

## Educating students with FASD: linking policy, research and practice

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**Fetal alcohol spectrum disorder (FASD) is a prevalent neurodevelopmental disability with significant implications for learning and behaviour. International research suggests that the prevalence of FASD in school-aged children is 2.3–6.3%. In this paper, we address the questions: (1) what is FASD; (2) what is the prevalence of FASD in schools; (3) what is the impact of FASD; and (4) why develop special FASD education strategies and programmes? We summarise the 18-year history of Winnipeg School Division's development of its FASD Programme of services, describe the specialised FASD classrooms and then present the results from a consensus-generating workshop comprised of 36 FASD education professionals, with over 209 years of collective FASD education programme experience, who were asked to identify and reach consensus on best strategies and lessons learned in FASD education programmes. We then suggest that effectively educating children with FASD is critical to get right if positive educational outcomes are to be realised.**

### Introduction

Fetal alcohol spectrum disorder (FASD) is the leading cause of developmental disabilities in Canada and is a leading cause worldwide (Carpenter, 2011; O'Leary, 2004; Spohr, Willms and Steinhausen, 1993; Stade, Ali and Bennett et al., 2008). It was first described in France by Lemoine and is caused by prenatal exposure to alcohol resulting in physical, mental and learning disabilities that are permanent (Lemoine, Harousseau and Borteryu et al., 1968). FASD has also been described as 'The Hidden Disability', in part, because there may be no physical characteristics to show an individual has FASD. Health Canada estimates that 1% of the Canadian population is affected by FASD; however, many of those affected with FASD have not been assessed and diagnosed.

Schools may be the first environment where children with complex learning difficulties and disabilities (CLDD) are identified. CLDD describes children with coexisting conditions that can include but are not limited to attention deficit hyperactivity disorder (ADHD), autism spectrum disorder (ASD) and FASD. Evidence indicates that the population of children with CLDD has been increasing. Blackburn and Carpenter (2012) suggest that meeting this need requires 'informed and reflective practitioners who are equipped with a range of observation and intervention tools to support their learning and development'. This is particularly germane to complex disabilities such as FASD and the associated diverse array of neurobehavioural and developmental issues.

In 1995, the Winnipeg School Division (WSD) established one of the first classrooms for students with FASD in Canada. This was in response to provincial surveillance data that identified 118 alcohol exposed infants born between 1993 and 1995 and the anticipation of increased identification and enrolment of children with FASD in schools. Based on early experiences in meeting the complex needs of these children within a regular classroom, the decision was made to develop a specialised programme that recognised and addressed the unique needs of children with FASD. What occurred at that time has been referred to as a *paradigm shift* in the understanding of the needs of individuals with FASD (Malbin, 2004). This has been further described by Malbin who said:

*'If FASD includes changes in the structure and function of the brain, then it follows that it is by definition a brain-based physical disability. In most cases, however, it is invisible, and behaviours are typically the only symptoms. Understanding FASD as a primary physical disability with behavioural symptoms redefines problems and solutions in a manner consistent with research' (Malbin cited in Jonsson, Dennitt and Littlejohn, 2009, p. 71).*

The Winnipeg School Division recognised that the needed approach to educating the children with FASD meant learning how to adapt and individualise the educational environment and academic programme to address their specific learning profiles. In this way, the Division showed early national leadership in positioning itself to be innovative and to develop successful strategies for educating children with FASD.

Since 1995, the programming for students with FASD within the WSD has grown, and in partnership with medical, clinical, education and social services professionals, the division has established itself as a North American leader in developing and implementing strategies for educating children with FASD. Supporting this assertion is the large number and types of professionals (within Canada and internationally) who have come to learn about the Division's FASD programmes or who have contacted the WSD for information. For example, the principals of the schools indicated that they host approximately 150–200 visitors per year. Visitors have come from France, Scotland and provinces across Canada. The visitors range from educators, other school division staff, those in the health care system, Department of Justice and child and family service agencies. The Governor General, Members of Parliament and other members of the Legislative Assembly have also visited. In addition, students from local colleges and universities have also come to study the FASD education programmes (J. Millar, personal communication, February 3, 2014).

This paper starts with a summary overview of FASD to address the questions: (1) what is FASD; (2) what is the prevalence of FASD in schools; (3) what is the impact of FASD; and (4) why develop special FASD education strategies and programmes? We summarise the 16-year history of Winnipeg School Division's development of its FASD programme of services, describe the specialised FASD classrooms and then present the results from a consensus-generating workshop comprised of FASD education professionals (N = 36, with over 209 years of collective FASD education programme experience) who were asked to identify and reach consensus on best strategies and lessons learned from the 16 years of experience in the WSD FASD education programmes. We also posit that effectively educating children affected by FASD is critical to get right if positive educational and social outcomes are to be realised.

## Background

### *What is fetal alcohol spectrum disorder (FASD)?*

FASD is a permanent neurodevelopmental disorder caused by prenatal exposure to alcohol. The first medical reports on fetal alcohol syndrome (FAS) were published in 1968 in France and later in 1973 in North America (Jones, Smith and Ulleland et al., 1973; Jonsson et al., 2009; Lemoine et al., 1968). Today, the term FASD is used to describe the full spectrum of effects associated with prenatal alcohol

exposure and includes FAS, partial fetal alcohol syndrome (PFAS) and alcohol-related neurodevelopmental disorder (ARND) (Carpenter, 2011; Chudley, Conry and Cook et al., 2005; Koren, Nulman and Chudley et al., 2003; Sokol, Delaney-Black and Nordstrom, 2003). FASD is considered the leading cause of developmental disabilities in children (PHAC, 2003; Stratton, Howe and Battaglia, 1996). The effects of alcohol exposure on the foetus are permanent and can include but are not limited to: growth restriction, heart defects and other physical malformations, facial characteristics, central nervous system and neurodevelopmental abnormalities including cognitive and executive functioning deficits, communication, sensory processing differences, spatial awareness problems and significant social adaptive challenges (Chudley et al., 2005; Mukherjee, Hollins and Curfs, 2012; Rasmussen, 2005; Streissguth and O'Malley, 2000). Individuals with FASD frequently develop secondary disabilities such as mental health issues, school withdrawal, legal problems and substance abuse in response to a lack of community and societal understanding and accommodation (Mukherjee et al., 2012; Streissguth, Barr and Kogan et al., 1996). The effects of FASD vary in range and severity for each individual, likely depending on individual biology, genetic and epigenetic factors and environmental influences.

The diagnosis of FASD in Canada is guided by the Canadian Diagnostic Guidelines, currently under revision, originally defined by Chudley et al. (2005) as well as by the four-digit code classification developed by Astley and Clarren (2000) at the University of Washington. The Canadian Guidelines address criteria to be met in facial dysmorphism, growth and neurodevelopmental multidisciplinary assessment. Internationally, complete agreement on diagnostic guidelines is yet to exist with disagreements focusing on cut-off criteria for measurements in facial dysmorphism (Mukherjee et al., 2012).

In the Canadian guidelines, the neurodevelopmental assessment is descriptively broken down into nine brain domains of functioning and structure including hard and soft neurologic signs, cognition, receptive and expressive communication, attention, academic achievement, memory, executive functioning, attention deficit/hyperactivity, social adaptive functioning and brain structure defined by the presence or absence of microcephaly or other structural findings (Chudley et al., 2005). The functional domains are further described in Table 1. A diagnosis of FASD typically requires a comprehensive assessment that includes an evaluation of each of the domains which then provides a detailed evaluation of the extent of the brain injury.

As noted above, FASD results in physical, emotional and intellectual disabilities that are unique to each child and where the effects may exist on a continuum from clinically indistinguishable to very severe (Streissguth and O'Malley, 2000). The specific range of impairments are influenced by

**Table 1: Brain domains affected by prenatal alcohol exposure**

Domain	Characteristics and commonly associated disabilities
Physical motor skills	Includes gross and fine motor skills. Examples include: running, rollerblading, bike riding, ball games, gymnastics, static or moving balance, writing/pencil holding, tying shoes, using scissors and opening packages. Children may have poor coordination (hand/eye and total body) and sensory input (regarding needed force/pressure) and abnormal muscle tone that affects balance. They may also have an immature grasp and manipulation patterns when using pencils and scissors.
Sensory processing skills	Describe how the children process/interpret everyday sensory information such as touch, sound, movement and smell. Children may be oversensitive and feel 'bombarded' by sensory information or they may seek out intense sensory information. The sense of overstimulation affects the inner sense of calm resulting in anxiety, aggressive or defiant behaviour and inability to learn/perform.
Cognition	Is defined by the process of knowing, perception, awareness and judgement. Problems include learning difficulties, deficits in school performance, poor impulse control, problems in social perception, deficits in higher level receptive and expressive language, poor capacity for abstract thinking; deficits in mathematical skills, and problems with memory, attention, judgment or organisation. (Children may seem above average in one area and well below average in another.)
Communication	Includes both expressive and receptive communication skills. Expressive language skills may develop at a slower rate than normal. They may have problems using complex language structures and problems retrieving words from memory. Receptive communication deficits may include problems with following instructions, comprehension, discrimination, generalisation, abstraction and sequencing.
Academic achievement	Deficits in comprehension, abstract thinking, comprehension and communication affect the ability to adapt as children progress through school and can impact academic achievement in multiple areas (e.g., math, science, vocabulary, direction/temporal concepts and arts).
Memory	Includes encoding, storage and retrieval processes. Children may have problems with each of these processes. They may have remembered or done something many times before and be unable to remember or do it on a given day.
Executive functioning Abstract reasoning	Describes a group of higher order cognitive processes including: inhibition, thinking flexibility, planning, cause and effect, judgement and organisation. Children may experience decreased capacity in these processes (e.g., decreased common sense) and repeat the same mistakes. They often do not recognise consequences, learn from past experiences or generalise possible outcomes from one behaviour to another.
Attention deficit/ hyperactivity	Includes difficulty maintaining focus of attention. Children may be easily distracted by visual and auditory stimulation that may not even be noticed by the other students. They may have problems self-regulating when they are overstimulated or tired.
Adaptive behaviour	Includes functioning independently and acquiring new daily living skills. Children have decreased capacity to develop/acquire new social, practical and conceptual skills to help them better respond to daily demands.

multiple factors including timing of alcohol exposure, other substance exposures, individual maternal metabolism of alcohol, maternal nutrition and environmental stressors during pregnancy. There is no safe known amount of alcohol use during pregnancy. The emotional, behavioural and cognitive behaviours observed in students with FASD may appear similar to the behaviours in children with other disorders, such as ADHD or oppositional disorder; however, the aetiology and social impact are different. Specifically, symptoms of FASD are due to the effects of alcohol on the developing brain, with profound impact on the individual, family and community. In short, FASD is a complex disability, combining neurodevelopmental impairment with severe adaptive disability and complex socioeco-

nomic factors. The needs of these children are often best addressed in a multi-sectoral strategy with school and community partnerships.

Research demonstrates that children with FASD have a unique and complex set of neurocognitive and behavioural characteristics when compared to children with other neurodevelopmental disorders (e.g., ADHD alone without FASD) (Coles, Platzman and Raskind-Hood et al., 1997; Greenbaum, Stevens and Nash et al., 2009; Nash, Rovet and Greenbaum et al., 2006; Nash, Sheard and Rovet et al., 2008; Tseng, Cameron and Pari et al., 2013; Vaurio, Riley and Mattson, 2008). Children with FASD process information and learn differently when compared to children with

other disorder types. Additionally, children with FASD illustrate significant individual variability, meaning that depending upon the different brain domains affected, each child may learn differently and subsequently the best approaches to learning may differ per child. This also helps to explain why common approaches such as pharmacotherapy or cognitive behavioural therapy frequently do not work (or work as well) with children with FASD (Blackburn, Carpenter and Egerton, 2012; Jonsson et al., 2009). Addressing the needs associated with FASD requires comprehensive, specialised assessments and individualised educational planning developed by a multidisciplinary educational team based on a comprehensive and multidisciplinary diagnostic evaluation.

#### *What is the prevalence of FASD in schools?*

Prevalence estimates for North America are frequently reported to be about 1% with higher rates in some at-risk communities (Health Canada, 2006). Internationally, rate estimates vary by country and at-risk subpopulations. For example, in a systematic literature review and meta-analysis of 33 studies (e.g., USA – 11, Canada – three, Brazil – one, Chile – two, Israel – one, Russia – 10, Spain – one, Romania – one and Sweden – three) on high-risk populations such as children in care, Lange, Shield and Rehm et al. (2013) estimated pooled prevalence rates of 16.9% for FASD and 6% for 'full' FAS (Lange et al., 2013). However, results from recent school studies in Croatia, Italy, South Africa, Sweden and the USA suggest rates of 2.3% to 6.3% among school-aged children (May, Fiorentino and Coriale et al., 2011; May, Gossage and Kalberg et al., 2009; Petković and Barišić, 2010). May et al. (2009) argued that the previous estimates were based upon clinic or records-based systems that did not use active recruitment methods and that those methodological approaches under-reported prevalence. In-school studies were recommended as the most complete and accurate way of determining the prevalence of FASD within a population (May et al., 2009). The above and other recent studies support the assertion that FASD is under-reported in both the general population and among regional or other at-risk subpopulations (Morleo, Woolfall and Dedman et al., 2011).

These figures have important implications for understanding the potential school prevalence of FASD in countries with higher rates of per capita alcohol consumption such as England, Ireland or the Czech Republic. For example, the World Health Organization reports that approximately 42% of women in the UK are heavy drinkers compared to 5% in the USA and that 9% of the women in the UK who drink reported episodes of heavy or binge drinking which is one of the main risk factors for FASD (WHO, 2004). Evidence suggests these rates and subsequent risk may be increasing as illustrated by increases in alcohol-related hospital admission rates (e.g., in England and Wales); a study in north west England, for example, showed women participating in nightlife activities were consuming on average five times the recommended daily maximum units of alcohol

(Anderson, Hughes and Morleo et al., 2009; Thomson, Westlake and Rahman et al., 2008). It is thus reasonable to conclude rates in a UK school population could be higher than those reported by May et al. (2009) for schools in the USA.

In addition, evidence also indicates that rates are higher in some at-risk school-aged populations. Specifically, there is growing evidence that children with FASD are over-represented in the child welfare system. Studies within the last decade estimate that between 17% and 50% of children in care have FASD (Fuchs, Burnside and Marchenski et al., 2010; Hutson, 2006), and they spend more time in care compared to children without or with other disabilities (Fuchs et al., 2010). This is further supported by a study in British Columbia which reported that 23% of children admitted for inpatient psychiatric assessment had FASD (Jonsson et al., 2009).

Current research is exploring methods to identify FASD in the absence of confirmed maternal drinking and to better distinguish FASD diagnoses from other disorders such as ADHD (Greenbaum et al., 2009; Nash et al., 2006; 2008; Tseng et al., 2013; Welch, 2013). This research, combined with increased societal awareness of FASD and the increasing clinical capacity to assess and diagnose children will result in significant increases in the numbers of school children formally diagnosed with FASD. Given the above, we know that FASD is a serious social, health and education issue that will likely increase.

#### *What is the impact of FASD?*

The costs associated with the care of individuals with FASD have been modelled and provide compelling data describing the complexity and needs associated with this disorder. The cost of course is not just economic in nature but speaks to the significant need for appropriate and skilled early and continued intervention throughout the lifespan. Skilled educational supports that address the learning and adaptive needs of individuals with FASD have the potential to address secondary disabilities and consequently to positively impact the long-term adult outcomes in this disorder (Blackburn et al., 2012).

*Economic impact.* Although only a few studies have evaluated the economic impact of FASD and examined the complexity of the associated costs, all the studies to date agree that the economic costs of FASD to society are high. For example, a recent Canadian study evaluated the cost of FASD from birth to 53 years; they reported the adjusted costs to be \$24 041 per individual for each year, which translated into an annual total Canadian cost of \$5.3 billion, which included direct costs (e.g., medical, education, social services, out-of-pocket) and indirect costs, such as productivity losses (Stade et al., 2008). The limitations of studies that examine the *economic cost of FASD* include limitations in the range of societal costs included, such as justice system charges, costs to schools and students such as

additional teacher and administration time or downstream costs associated with decreased quantity and quality of learning for both affected and non-affected children.

*Health and human impact.* Alcohol is a teratogen that significantly impacts the brain and central nervous system (Streissguth and O'Malley, 2000). However, prenatal exposure affects all aspects of future health (e.g., physical, emotional, social, intellectual, family, communities, economic potential and overall health status). Children with FASD have diverse complex physical and mental health problems as well as cognitive and developmental/learning disabilities (Blackburn and Carpenter, 2012; Blackburn and Whitehurst, 2010; Brownell, de B Hanlon-Dearman and Macwilliam et al., 2013; Chudley et al., 2005; O'Malley and Nanson, 2002). This diversity within group range makes working with FASD different from other children with special needs (Mukherjee, Wray and Commers et al., 2013). Each domain is affected differently in each child and is associated with a different spectrum of abilities and challenges affecting physical motor skills, sensory processing skills, cognition, communication, academic achievement, memory, executive functioning/abstract reasoning, attention deficit/hyperactivity and adaptive behaviour (Chudley et al., 2005; HCMO, 2009; Lang, 2006). Consequently, children with FASD often require a range of treatments and supports that encompass the medical, social, therapeutic and educational areas.

As noted previously, children and adults with FASD who have received insufficient supports are at risk of developing secondary disabilities such as mental health issues, school withdrawal, legal problems and alcohol and drug problems that are linked to having FASD (Streissguth et al., 1996). Children with FASD are much more likely to 'drop out' of school or be suspended, both of which are risk factors for involvement in crime and subsequently the criminal justice system (Burd, Selfridge and Klug et al., 2003). In a recent systematic review of Canadian data, Popova, Lange and Bekmuradov et al. (2011) reported that in a given year youths with FASD were 19 times more likely to be incarcerated than youths without FASD. In addition, the United States Department of Health and Human Services reported a Washington study which estimated that 35% of individuals with FASD had been in jail or prison and that more than 50% had been in trouble with the law (DHHS, 2007). Given this, there is societal advantage to adapting the education system to meet the needs of individuals with FASD in order to support completion of education and occupational training.

#### *Why develop special FASD education strategies and programmes?*

Current prevalence estimates suggest that schools have higher numbers of students with FASD than typically reported and that FASD is under-diagnosed. Those affected with FASD may have IQs in the normal range, suggesting they may not be readily identified by standardised cognitive

measurements alone (Streissguth and O'Malley, 2000). However, they may be identified differently. For example, Streissguth and O'Malley (2000) indicate that their achievement scores are often lower than their IQ scores and that frequent deficits are observed in areas such as arithmetic functions, adaptive functioning and communication and socialisation skills. These deficits often result in observable behaviour and learning difficulties that frequently do not respond well to approaches used with other students with problems. As a result, students with FASD are more likely to have attracted the attention of educational psychologists or other education and clinical professionals (Westrup, 2013). For example, Carpenter (2011) suggested that the intensity of the school experience frequently highlights the needs of those with FASD and that:

*'... children with FASD are difficult to accommodate within any Key Stage of the English National Curriculum'. He also concluded: 'There is a clearly significant shortfall in guidance for teachers on how to educate children with FASD in the UK... Their unusual style of learning and their extreme challenging behaviour is out of the experience of many teachers, ...'* (Carpenter, 2011)

Given this, it is clear that the increasing number of identified students with FASD and their complex and unique learning characteristics support the need to provide educators with appropriate tools and strategies. There is clearly a need to increase overall FASD education capacity by developing, documenting and evaluating FASD-specific educational strategies. For example, Carpenter reported a 2008 qualitative study, comprised of 20 teachers in the UK with FASD educational experience who were asked to identify FASD-related challenges to classroom learning. Results from the teacher interviews were combined with an extensive international literature survey to synthesise/identify 10 major teaching responses (i.e., best practices) to address the learning needs of children with FASD. These are illustrated in Table 2. In another example, Mukherjee et al. (2012) suggest that the cognitive profile of those with FASD indicates that their performance can be improved by changing teaching strategies such as reducing external expectations and time pressures.

The following section describes the history, programmes and lessons learned associated with the WSD's 18-year experience with FASD-specific education strategies that were implemented in 1995. The WSD's response was supported by policy and informed by the literature, the prevalence of FASD in the general and at-risk populations and the poor educational track records of children with FASD. The Division concluded there was a clear and compelling need to develop specialised FASD education strategies and programmes for both 'inclusive classrooms' and 'FASD-specific classrooms' for children who were not experiencing success in a traditional classroom setting. Innovative FASD-specific education approaches can both support

**Table 2: Ten major fetal alcohol spectrum disorder (FASD) teaching responses**

<ol style="list-style-type: none"> <li>1. A calm learning environment, free from clutter;</li> <li>2. Focused tasks presented in small steps;</li> <li>3. Personal space for the student with plenty of support and praise;</li> <li>4. Visual structuring;</li> <li>5. Scripted/role play;</li> <li>6. Short, key information-carrying word instructions;</li> <li>7. Visual clarity and graphic simplicity;</li> <li>8. Frequent, short exercise programmes during the day;</li> <li>9. A breakdown of tasks with visual and tactile clues;</li> <li>10. Multisensory learning – giving messages through a variety of sensory pathways (Carpenter, 2011).</li> </ol>
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learning and social skills development and have the potential to mitigate the secondary disabilities associated with FASD. Of importance, a more global, education strategy reduces stigma and is more inclusive, allowing families and caregivers, as well as the children's communities, to be involved in the child's plan.

#### *Education policy in Manitoba and FASD*

Education is a provincial responsibility in Canada (Ghosh, 2004; Jordan, 2010). Manitoba, like other Canadian provinces has an educational policy that is intended to ensure that students with special learning needs receive appropriate programming and supports that foster student participation in both the academic and the social life of the school. In 2006, Manitoba Education released *Appropriate Educational Programming in Manitoba: Standards of Student Services* which reflects the base or minimum practices and services that should be available to all students in Manitoba; it is intended to assist school divisions in setting direction and planning for the implementation of appropriate educational programming for all students with special needs. It is an expectation that students are assessed as soon as reasonably possible when they are not meeting the expected learning outcomes, and an individual education plan (IEP) be developed and implemented by a team, which outlines a plan to address the individual learning needs of students.

Manitoba embraces a philosophy of inclusion that allows every student to feel accepted, valued and safe. Inclusive schools provide a learning environment that is accessible to all students as a place to learn, grow, be accepted and enjoy all the benefits of citizenship (Manitoba, 2006). In an inclusive school environment, students with diverse learning needs have access to a continuum of services and supports to address their unique abilities and needs. Inclusive education is not without challenges for teachers, schools and school boards:

*'In inclusive education the challenge for teachers is the quality of learning and participation of all the*

*pupils located therein. Inclusive schools are understood to be those that make major adjustments to their organisation and processes in response to their diverse populations. A key element of adjustment is in the way that teachers teach: to develop inclusive pedagogy teachers need access to good information.'* (Nind and Wearmouth, 2006, p. 216)

There is great variance in FASD education policy across the provinces in Canada. Elizabeth Bredberg, a Canadian educational consultant, describes the policy continuum as: (1) generic education policy, (2) special education policy (and 3) explicit FASD policy (Jonsson et al., 2009). Bredberg describes 'Generic Policy' as generally treating all students the same in areas such as: eligibility criteria for education, rules/standards of conduct, attendance, curriculum, achievement and disciplinary policies. She indicates that 'Special Education Policy' allows for differential treatment, policies and both learning characteristics and expectations for students (e.g., those with or without a learning or other disabilities). She also suggests that 'Explicit FASD Policy' (1) falls within provincial special education policies; (2) is not very common across Canadian provinces; and (3) can include FASD-specific classrooms and/or guidelines on supporting students with FASD in the classroom (e.g., integrated or inclusive classrooms) and other settings through collaborative interdisciplinary models of support for affected students and their families.

As an education consultant, Bredberg visited 460 schools with children diagnosed with FASD. She concluded that *FASD professionals were not adequately getting the message across to education professionals that there are neuro-behavioural differences in FASD that differ from other learning disabilities*. She argued that we need to better integrate findings from multidisciplinary diagnoses into educational programmes for students, a process described as *bidirectional capacity building*:

*'Not only can education practice be informed by multidisciplinary diagnoses, but it was our observation that diagnostic practice can be informed and enlightened by hearing from education.'* (Bredberg cited in Jonsson et al., 2009, p. 123)

#### *FASD in the classroom – why does it matter?*

The cognitive range for children with FASD is quite broad, ranging from normal, to specific learning disability, to intellectual disability. This wide variance means children with FASD may not directly qualify for 'special education' programmes/services despite their learning challenges. Children with FASD typically experience significant deficits in 'Executive Functioning' area when compared to both non-FASD children and children with ADHD (Rasmussen, 2005). Children with deficits in executive functioning struggle with inhibition, impulse control problems, difficulty in planning and organising and challenges with emotional regulation (Green, 2007; HCMO, 2009). Studies of

**Table 3: Strategies and factors that support positive school experiences for students with fetal alcohol spectrum disorder (FASD)**

- Personalised learning – recognise neurobehavioural diversity which results in individual learning characteristics that need to be identified, assessed and incorporated into teaching such as individual strengths, weaknesses, capacities and interests. This can be supported by involving families and caregivers who provide valuable information on the curriculum and how the child is coping. (Blackburn et al., 2012);
- Student perceptions of ‘caring teachers’, appropriate programmes and services, child having a medical diagnosis of FASD, and the involvement and support from family/caregivers in education planning/goals (Duquette and Stodel, 2005; Duquette, Stodel and Fullarton et al., 2006; Job, Poth and Pei et al., 2013; Kalberg and Buckley, 2007);
- Multidisciplinary teams that include physical therapists, occupational therapists, speech language pathologists, psychologists, special education and regular teachers and other support staff (Green, 2007; Jirikowic et al., 2008);
- Using caregivers, teachers and others as the ‘external brain’ to help with executive functioning (Chudley, Kilgour and Cranston et al., 2007; Green, 2007);
- Child-specific interventions based upon the child’s neurobehavioural development. Implementing strategies to address cognitive, communication, social, emotional and physical developmental delays and preparation for employment among older students. Examples include strategies to improve/support: communication, literacy, abstract thinking, concept and sense of time, use of money, memory, organisation skills, understanding and following rules, sensory processing (e.g., sound, smell, movement, light, coping with over stimulation), supporting relationships and role models, understanding inappropriate behaviours, understanding danger and impulse control and adapting the physical environment to work with FASD and individual differences. (Blackburn et al., 2012; Green, 2007);
- Placing appropriate structure (e.g., routines, consistency, supervision, specific work areas and visual aids/instructions) in the environment to help the student know what is expected or decreased visual and auditory stimulation to decrease distractions (Blackburn and Whitehurst, 2010; Kalberg and Buckley, 2007);
- Recognising that a student with FASD may not function at the same level as peers at the same age and then appropriately modifying the approach and environment to support the student’s needs (Kalberg and Buckley, 2007).

students with FASD also indicate significantly challenges with sensory processing, motor control, adaptive and academic achievement (Jirikowic, Olson and Kartin, 2008). The net result is that children with FASD face considerable challenges in learning beyond their specific cognitive impairment. Thus, addressing the specific learning needs of students with FASD requires a continuum of supportive policies, sustained funding and evidence-informed practices, all underpinned by a long-term commitment by the boards, schools, communities and families. Illustrations of strategies associated with positive school experiences for students with FASD that have been used in the Winnipeg School Division and in the UK are presented in Tables 2 and 3. We do not combine these because we feel the results of the Blackburn study (Table 2 – Ten Major FASD Teaching Responses) warrant separate illustration because the results identify a prioritised list of applied best practices that were identified in a specific study.

### **FASD education strategies in the WSD**

In 1995, the WSD established one of the first FASD classrooms in Canada in response to data from a preschool surveillance programme by the Division’s Early Childhood Transition Network. This data identified 118 alcohol-exposed infants between 1993 and 1995 who were born in Winnipeg and where many were expected to attend the WSD in the near future. Reinforced by policy, informed by evidence and supported through the school collaborations,

the decision was made to develop a special programme to better address the needs of those children.

In the same year, an FASD education programme was created for Kindergarten students. Its genesis coincided with a rising awareness of FASD by the public, government and health-care systems coupled with an increased system-wide capacity to refer, assess and diagnose children with FASD. Since 1995, based on need and enrolment demand and along with the positive educational outcome results, the FASD programme expanded from one classroom in 1995 to three by 2004 to the current roster of 10 classrooms across five schools. There are two primary classrooms, three intermediate classrooms, and three junior high classrooms. Two senior high school classrooms were established in 2010. The total number of individual students enrolled in the 10 FASD classes to date is 164, and in the 2013–2014 calendar year, there were 66 students.

Parallel to the FASD curriculum development, and supporting and honing the teachers’ expertise, an FASD advisory committee was formed. It was comprised of education professionals, health professionals, social services and other system stakeholders. The purpose of the FASD advisory committee was to bring together key players in the schools and community to network, identify issues, bring in renowned speakers and work on professional development relating to FASD in schools. Committee activities included

recognising (1) the need to develop a strong partnership with the Manitoba FASD Centre [previously the ‘Clinic for Alcohol and Drug Exposed Children’ (CADEC)] and (2) the value of educating the community. The purpose of the relationship with the FASD Centre was to support and better streamline the process from referral to assessment and follow-up and to ultimately implement a more coordinated system-level approach.

As the FASD programme expanded, so did the need to increase training and capacity. The WSD with support from the provincial government implemented ‘Project 2000’ which was designed to train an initial group of six teachers in FASD programming and teaching strategies. These six were then expected to be peer mentors and train an additional eight teachers (McCaig, 2003), develop ‘FASD Resource Kits’ for distribution to other teachers and provide yearly FASD training for each school team. In response to the programme’s growth, the WSD created two new FASD support teacher positions to enhance FASD programming across the division.

The WSD’s FASD programme is a coordinated systems-level approach that works closely with health services and other local government and non-government professionals. This systems level approach and the cumulative experiences and knowledge have made the WSD a North America leader in FASD education (Sanders and Welch, 2011). The result has seen important lessons learned and innovative strategies and best practices that have provided many benefits to both students and education professionals. Figure 1 illustrates this systems-level approach through the process starting with identification of children through multidisciplinary assessment. The communication of a diagnosis of FASD with the consent of family supports educational planning that is responsive to the specific learning and behavioural challenges of each child, based on their diagnostic assessment.

#### *Specialised FASD classrooms and inclusive classrooms with FASD supports*

Educational programming is adapted to meet the individual needs of each child, recognising the needs of each child based on the assessment of their brain domains (see Table 1). Thus, some students with FASD will do well in regular classrooms with adequate interventions, adaptations and understanding, and some will benefit from a specialised environment designed to reduce barriers and provide additional structure and support. The WSD recognised this when determining the supports that would be required in inclusive classroom settings and in specialised FASD classrooms for the benefit of all students with FASD.

Criteria for enrollment in the specialised FASD programme include a comprehensive assessment and medical diagnosis of FASD (See Figure 1). The students are assessed to determine their current level of performance and their eligibility for additional special education support from the province.

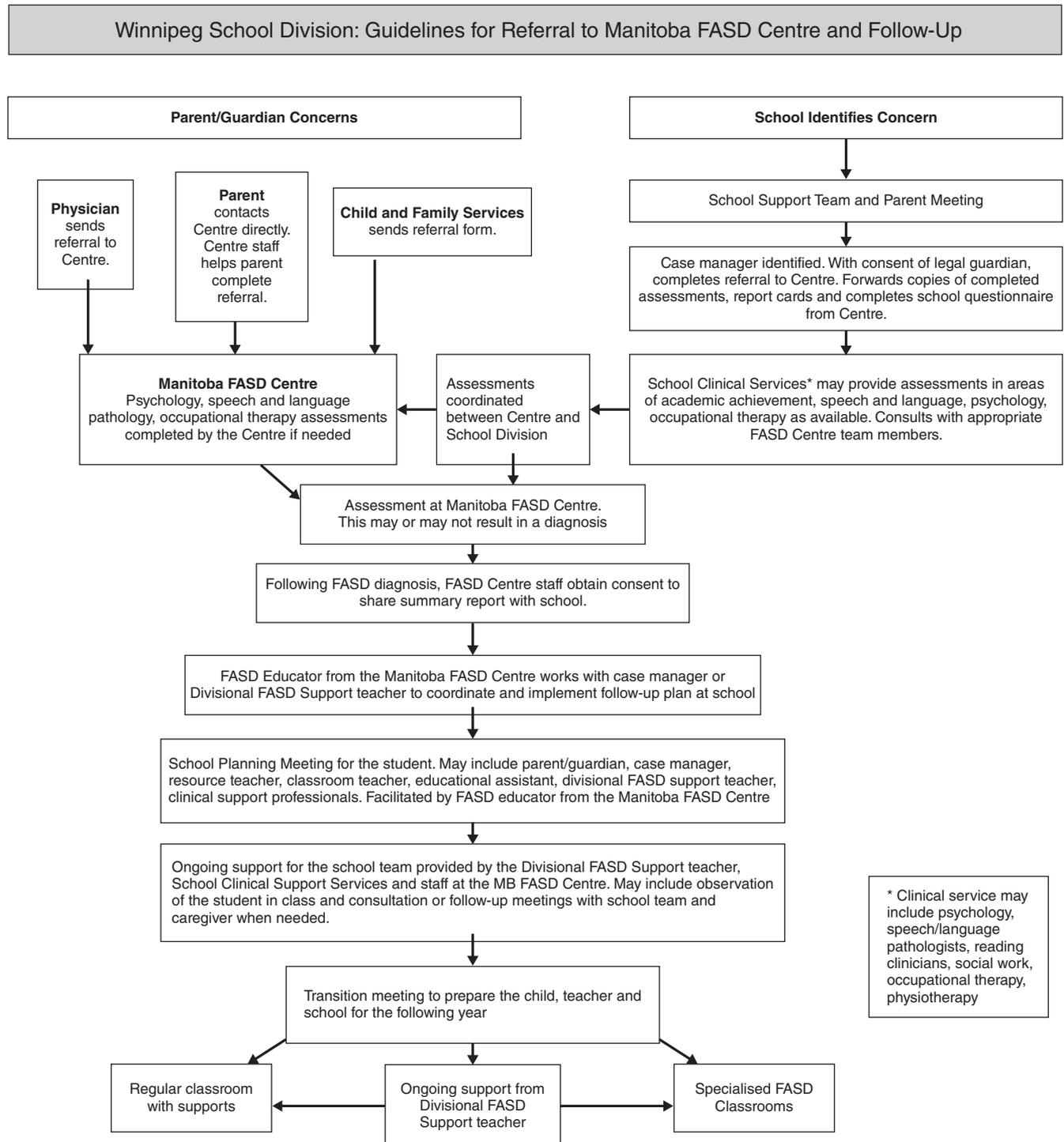
Students are only placed in the specialised FASD classroom after it is determined that the inclusive classroom setting is unable to meet the student’s needs and with the permission from the parent or legal guardian.

*Specialised FASD classrooms.* Each classroom is comprised of eight students and one teacher and two educational assistants; all staff have had specialised FASD professional development training. The FASD classrooms combine multiple grades: Grades 1 to 3, Grades 4 to 6, Grades 7 to 8, Grades 9 to 10 and Grades 11 to 12. Students with FASD are provided with a wrap-around model which includes appropriate programming to meet their social, educational and emotional needs. Programming includes a more structured day with constant supervision in the class and during non-instructional times (e.g., lunch, recess and class change). Instruction is based upon the Manitoba education curriculum and can be adapted or modified based upon the student’s learning needs. Students in these classes have IEPs that detail student-specific outcomes and an implementation plan identified in the comprehensive and specialised assessments completed by the multidisciplinary teams. In addition, the IEP is developed by the student support team which includes the teacher, parents and student when possible along with other members of the team outlined in Table 4.

The physical environment of each class may be adapted to address the different learning needs. Examples include: (1) reducing visual and auditory stimulation, (2) allocating space for a quiet area (e.g., tent or cubical) for when children are frustrated or over stimulated or need a quiet place to work, (3) adapting a specific student’s work station/desk and (4) using special equipment and tools (e.g., smart boards, iPad, lap top computers, visual cues and head phones to reduce auditory distractions).

The students experience success in school and attendance is rarely an issue. Other observed benefits include increased social skills and self-esteem as well as a better understanding of how their brains work and consequently increased understanding and acceptance of their diagnosis. Supporting this assertion are preliminary results from a Canadian Foundation on Fetal Alcohol Research-funded project (D. Goodman, personal communication, January 14, 2014). These outcomes may be a result of strengths of the specialised FASD classroom programme which include: (1) students may stay with the same teacher longer (e.g., about 3 years), (2) teachers and educational assistants knowledge and training about FASD and strategies for educating students with FASD, (3) inclusion of the multidisciplinary clinical/educational support team and (4) involvement of family or caregivers.

*Inclusive classroom settings with FASD supports.* The inclusive or regular classes include students with FASD and other students with and without learning or other disabilities. Many of the students in these classes are provided with

**Figure 1: Fetal alcohol spectrum disorder referral and follow-up**

the additional support and specific learning strategies they need based upon the results of their multidisciplinary assessment. This may include increased supervision during unstructured times (e.g., lunch or recess) or use of visual cues and other tools in the classrooms. Tables 2 and 3 provide examples of strategies used by the WSD in both specialised and inclusive classrooms and additional strategies and best practices identified or implemented interna-

tionally. In addition, whenever possible, their IEP also includes support where needed from the appropriate members of the multidisciplinary FASD education team.

#### *WSD: strategies and lessons learned for educating children with FASD*

In January 2013, a workshop titled 'Best Practice Exchange: Working with Students with FASD' was held in

**Table 4: Suggestions for schools**

Topic/Area	Strategy or action
Paradigm shift	Addressing fetal alcohol spectrum disorder (FASD) requires a paradigm shift. The goal is not to figure out how to get the children with FASD to 'fit in' or to behave like the other students, it is to figure out how to teach and adapt the school environment to meet the students' learning styles. This requires recognising that these children process information and learn differently as reflected by assessments in the nine brain domains affected by prenatal alcohol exposure.
System-level response/ partnership	This is not a 'school only' issue or responsibility. The best approach to addressing FASD in schools requires a community-wide (systems level) response (i.e., that includes: education, healthcare professionals, social services, youth justice, family and community organisations). It also helps to create a school division-wide FASD support teacher/consultant position to support development and implementation.
The education team	Consulting and partnering with medical specialists, social services, community organisations and family/caregivers.
Teacher training	Teachers need specific and up-to-date training on FASD and FASD education practices. Teachers are key to understanding behaviours and learning. It is important to recognise that the behaviours are brain based. Consequently, this warrants a different approach than those typically used in regular classrooms.
Resource needs	Provide as much individualised support whenever possible as well as providing resource teacher support. Up-to-date technology such as: iPads, Smart Boards, Lap tops.
Individualised education plan	Comprehensive assessment and individualised education plan (IEP) developed by a multidisciplinary team (e.g., comprised of physician, psychologist, speech language pathologist, occupational therapist, social worker, physical therapist, school guidance counselor, teacher and family/caregiver.)
Procedures and rules	Part of the paradigm shift is recognising that traditional practices and rules will not always work with the children.
Additional programming suggestions	Social skills programming, self-regulation, safety skills/community awareness, vocational training/work experience, learning profiles, transition planning [through the PATH (Planning Alternative Tomorrows with Hope process)], community-based activities, life skills.
Time periods before and after school	Awareness of supports, programmes that are available and encourage participation with the student through communication with the family/legal guardians.
Developing and implementing FASD programmes	Start with the mandate that no child diagnosed with FASD will get lost and the understanding that with each child comes a parent or caregiver whom you also need to work with. Identify key education, health, government and community-based stakeholders. Develop and maintain collaborative partnerships with decision-makers. Establish an interagency FASD advisory committee and links with key providers such as diagnostic clinics. Create a school division-wide FASD support teacher/consultant position to support development and implementation.

Winnipeg. It was attended by 36 invited experts from the provinces of Manitoba, Ontario, British Columbia and Alberta who were involved in FASD education. In this section, we present an overview of strategies, lessons learned and suggestions for addressing and developing FASD education programming. The information in this section comes from the informed opinions and experiences of key informants and the consensus generating workshop comprised of education/FASD professionals.

#### *Workshop methods*

*Participants.* The 36 workshop participants were identified because of their employment status and expertise. They had worked in or were knowledgeable of the WSD's programme or similar FASD education programmes in the other provinces. Their collective FASD-specific education programme experience was estimated to be over 209 years. Participants were grouped at grade-specific tables based upon their FASD educational expertise in four categories:

(1) primary grades 1–3, (2) intermediate grades 4–6, (3) junior high grades 7–8 and (4) high school grades 9–12.

*Presentations.* Prior to the working groups taking place and to contextualise the issues, three presentations were delivered by invited experts: (1) Dr Ana Hanlon-Dearman (Manitoba FASD Research Scientist, Developmental Pediatrics with the Manitoba FASD Centre) provided an update on current FASD research; (2) Dr Kim Kearns (Clinical Neuropsychology Program, University of Victoria) illustrated new approaches for cognitive deficits in children with FASD; and (3) Sandra Swaffield (Edmonton Public School Board) provided an overview of the WRaP Project (FASD education programme in Edmonton).

*Consensus.* Group consensus was achieved using a group consultation approach similar to the Nominal Group Technique (Jones and Hunter, 1995; Lloyd-Jones, Fowel and

**Table 5: Strategies, lessons learned and suggestions for the classroom**

Topic/Area	Strategy, lesson learned or suggestion
Innovative teaching approaches	The approaches are first based upon recognising that children affected with fetal alcohol spectrum disorder (FASD) process information differently and react to the environment differently. Then they are based upon an assessment of how the specific child's brain works within the nine brain domains. The approaches then acknowledge the individual students strengths/weaknesses that were identified in the assessment by the multidisciplinary team and then adapt the teaching style, curriculum and physical environment based upon that information to develop individual education plans (IEPs) for each child.
FASD across all grades	There are common best practices in education for all years (Kindergarten – Grade 12). However, at different grade levels (e.g., primary, intermediate, junior high and high school), there is a need to focus more attention on best practices for that age. Need to recognise that children may be strong in some areas such as visual hands on learner and also more challenged through language-based learning. In addition, because of their brain differences recognise that sometimes children will be unable to do some tasks that they have successfully done many times before.
Tools and technology	Learn to use and adapt tools and technology to support the way FASD brains work. Examples include using: head phones, smart boards, calming spaces, handheld listening helpers and other learning aids.
Procedures and rules	Part of the paradigm shift is recognising that traditional practices and rules will not always work with the children. Traditional rules may need to be adapted and other activities/procedures done differently. Examples include: allowing movement breaks, adaptive seating, gum chewing, using listening helpers to keep them calm.
The physical environment	<p>The usual classroom environment may be overstimulating for children with FASD. Busy walls, pictures or chalk boards with writing on them, open windows, noise from the hallways, flickering from fluorescent lights and even articles on a desk may distract and subsequently cause anxiety. There is a need to recognise that there is a time to increase stimulation and a time to decrease it:</p> <ul style="list-style-type: none"> <li>a) In general, classroom environments need to be restructured to decrease visual, auditory and physical stimulation that can distract or overload students with FASD whenever possible. (Examples include using natural light versus fluorescent light, using room dividers, covering windows and walls with pictures or signs not being used with curtains, using head phones so the student only hears the teacher, modified desks and chairs that reduce stimulation/distractions or a special calming space/place in the room [e.g., tent or enclosed space] for a sensory overload break. Other examples that sound counter intuitive include letting children chew gum or use a 'squishy ball or fidget toy' to help them relax.</li> <li>b) Children with FASD need more frequent movement breaks.</li> <li>c) Some children need to be able to move, wiggle, fidget, chew gum, use toys or do other physical movements in order to listen.</li> </ul>

Bligh, 1999). Activities at each of the four grade-specific tables were directed by a facilitator who used a terms of reference document to guide the process. Participants were asked to think about, identify, discuss and reach consensus on effective strategies and best practices that were being used in the FASD classrooms. This activity was repeated nine times at each of the four tables to separately address the nine brain domains.

#### *Workshop results*

The large number of examples generated from the workshop and interviews fit into two main thematic categories based upon system-level or classroom-level suggestions/strategies: (1) suggestions for schools and (2) strategies, lessons learned and teaching suggestions for the classroom. These are summarised in Tables 4 and 5.

#### **Discussion**

FASD has been described as a 'hidden disability' in part because there often are no overt physical signs to easily identify an affected child. However, this disability may be 'less hidden' in schools. In fact, schools may be one of the best settings to identify and effectively address the educational needs unique to children with FASD. Schools are also well positioned to ameliorate secondary disabilities commonly associated with FASD by helping affected children understand their different learning profiles and utilising their strengths and interests to support both education and future endeavours such as employment and relationships. In addition, school-based FASD programmes may also help decrease stigma. This includes stigma at multiple levels such as: (1) the effects of self-stigma experienced by the students with FASD (e.g., shame, isolation and social

exclusion), (2) stigma experienced by parents/family and (3) stigma among the general population (Byrne, 2000). For example, actions that may serve to reduce stigma include letting affected children know they are not 'alone' whether in inclusive or FASD-specific classes and also by increasing understanding and acceptance among non-affected students and their families.

Given the above, we feel it is important for school systems to adapt educational practice and policy to support the needs of children with FASD, particularly as systems are being faced with increasing identification and thus prevalence of this previously under-reported and complex disorder. Furthermore, public and government awareness of FASD has been increasing as has clinical awareness and FASD diagnostic capacity. Current research continues to augment this capacity, now and in the future, by developing tools which may permit the identification of individuals with prenatal alcohol exposure without requiring confirmation of maternal drinking. Examples include research in areas such as school-based surveys of behavioural phenotypes, bio-markers and saccadic eye movements (Nash et al., 2008; Tseng et al., 2013; Welch, 2013).

Students with FASD have complex learning and behavioural support requirements presenting challenges for educators who need to address uneven learning profiles and opportunities by planning individual curricula and tasks around the student's strengths and interests identified in their comprehensive assessments (Blackburn et al., 2012). Flexible and accommodating approaches to teaching children with FASD are needed along with additional support which may or may not include specialised FASD classrooms. Achieving this level of support requires political will, policy development, sustained funding, staff training, evidence-informed practice, individualised educational planning and collaborative partnerships between schools, clinical and non-clinical professionals, families and the community.

In 1995, the WSD was forward thinking in developing multiple approaches to the education of children with FASD and in basing the educational strategies on the individualised neurocognitive profile of each child. The partnerships developed with the community and the clinical assessment centre have resulted in expertise and experience where positive outcomes include better attendance, remaining in school longer and success in school (D. Goodman, personal communication, January 14, 2014).

#### *Implications for future research*

Additional research is needed to evaluate the educational, social and mental health outcomes of youth receiving the specialised FASD programmes (in both inclusive and FASD-specific classrooms) compared to a cohort of youth with FASD who do not receive the service. This includes development, implementation and outcomes research on

specific 'best practice' strategies for children with different FASD-based disabilities and learning characteristics. This research could also further the development of an evidence-based curriculum for educators and other school practitioners (e.g., psychologists, social workers, occupational therapists and speech language pathologists) related to youth with FASD through examining and comparing current practices against known best practices. In addition, other research could also evaluate differences between inclusive and FASD-specific classrooms to help provide information to guide decisions such as under what conditions the development and implementation of FASD-specific classrooms are warranted.

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