EAs do not understand FASD or how to work with students with FASD in inclusive classrooms. Several participants reported that when appropriate instructional and behavioural management strategies are not implemented, students become frustrated and act out, sometimes violently, which leads to suspensions. The following recommendations are made.

- The Ministry of Education and FASD ONE should prepare a comprehensive guide for educators on working with students who have FASD in inclusive classrooms within the framework of collaboration among parents/caregivers and community stakeholders. 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.
- The Ministry of Education should mandate training on FASD for administrators and educators across Ontario, which should be conducted in partnership with FASD ONE.

Educating the Public

Participants in this study recommended that the public at large become better informed about FASD. Their knowledge of this disorder and its effects on individuals, families, and society could reduce the incidence of maternal drinking during pregnancy and

provide the public with a sympathetic understanding of educational needs of students with FASD.

- Local newspapers should be contacted by parents, knowledgeable service providers, local public health, and FASD networks to offer stories about how FASD affects individuals and families over the long term. The outcomes of academic failure, frustration, suspensions, dropping out, early or unplanned pregnancy, encounters with the law, and difficulty living independently should be highlighted.
- National magazines should also be contacted to suggest stories on the challenges parents and caregivers experience in obtaining a diagnosis and educational services and supports for students with FASD. How tired parents of children and adolescents with FASD are and the need for respite should be underscored. (See companion report, *Towards a Provincial Strategy: Advancing Effective Respite Services in Fetal Alcohol Spectrum Disorder [FASD]* [Whyte, 2010].) It should also be pointed out that FASD affects individuals of all races, cultures, and income levels and that early identification and intervention can ultimately save society millions of dollars in the long term.

Making the Case with Schools and Districts

Although some participants were satisfied with the educational services and supports provided to students with FASD, the qualitative data showed that many parents regularly advocate for the educational needs of their children and with some success. There were also parents who felt they need information on how to advocate, a list of community services available in Ontario, and access to education advocates.

- 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.
- Request that boards of education designate at least one special education consultant to students with FASD. This consultant would work with individual teachers and other school personnel in collaborating with others to provide effective educational programs for students with FASD.
- Provide workshops for parents on information about the IPRC process and how to present the case for their children. Specific activities should be addressed, such as how to seek for information, how to prepare for meetings, the role of education advocates, how to collaborate with teachers and service providers.
- Prepare a list of community services and education advocates for reference by parent support groups that could be put on the FASD ONE website and maintained regularly to ensure that links are working and the information is correct.

Collaborating with Partners

The qualitative data suggested that when social service agencies, parents/caregivers, and educators work together the needs of the students are more likely to be met. The importance of early diagnosis and intervention was raised by some respondents and is supported in the companion report *Towards a Provincial Strategy: Advancing Effective Service Provider Practices in Fetal Alcohol Spectrum Disorder (FASD)* (Hall, Cunningham, & Jones, 2010). Additionally, parents and caregivers can draw on the support that social service providers can offer.

- Ministries should 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 and field-test a screening instrument for FASD that could be administered in kindergarten.
- Service providers should 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.
- Service providers, educators, and networks should contact FASD support groups and give presentations on the services offered by their organization and the process followed to obtain a diagnosis. Parents should be encouraged to contact support groups and the service providers who can give ongoing information and assistance. See the list of support groups across Ontario on the FASD ONE website (<http://www.fasdontario.ca/>).
- Service providers and networks should 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.

Becoming Involved at the District Level

Some parents/caregivers recommended that parents should become active in school councils and their board's SEAC. Research on parental advocacy in Ontario has shown that membership on SEAC and becoming a trustee raises the profile of the needs of students with specific exceptionalities and improves service delivery.

- According to Ontario Regulation 464/97 up to 12 parent representatives from local associations may sit on SEAC. The local associations must be affiliated with a provincial organization. It is recommended that a provincial organization be established to which local FASD support groups and networks may be affiliated.
- FASD advocates should be encouraged to run as a school board trustee to further the interests of students with this disability.

Assess the Effectiveness of the Solutions

Some parents noted that Canadian research should be undertaken on instructional and assessment strategies for students with FASD. It is recommended that the Ministry of Education and FASD ONE commission research in the following areas:

- Effective screening, instructional, assessment, adaptive, and behavioural strategies used with students who have FASD and models of effective practices within 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

Limitations

The data collected through this survey provides an overview of the perceptions and opinions of parents, caregivers, teachers, and service providers in Ontario. Due to the limited length of survey responses on the educational services and supports for students with FASD, the data do not provide a deep understanding of processes and contextual differences. A second limitation is that participation was limited to those people who had access to a computer or were among the group of parents who attended the two FASD camps. Hence, the survey only reached a subset of the population of parents of FASD affected children rather than all potential participants. Certainly, few birth parents participated in this study, which may limit the generalizability and transferability of the results. The third limitation is that the anonymity of the survey may have lead to more candid responses than from less anonymous methods, such as an in-depth interview. However, the anonymity of the survey allowed the participants to share their experiences freely.

Conclusions

Parents/caregivers and teachers/service providers told of their successes and challenges in obtaining educational services and supports for students in Ontario with FASD. Recommendations for collaboration between the Ministry of Education and FASD ONE to address the needs for increased awareness and training and service delivery were proposed. The next challenge will be for all stakeholders to work together to meet the educational needs for students with FASD that will contribute to improved academic outcomes, decreased behavioural problems, and increased rates of high school graduation.

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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: Recruitment Notice

Parents, Caregivers, Service Providers, and Teachers of Children and Adolescents with FASD Speak Out about Educational Services and Supports in Ontario Schools

You are invited to participate in an online survey of service providers for children with Fetal Alcohol Spectrum Disorder (FASD) about educational services and supports in Ontario. This research is supported by the Intervention and Support Working Group, FASD Stakeholders for Ontario [now FASD ONE].

Specifically, we are looking for parents, caregivers, service providers, and teachers of children and adolescents who are currently enrolled in **Ontario** elementary or secondary schools or have left school within the last 6 months. In this on-line survey, you will be asked about the educational services and supports for these individuals, how they were obtained, and recommendations for teachers and administrators. This survey should take about 15 to 20 minutes to complete and your responses are confidential as only the researchers will have access to the data.

The results of this study on educational services and supports for students with FASD in Ontario schools will be used to prepare recommendations for action to the FASD stakeholders. The report will be available on the website of the FASD Stakeholders of Ontario [now FASD ONE] (www.fasdontario.ca).

This survey will be accessible until **Monday April 13, 2009**.

If you are a **parent or caregiver** and would like to participate, please go to http://www.surveymonkey.com/s.aspx?sm=RGrUkO4cgvm4BLKx2IF4dA_3d_3d

If you are a **service provider or teacher** and would like to participate, please go to http://www.surveymonkey.com/s.aspx?sm=atUeMDVCKsOS2E4OyGE8dg_3d_3d

Please forward this message on to those in your networks who may be interested in participating in this survey. We would like to hear from as many people as possible.

If you would like more information about this study, feel free to contact Cheryll Duquette and Shari Orders at FASDEducationssurvey@gmail.com.

Thank you.

Appendix C: Survey for Camp Parents

FASD Education Survey for Parents and Caregivers

Thank you for participating in this survey. It is for Ontario residents only. We expect that it will take you 15 - 20 minutes to complete.

If you prefer to do this survey online, please send an email to fasdeducationsurvey@gmail.com for the link.

1. What is your relationship to your child (children) with FASD or suspected FASD?

<input type="checkbox"/> Adoptive mother	<input type="checkbox"/> Adoptive father
<input type="checkbox"/> Foster mother	<input type="checkbox"/> Foster father
<input type="checkbox"/> Birth mother	<input type="checkbox"/> Birth father
<input type="checkbox"/> Kinship family (e.g., grandparent, other family member)	
<input type="checkbox"/> Other (please specify): _____	

2. Are you living with a partner or spouse?

<input type="checkbox"/> Yes
<input type="checkbox"/> No

3. How many children are in your family?

4. What is the age, sex, and grade in school of your child (children) with FASD or suspected FASD?

Child	Sex (M/F)	Age (years)	Grade in school	Has this child failed a grade/grades? (circle one)	Has this child had a "social" pass to the next grade? (circle one)
Child 1				Yes No Don't know	Yes No Don't know
Child 2				Yes No Don't know	Yes No Don't know
Child 3				Yes No Don't know	Yes No Don't know
Child 4				Yes No Don't know	Yes No Don't know
Child 5				Yes No Don't know	Yes No Don't know

5. If your child with FASD was identified by an IPRC, what was the category?

Child	Exceptionality (circle one)				
Child 1	behaviour	communication	intellectual	physical	multiple
Child 2	behaviour	communication	intellectual	physical	multiple
Child 3	behaviour	communication	intellectual	physical	multiple
Child 4	behaviour	communication	intellectual	physical	multiple
Child 5	behaviour	communication	intellectual	physical	multiple

6. In what region of Ontario do you live?

- NW Ontario (includes Kenora, Thunder Bay, Longlac, and Marathon)
- NE Ontario (includes Sault Ste Marie, Sudbury, Timmins, Kirkland Lake, and North Bay)
- SE Ontario (includes Kingston, and Ottawa)
- SW Ontario (includes Waterloo, Guelph, London, and Windsor)
- GTA (Greater Toronto Area)
- Golden Horseshoe (includes Hamilton, St. Catharines, and Niagara)

7. Does your school board mostly serve an urban or rural area?

- Rural
- Urban
- Rural and urban

8. What educational accommodations, supports, services, or programs have worked for your child/children?

9. Did the school board initially agree to provide these services and supports?

- Yes (go to question 10, then 12)
- No (go to question 11)

10. If you answered yes to question 8, why do you think the board initially agreed to provide them?

11. If you answered no to question 8, how did you obtain the services and support for your child/children?

12. What happens when your child does not receive the educational services or supports that are needed?

13. What challenges do you face with your child's/children's teachers and principal with regard to FASD?

14. What recommendations do you have for your child's/children's teachers and principal with regard to FASD?

15. What challenges do you face with your board of education with regard to your child/children with FASD?

16. What recommendations do you have for your board of education with regard to students with FASD?

17. What challenges, if any, have you faced with the Ministry of Education with regard to your child/children with FASD?

18. What recommendations do you have for the Ministry of Education with regard to students with FASD?

19. What would help you advocate for educational services and supports for your child/children with FASD?

Thank you for completing this survey.

Please return by Monday, April 13, 2009 to:

Shari Orders
FASD Education Survey
69 Grove Ave.
Ottawa, ON
K1S 3A7