Mental health service provision in schools for children with Fetal Alcohol Spectrum Disorder
The following Evidence In-Sight report involved a non-systematic search and summary of the research and grey literature. These findings are intended to inform the requesting organization, in a timely fashion, rather than providing an exhaustive search or systematic review. This report reflects the literature and evidence available at the time of writing. As new evidence emerges, knowledge on evidence-informed practices can evolve. It may be useful to re-examine and update the evidence over time and/or as new findings emerge.

Evidence In-Sight primarily presents research findings, along with consultations with experts where feasible and constructive. Since scientific research represents only one type of evidence, we encourage you to combine these findings with the expertise of practitioners and the experiences of children, youth and families to develop the best evidence-informed practices for your setting.

While this report may describe best practices or models of evidence-informed programs, Evidence In-Sight does not include direct recommendations or endorsement of a particular practice or program.

This report was researched and written to address the following question(s):

- What evidence-informed practices should be available for children Fetal Alcohol Spectrum Disorder in an educational setting (Section 23 or otherwise)?
- What are the unique needs, accommodations and considerations for this population in planning and delivering services?
- What are the education and training needs of staff?

We prepared the report given the contextual information provided in our first communications (see Overview of inquiry). We are available at any time to discuss potential next steps.

We appreciate your responding to a brief satisfaction survey that the Centre will e-mail to you within two weeks. We would also like to schedule a brief phone call to assess your satisfaction with the information provided in the report. Please let us know when you would be available to schedule a 15-minute phone conversation.

Thank you for contacting Evidence In-Sight. Please do not hesitate to follow up or contact us at evidenceinsight@cheo.on.ca or by phone at 613-737-2297.
1. Overview of inquiry
The agency that requested this report provides early intervention and mental health services to children and families in a large urban setting. The local school board approached the agency to provide clinical support for children 6 to 13 years of age with a diagnosis of Fetal Alcohol Spectrum Disorder (FASD) who would receive special education and support in a Section 23 class. Each class would include 5 to 6 children.

The agency asked Evidence In-Sight to determine the key requirements for service provision, including the best practices, required spectrum of services for children with FASD and roles in a multidisciplinary team. Their current staffing model for FASD service provision includes teachers, child and youth workers, educational assistants, a lead child and youth worker (CYW), one to two counseling staff, a psychological consultant and a supervisor.

2. Summary of findings
A summary table of research on services for children with FASD in the education system can be found in Appendix A. The table is divided into two sections, including studies addressing screening, assessment and diagnosis, and studies regarding planning and implementing interventions.

The evidence on service provision for children with FASD has some key messages:

- Fetal Alcohol Syndrome (FAS) is the leading cause of developmental disability among Canadian children.
- Since FASD includes a complex spectrum of disorders it can be challenging to correctly identify, diagnose and treat the disorders. Understanding the evidence base of the nature of the disorders and the unique needs of these children can be important for education and training opportunities, which could contribute to better identification, treatment and support services.
- The Public Health Agency of Canada (PHAC) developed the Canadian guidelines for diagnosis of FASD to respond to the lack of consensus in identification and diagnosis.
- Secondary disabilities, especially mental health challenges, for children with FASD are important considerations in planning and delivering support. The most common mental illnesses in children with FASD are attention deficit hyperactivity disorder, conduct disorders and mood disorders.
- Many studies state the importance of the assessment process in a multidisciplinary, strengths-based and collaborative approach for understanding the unique learning profile of students with FASD.
- Recommendations to accommodate the learning needs of the child are shared with teachers and parents in a report, but they have found the reports to be too technical, too general, not focused on what will work or not including the strengths of the child in order to improve the child’s functioning.
- Research presents some common planning and implementation elements and components:
  - Case management is essential for coordinating services and planning an intervention that is individualized, inclusive of family engagement and collaboration, targeting known deficits in neurocognitive abilities and executive functioning, and adapting the environment.
  - Interventions often aim to improve behaviours and performance through addressing specific skill deficits (e.g. social skills, communication, attention).
- The U.S. Centers for Disease Control and Prevention (CDC) are funding a research consortium to develop, implement, and evaluate interventions for children with FASD and their families.
In addition, organizations across Canada, including various Ministries, have been establishing frameworks and practices for communities and education systems to implement more consistent practices (see Resources section).

- Reviews of the literature on interventions for children with FASD report a need for more rigorous and clear methodologies, reporting of procedures and analysis, along with larger sample sizes and targeted interventions based on the specific needs of these children. A few randomized control trials and studies assessing interventions have been completed, are underway or show promising outcomes.

3. Answer search strategy

- Search terms: Fetal alcohol spectrum disorder, Fetal alcohol syndrome FASD, FAS, child welfare, Ontario, Alberta FASD clinical and school, mental health support, children, interventions, models of intervention, school, screening, wrap-around services, evidence-based, practices
- Databases searched: Google, Google Scholar, University of Ottawa Library (Scholars portal, PubMed, AMED Allied and Complementary Medicine, Mental Measurements Yearbook, PsycINFO, Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations, Ovid MEDLINE(R) without Revisions)

4. Findings

Fetal Alcohol Spectrum Disorders (FASD) is a developmental disability considered an umbrella term that describes a range of disabilities, conditions and diagnoses resulting from alcohol consumption during pregnancy (Public Health Agency of Canada, 2005). These diagnoses include:

- Fetal Alcohol Syndrome (FAS)
- Partial FAS (pFAS)
- Alcohol-Related Neuro-developmental Disorder (ARND)
- Alcohol-Related Birth Defects (ARBD)

FASD conditions are the leading cause of developmental disabilities in the general population, and FAS is the leading cause of developmental disability among Canadian children (Public Health Agency of Canada, 2005). FASD is a serious public health and social concern for the Canadian population and has life-long implications for those affected, with major economic costs to society (Popova et al., 2012; Public Health Agency of Canada, 2005). FASD is a complex issue that affects the physical, mental and behavioural states of an individual, while it remains the leading preventable health condition among children in Canada (Chudley et al., 2005).

FASD occurs when alcohol is exposed to and causes brain damage to the developing fetus during pregnancy, which results in varied physical and mental defects (Public Health Agency of Canada, 2005). Factors that impact the range of possible defects include how much, when and how often alcohol was consumed, genetic factors, the health of the mother, and other social, economic, physical and environmental factors (Public Health Agency of Canada, 2005).

Prevention is a major focus in the public health agenda to help parents make positive and informed decisions surrounding alcohol and pregnancy (Public Health Agency of Canada, 2005). It is recommended that no amount of
alcohol is consumed during pregnancy, but many pregnancies in Canada are unplanned, so alcohol might be consumed without being aware of being pregnant (Health Canada, 2006).

4.1 Prevalence and incidence rates
Prevalence data estimates that nine of 1,000 children in Canada, more than 3,000 children per year, are born with FASD (Health Canada, 2006). The prevalence of FAS alone is estimated at one to two out of 1,000 live births (Roberts & Nanson, 2000). Aboriginal populations and remote and rural communities have prevalence rates that are estimated to be significantly higher than the general population (Health Canada, 2006), for instance studies assessing prevalence rates in isolated communities have found rates as high as 190 per 1,000 live births in an Aboriginal community in British Columbia (Chudley et al., 2005). In general, rates between and within communities tend to vary and generalizations should be avoided (Chudley et al., 2005).

Due to the complex nature of the disorders, the lack of knowledge regarding these disorders, and the gap in services and support within and across systems, there is a high rate of misdiagnosis and underdiagnosis (Hall, Cunningham & Jones, 2010). These challenges pose many barriers to effective identification, diagnosis, treatment, intervention, and the lifelong support that is needed for individuals with FASD. A major challenge is that many of the individuals who have FASD have unrecognizable underlying features associated to brain damage along with few of the physical characteristics commonly associated with FASD. This can lead to missing the diagnosis altogether, contributing to this population being underserved and experiencing further disability (Hall et al., 2010).

4.2 Barriers to addressing FASD in Ontario schools
The literature highlights barriers to FASD support and service provision in educational settings. Schools are under-resourced for providing effective and appropriate interventions for those with FASD, especially in terms of education, awareness and professional development opportunities for teachers, and resources for assessment, collaboration and follow-up with individual clients (Duquette & Orders, 2010; Hall et al., 2010; Job et al., 2013; Koren et al., 2010; Pei et al., 2013). Finding and implementing services that are cost-effective and that meet the needs of the population is a challenge, and schools and community agencies often need to adapt available resources to establish a program or intervention (Bertrand, 2009; Koren et al., 2010). Many schools are already challenged by behavioural issues which are more overt, such as impulsivity and hyperactivity (Kalberg & Buckley, 2007; Koren et al., 2010). However, many children with FASD experience internal challenges from the underlying brain damage of FASD, such as impaired working memory or sensory-processing challenges, and schools are not as prepared to support these types of challenges (Koren et al., 2010).

One major challenge to supporting children with FASD in the school system is that it is very difficult for these children to receive a diagnosis. The Ministry of Education recognizes certain categories of special needs and provides resources and supports for students that fall within those categories (Duquette and Orders, 2010). FASD is not recognized in one of those categories, but getting an FASD diagnosis might improve support provided (Koren et al., 2010; Blackburn et al., 2010; Pei et al., 2013). Suggestions have been made to classify the FASD diagnosis as a Learning Disorder (LD) in order to help establish support and services (Koren et al., 2010; Blackburn et al., 2010). The learning and behavioural difficulties of children with FASD are often mislabeled as behavioural issues instead of recognizing the underlying brain damage that might be causing these difficulties (Koren et al., 2010; Blackburn et al., 2010).
Children with FASD also have many challenges with adaptive behaviour, but these issues may not appear through common IQ testing in the education system and academic assessments which are often the primary means for assessing whether a child has special needs. IQ scores for individuals with FASD are variable, ranging from severely below average to high average, which make it difficult to recognize whether there is a need for more supports and resources (Kalberg & Buckley, 2007). Not receiving a diagnosis reduces the chances for those with FASD to receive specialized services and financial benefits that could improve life outcomes (Kalberg & Buckley, 2007; Koren et al., 2010; Petrenko et al., 2013; Streissguth et al., 2004).

**4.3 Nature of the disorders**

Different terms are used in the literature for individuals who are exposed to alcohol during pregnancy, including fetal-alcohol effects (FAE), alcohol-related effects and prenatal-alcohol effects (PAE), but the terminology is moving toward using the diagnostic terms under FASD.

It is clear that the impact of FASD is unique to each individual, including the presentation of the disorder, the range of health outcomes and especially the learning profile (Blackburn et al., 2010; Kalberg & Buckley, 2007; Hall et al., 2010). Common experiences and characteristics across the spectrum of the disorders exist, which can help improve identification, diagnosis and treatment (Public Health Agency of Canada, 2004, p.25). A table of the common characteristics of people diagnosed with FASD can be found in this reference.

The following table describes some common barriers to correctly identifying and diagnosing FASD:

<table>
<thead>
<tr>
<th>Disorder</th>
<th>Barriers and implications for diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>FAS, pFAS</td>
<td>• Along the FASD spectrum, children diagnosed with FAS and pFAS have more of the FASD characteristics. These individuals often experience more severe primary disability and more visible facial characteristics, which helps to identify and diagnose the disorder (Chudley et al., 2005; Hall et al., 2010).</td>
</tr>
<tr>
<td></td>
<td>• FAS has been known to have the highest prevalence rates and research suggests these rates are fairly accurate because the diagnostic criteria is more well-known by the public and the disorder has more visible facial characteristics than other FASDs (Abel, 2006; Chudley et al., 2005; Hall et al., 2010).</td>
</tr>
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<td></td>
<td>• For individuals diagnosed with FAS, there seems to be a lower rate of secondary conditions that follow, such as mental health challenges. However, the lower rates of secondary conditions for FAS might be a result of the services and support that become available for individuals with recognizable and diagnosed disorders (Public Health Agency of Canada, 2004).</td>
</tr>
<tr>
<td></td>
<td>• Common behavioural challenges include extreme hyperactivity, aggressiveness, poor judgment, and speech and language difficulties (Popova et al., 2012).</td>
</tr>
<tr>
<td>ARND, ARBD</td>
<td>• Most people who have FASD meet the criteria for ARND (Hall et al., 2010). However, ARND has fewer of the visible characteristics.</td>
</tr>
<tr>
<td></td>
<td>• Individuals who have fewer visible FASD characteristics often have secondary conditions (Hall et al., 2010; Kalberg &amp; Buckley, 2007). The less obvious presentation of the disorder related to brain damage makes it difficult to identify and diagnose those with FASD. This has contributed to it being termed as</td>
</tr>
</tbody>
</table>
Fetal Alcohol Spectrum Disorder (FASD)

an ‘invisible’ or ‘hidden’ disability (Koren et al., 2010).

Primary and secondary disabilities

Individuals with FASD can have primary and secondary disabilities. Primary disabilities are the result of brain damage from alcohol exposure during pregnancy affecting infant brain structure and function (Hall et al., 2010). Primary disabilities first appear at birth include (Alberta Learning, 2004; Saskatchewan Learning, 2004 found in Hall et al., 2010):

- physical and health conditions (e.g., issues with oral palate, kidneys, heart, spine and sensory systems);
- delays in meeting developmental milestones;
- difficulties with memory, comprehension of language (written and oral) and social cues, and cognitive functioning (slow mental processing, difficulty with abstract thinking and reasoning);
- poor fine and gross motor skills;
- poor behaviour regulation;
- trouble maintaining appropriate attention and focus;
- problems with adaptive skills.

Secondary disabilities occur after birth as a result of the primary disabilities present at birth, and have been reported to cause a large amount of stress and emotional distress on the family and the individual (Hall et al., 2010; Petrenko et al., 2013). Streissguth and colleagues (2004) found that for those with FAS or experiencing FAE, many of the secondary disabilities and adverse life outcomes were inter-related and happened in combination, including mental health challenges, disrupted school experiences (e.g. being suspended or expelled), trouble with the law, confinement (e.g. inpatient treatment, jail), inappropriate sexual behaviours and alcohol and drug problems. Case management is essential in supporting and effectively coordinating between co-morbidities, substance and alcohol use, legal problems and further medical issues associated to FASD (Paley & O’Conner, 2009). As mentioned, secondary disabilities are often mistaken as the primary diagnosis of FASD, especially for those with fewer obvious facial characteristics of FASD (Hall et al., 2010; Pei et al., 2011).

Mental health and FASD

About 94% of people with FASD experience a mental health issue in their lifetime (Streissguth, 1997), and it is clear that the rates of mental health disorders are disproportionately high for those with FASD (Pei et al., 2011). The presentation of mental health disorders for those with FASD also seems to be different in consideration of many biological, genetic and environmental factors. Understanding of the prevalence of mental disorders among children and youth with FASD is limited by the quality of the available research. Many studies included small, possibly unrepresentative samples, plus there are challenges with consistent diagnostic criteria in defining prenatal alcohol exposure (Pei et al., 2011).

The literature indicates that children and youth with FASD may experience any of a range of mental health problems, including:

- Attention Deficit Disorder/ Attention Deficit and Hyperactivity Disorder (ADD/ADHD)
- Depressive Disorders
- Panic/Anxiety Disorders
- Oppositional Defiant Disorder
ADD/ADHD, mood disorders, particularly depressive disorders, oppositional defiant disorder and conduct disorder have been found to be more common among children with FASD than children not exposed to alcohol during pregnancy (Fryer et al. 2007; O’Connor et al., 2002; Pei et al., 2011; Streissguth, 1997). For internalizing disorders, Pei and colleagues (2011) identified a strong link between FASD and a diagnosis of mood and anxiety disorders in childhood and adolescence; however, the link between anxiety and FASD is less well-known. Among externalizing disorders, they found that ADHD and conduct disorders are more well-known and commonly reported in children and adolescents with FASD. Panic/anxiety disorders, obsessive/compulsive disorder and attachment disorder are also common among children with FASD. There are also high rates of panic attacks and suicide threats/attemptst across the lifespan, while psychiatric services are often required starting at age seven (Streissguth, 1997).

A review of the research on children with comorbidities of FASD and ADHD found that the nature and presentation of ADHD is unique in these children (O’Malley & Nansen, 2002). O’Malley & Nansen (2002) found that for children with FASD and co-occurring ADHD compared to those with only ADHD, ADHD has earlier onset, shows different challenges with attention and has reactions to medication that are less well-known. Studies assessing children diagnosed with FASD compared to children with ADHD found that children with ADHD are more likely to struggle with focused and sustained attention and those with FASD struggle more with working memory deficits (Pei et al., 2011). Recent doctoral dissertations show important differences between cognitive and adaptive skills in those with ADHD compared to those with FASD and co-occurring ADHD, which should be considered in both pharmacological and non-pharmacological interventions (Boseck, 2012; Someki, 2012). For pharmacological interventions, O’Malley and Rich (2013) stated that there are currently no clinical instruments that are validated in order to assess the effectiveness of psychotropic medication for individuals diagnosed with FASD, including those with the most common co-occurring mental illnesses.

**Social-environmental variables**

Secondary disabilities should also be considered alongside experiences in child rearing environments, such as experiences with adoption or foster care, differences in age, gender, and other environmental and societal factors (Hall et al., 2010; Pei et al., 2011; Streissguth et al., 2004). Studies of children diagnosed with conduct disorder and prenatal alcohol exposure, with or without a diagnosis of FAS, show relationships to environmental and individual factors such as age, gender, group membership, housing, and social desirability. A study assessing a sample of 44 children between the ages of 5-10 with prenatal alcohol exposure and conduct disorder found that issues with externalizing behaviours might be due to challenges with adapting behaviour to the environment through sensory-processing deficits (Franklin et al., 2008). It is abundantly clear that FASD is directly tied to a variety of problematic outcomes, but treatment planning must consider individual and environmental factors that serve as strengths or further contribute to difficulties.
**Risk factors**

For children showing symptoms of depression, studies have found relationships to genetics, maternal depression, the amount of alcohol consumed during pregnancy, and poorer quality relationships and attachment between mothers and children (Pei et al., 2011). Another study suggested that women with ADHD may be more likely to drink during pregnancy (O’Malley & Nansen, 2002), and they seem to have more difficulty with attachment and substance use after the birth (Bhatara et al., 2006). Bertrand (2009) found other risk factors to be children who live in foster care or institutions, or a caregiver who is divorced, single or not the biological parent. Experiences with foster care and adoption are extremely common among children with FASD (Bertrand, 2009). Lower IQ and poorer social skills were also reported as risk factors (Bertrand, 2009).

**Protective factors**

Some protective factors include:

- Early and appropriate diagnosis
- Stable and nurturing home with minimal changes in households
- Family support and stability for the individual, and training to the family on coping and behaviour management strategies
- Coordinated, knowledgeable and well-managed case management and advocacy
- Coordinated developmental disability services, and effective integration with existing services
- Not being a victim of violence or physical/sexual abuse
- Focusing on individual strengths and a positive, strengths-based approach
- Aligning external expectations with the individual’s ability to perform
- Assessing and adapting the fit between the individual’s environment, including the senses and the cultural attitudes and assumptions, and the individual’s needs, including the neurological differences and the impact on behaviour (for example: structure, routine and supervision, effective communication approaches, awareness of and supports for Sensory Processing Disorder) (Blackburn, Carpenter & Egerton, 2010; Hall et al., 2010; Petrenko et al., 2013; Streissguth et al., 2004).

A large barrier to early diagnosis and intervention which could enhance protective factors and prevent secondary disabilities is the lack of capacity in understanding and recognizing the brain damage from FASD, which often underlies mental health problems and substance abuse considered to be the primary diagnoses. One recommendation to help support the health outcomes of those affected by FASD and to prevent secondary disabilities is to “Think FASD first” when considering a child presenting with learning and behaviour difficulties (Hall et al., 2010).

Proper early diagnosis, especially before the age of six, and a well-managed and coordinated support plan are strongly related to prevention of secondary disabilities (Hall et al., 2010; Health Canada, 2006). In addition, this can help contribute to prevention and intervention for the mother as well as assessment of other undiagnosed siblings (Chudley et al., 2005).

**4.5 Evidence-informed practices for screening, diagnosis and assessment**

*The Canadian guidelines for diagnosis*, developed by a subcommittee of the Public Health Agency of Canada’s (PHAC)
National Advisory Committee on FASD (Chudley et al., 2005), can be found here: [http://www.phac-aspc.gc.ca/hp-ps/dca-dea/prog-ini/fasd-etcaf/publications/can-gu-id-eng.php](http://www.phac-aspc.gc.ca/hp-ps/dca-dea/prog-ini/fasd-etcaf/publications/can-gu-id-eng.php). The diagnostic standards are organized into seven categories and consider the need for a multidisciplinary approach in order to improve planning and implementation of services:

1) Screening and referral  
2) Physical examination and differential diagnosis  
3) Neurobehavioural assessment  
4) Treatment and follow-up  
5) Maternal alcohol history in pregnancy  
6) Diagnostic criteria for FAS, Partial FAS and ARND  
7) Recommendations for harmonization of Institute of Medicine (IOM) and 4-Digit Diagnostic Code approaches (two main approaches to the diagnosis)

The diagnostic process involves categories 1 through 4. The goal of this process is to establish clear recommendations for management that could be provided in a report and will enhance life outcomes for the child and family. Table 1 in the guidelines outlines the Institute of Medicine (IOM) diagnostic criteria for fetal alcohol syndrome and alcohol-related effects developed in the United States in 1996. Table 2 outlines the 4-Digit Diagnostic Code used for surveillance, diagnosis and screening in clinical settings throughout the United States and Canada. As integration of these two clinical tools is also taking place, PHAC provides recommendations for integrating the IOM and 4-Digit Diagnostic Code, outlined in Table 4 and Table 5, and included in the seventh category of the article.

The following is a table on potentially useful diagnostic and screening tools that were found in the literature to help identify, screen and diagnosis children with FASD:

<table>
<thead>
<tr>
<th>Measure name: Author &amp; Date</th>
<th>Description</th>
<th>Availability</th>
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</table>
| The 4-Digit Diagnostic Code: Astley & Clarren, 2000 | The measure was developed by the FAS Diagnostic and Prevention Network (FAS DPN) clinical staff and medical records used for research on 1,1014 patients diagnosed with FAS. The tool covers four key features: growth deficiency, the FAS facial phenotype, brain damage/dysfunction, and gestational alcohol exposure. | For more information, online training, latest versions and the manual: [http://depts.washington.edu/fasdpn/htmls/4-digit-code.htm](http://depts.washington.edu/fasdpn/htmls/4-digit-code.htm)  
Original article: [https://depts.washington.edu/fasdpn/pdfs/AA2.PDF](https://depts.washington.edu/fasdpn/pdfs/AA2.PDF)  
| The Institute of Medicine (IOM) diagnostic | A study group from the IOM established the 5 diagnostic categories for FAS and alcohol-related effects. | Hoyme and colleagues (2005) clinical application of the IOM: [http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1](http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1) |
The multidisciplinary team (core team)

A multidisciplinary team (core team) must be considered to carry out the process, from recognition to implementation of intervention or treatment procedures. Composition of the core team varies according to context, but it should include professionals with training and expertise in the following roles:

1. Coordinator for case management (e.g. nurse, social worker)
2. Physician trained in FASD diagnosis
3. Psychologist
4. Occupational therapist
5. Speech-language pathologist

Other possible roles identified by PHAC, depending on the context, include addiction counselors, childcare workers, cultural interpreters, mental health workers, parents or caregivers, probation officers, psychiatrists, teachers, nurses, vocational counselors, geneticists or dysmorphologists, neuropsychologists, or family therapists.

A multidisciplinary team from The Alberta Clinical Practice Guidelines Program developed Diagnosis of FAS guidelines based on evidence and surveys of physicians in the province. They adapted a figure of an FAS Multidisciplinary Team Approach (used to describe all individuals with prenatal alcohol exposure) shown here: http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2582739/.
According to Chudley and colleagues (2005), a few other considerations need to be taken into account when developing a management plan:

1) Involvement and preparedness of families and caregivers – adapt the plan to the needs of the family; involve families and caregivers in the planning process; ensure understanding of the assessment; educate and train the family on potential outcomes of the diagnosis (i.e. stigmatization, negative feelings of guilt and blame by the birth mother); connect the family to necessary support systems and resources

2) Acquire information from a wide range of sources – family history, records from school, hospitals, social services, previous assessments, consult with key professionals knowledgeable about the individual

3) Develop a report on the basis for diagnosis – use this information to adapt an additional report on recommendations for the management plan, including intervention and treatment plans and individual and family needs

4) Share the findings for the management plan with relevant professionals and family members – prepare and assist older children to be involved, do a follow-up with the family on the recommendations and on necessary community resources

4.7 Screening

Screening is a separate process from diagnosis. Individuals at risk for the development of alcohol-related effects are screened to find out whether learning and behavioural problems can be attributed to prenatal alcohol exposure and the associated brain damage. PHAC provides recommendations for the screening phase, including the use of screening tools among pregnant and post-partum women, providing counseling to these women in certain cases, and promoting abstinence from substance use. Referrals are made following specific guidelines, which can be found in the article by PHAC. Following screening, individuals are referred to diagnostic clinics with additional emphasis on support required for the birth mother.

A few studies assess the feasibility of carrying out screening within a school or community context using existing resources and tools (Clarren, Randels, Sandersan & Fineman, 2001; Poitra et al., 2003). Clarren and colleagues (2001) demonstrated the reliability and feasibility of a screening tool, the FAS Screen, and a low-cost process for identifying children with FASD in kindergarten, including using the IOM criteria in assessment. The FAS Screen in this study shows reliability in differentiating those who have FAS or pFAS from those who do not and categorizing children appropriately. The authors consider acceptance of the program by the community as a key aspect of the model. Poitra and colleagues (2003) conducted a county-wide study for screening in schools, using the 4-Digit Diagnostic criteria in their assessment, and found that the low follow-up of families to visit the clinic after screening was an important consideration for future implementation of programs.

4.8 Assessment

Assessments are a key process in working on a multidisciplinary team to determine care, supports and management plan for the child. They should be done by professionals that are specialized in the field mentioned in the referral, with consideration of those without prenatal alcohol exposure, for example, psychiatry, psychology or clinical genetics (Chudley et al., 2005). Assessments help teachers, parents, caregivers, health professionals and other professionals work collaboratively and consistently to carry out programs and accommodations that match the unique needs of the child in
their home and school environments (Blackburn et al., 2010; Chudley et al., 2005; Hall et al., 2010; Kalberg & Buckley, 2007; Koren et al., 2010).

During the assessment, the child should be observed in multiple natural settings (at least 2-3 times) and over time to look for performance across different settings and how environmental conditions may have specific triggers and impact ability (Chudley et al., 2005; Kalberg & Buckley, 2007; Pei et al., 2013). From these observations, realistic expectations can be created and specific conditions that help or hinder the child’s performance can be recognized. Observation should be based on a few key elements: skills, attention, independence, social interactions, functional language, strengths and interests, and behaviour (Kalberg & Buckley, 2007).

Pei and colleagues (2010) carried out a qualitative study with 60 key stakeholders to establish the groundwork for a model of assessment for intervention for children with FASD in schools. This model re-conceptualizes the current practices of assessment from simply diagnosing a child to assessing all aspects of a child or the “whole child” within their environment. Their study supports the view that the focus of the assessment should be to inform the implementation of intervention for the child. In particular, Pei and colleagues (2010) summarized research surrounding the usefulness and understandability of psychological reports shared with teachers and parents following the assessment. In general, teachers and parents find it challenging to understand the technical aspects of these reports while the reports are often too general, are not focused on what will work or don’t include the strengths of the child in order to improve the child’s functioning.

**Understanding the learning profile of the child**

A first step in building a program for a child with FASD is to establish a clear learning profile unique to the child by assessing their academic and functional abilities (Kalberg and Buckley, 2007). Many studies state that this learning profile is essential to make sure support is tailored to and useful for the individual (Blackburn, Carpenter & Egerton, 2010; Hall et al., 2010; Job et al., 2013; Kalberg & Buckley, 2007; Koren, Fantus & Nulman, 2010; Petrenko, Tahir, Mahoney & Chin, 2013; Pei et al., 2013). Multidisciplinary and ongoing assessments, observation across multiple settings at different times and team collaboration are essential to planning interventions around the cognitive and behavioural profile of the child (Chudley et al., 2005; Kalberg & Buckley, 2007).

Usually a child is assessed when learning and/or behavioural issues are found, rather than during a formal diagnosis, so considering the presentation of the disorder, the nature of brain damage and the variability of the IQ is important at this stage (Kalberg & Buckley, 2007; Koren et al., 2010). A neurobehavioural assessment should be carried out assessing impairment on multiple standardized tests and identifying strengths, challenges and other social and environmental factors that could impact the cognitive and behavioural outcomes of a child (Chudley et al., 2005). These assessments are used to guide the development of the goals and objectives of the individualized education plan. It is essential that in establishing an individualized plan, in-depth information is gathered from many different sources, including parents, teachers, and observation across different settings (Chudley et al., 2005; Kalberg & Buckley, 2007).

A few recommendations for developing the individual learning profile were presented by Kalberg and Buckley (2007) based on the developmental needs of these children and their link to behavioural outcomes and challenges:
• For children with average intelligence and prenatal alcohol exposure it is recommended to use a battery of tests to identify issues in specific areas, including attention, verbal learning and recall, verbal memory, auditory memory, spatial memory, auditory processing and verbal processing.

• For children with moderate exposure to alcohol, neurobehavioural issues, especially in executive functioning, may be present despite a low presentation of physical features. Deficits in executive functioning have been found in children prenatally exposed to alcohol, with or without a diagnosis of FAS and with children of average intelligence. Difficulties have been reported in the following:
  o Complex working memory tasks and shifting sets in both cognitive and emotion-based tasks (p. 279-280).
  o Planning, cognitive flexibility, selective inhibition, concept formation and reasoning (p. 280).

To help tailor interventions appropriately, additional understanding of the unique cognitive and emotion-based difficulties is beneficial. The following is a table based on the deficits in executive functioning outlined in Kalberg & Buckley (2007) and what it might look like in a school setting:

<table>
<thead>
<tr>
<th>Cognition-based</th>
<th>Emotion-based</th>
</tr>
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<tbody>
<tr>
<td>• Children have challenges in understanding and keeping in memory sequences of daily living and academic processes:</td>
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<tr>
<td>- Following a daily routine requires help from tools in the environment.</td>
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<tr>
<td>- Appropriate social interactions and exchanges may need to be taught by rote and through repetition.</td>
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<tr>
<td>- Tasks and academic skills related to working memory are more challenging, such as solving problems, planning outcomes of a task, keeping attention toward goal completion, following directions, creating and organizing events or timelines, using the same information across different situations, or learning basic concepts (e.g. shapes, letters, numbers).</td>
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<tr>
<td>• Children have difficulties in memory processes of auditory verbal information, for example recalling the information, following verbal directions, and using this information across situations.</td>
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<tr>
<td>• A Speech/Comprehension Paradox is developed through challenges in verbal memory in which verbal expression is at a higher level than comprehension, thus children with FAS may seem to have more abilities than reality.</td>
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<tr>
<td>• Children have challenges in abilities to inhibit responses which show in how they may react inappropriately in a given situation or social interaction based on what is considered acceptable.</td>
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<td>• Children may seem to act out, be too active or have trouble controlling one’s emotions in the classroom and in response to others.</td>
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<tr>
<td>• Being aware of consequences of behaviours before reacting is a challenge for children with FASD, which can lead to communicating inappropriately and not understanding the concept of personal space or waiting one’s turn among peers.</td>
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<tr>
<td>• Troubles in interactions with peers, making friends, and fostering relationships are all related to these deficits.</td>
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</table>

Burd and colleagues (2003) provide a brief overview of how the functional area of impairment results in behaviours, which depends on age and IQ. Functional impairment included attention (concentration), predictive planning, adaptive planning, short-term planning, social skills, thematic understanding, inhibition, and motivation. PHAC provides an
4.9 Diagnosis

Information on maternal alcohol use in pregnancy is an essential component of diagnosis. Different levels and timing of alcohol consumption impact the severity of the presenting characteristics on the FASD spectrum, although more research is needed on these associations (Chudley et al., 2005). Tools need to be developed and tested to have more accurate indications of the impact of alcohol consumption during pregnancy in order to have effective prevention, monitoring and intervention.

Recommendations for the diagnostic criteria of FAS, pFAS and ARND are provided by the Public Health Agency of Canada, although the IOM criteria for diagnosis of pFAS differ from the diagnosis criteria of PHAC. They recommend that under the age of six, if a child does not present with underlying brain dysfunction, then a diagnosis of pFAS should not be made, but the child should be monitored. The IOM criteria allow for a diagnosis of pFAS to be made without brain dysfunction, but with other significant deficits.

Chudley and colleagues (2005) provide recommendations for a physical examination and differential diagnosis:

- A dysmorphology assessment takes place to find out whether features are related to prenatal alcohol exposure and other possible comorbidities. PHAC recommends a genetic dysmorphology assessment if this is possible.
- A general physical and neurological examination is necessary to exclude other genetic disorders and features similar to pFAS or FAS. Documentation of neurological deficits should be core components of the assessment, for example seizures or blindness.
- It is important to be aware of past history of exposure to reduce the chances of misdiagnosis, as overlapping facial development from other syndromes may exist (Table 3 reports on syndromes with features that overlap with those of FAS).
- Being aware of the possibility of co-occurring challenges in children is important, in case further medical assessments are required.
- Attention should be paid to monitoring growth deficiencies in association with variables such as parental size, genetics and other medical or environmental conditions.
- Three types of facial features help to distinguish those with FAS, which are outlined in the article. These should be noted in reference to when they were most severe in expression. Growing older may make the expression of facial features less noticeable. There are no norms available for the Canadian population and for subpopulations to measure and differentiate growth and facial features from the general population.

A more recent study by Clarren and colleagues (2010) was conducted to establish normal distribution of palpebral fissure (PFs) lengths (the distance from one corner of the eye-lid to the other corner) in Canadian school age children in order to more accurately identify this physical marker among those with FASD. The norms were developed to be representative of the growth in different school aged groups and the racial, ethnic and national diversity of children in Canada; however, a few specific First Nations groups were underrepresented and the Inuit population was almost absent from the study. They found that PFs grow with age until later in adolescence, similar to previous evidence, but
that boys have larger PFs throughout all age groups. Figures providing norms for boy’s age 6 to 16 years with cut-off scores and for girls age 6 to 16 years with and without cut-off scores are available.

### 4.10 Considerations for planning and delivering services

Given the co-occurrence of mental health problems, substance use and legal problems, a well-established service coordination plan is necessary (Hall et al., 2010). Hall and colleagues (2010) found supports, services and systems that can help improve coordination for those with FASD:

- Establish a wraparound system in which a team of family members and professionals across different sectors (i.e. therapist and school personnel) work through a strengths-based and family-based approach to “wrap” supports around the needs of the individual toward a life-long support plan.
- Establish expectations of life-long interdependent and external “circle of supports” at an early age through valued and meaningful perspectives, networks and partnerships with the individual and between support systems.
- Ensure consistent direct supervision throughout childhood and into adolescence to ensure structure, routine and environmental fit which supports the self-regulation and self-management skills of the individual.
- Accommodate communication approaches and strategies to impairments in receptive and expressive language, sensitivity to non-verbal and visual cues, and sensitivity to different ways of speaking, for example during therapeutic treatment or in educational settings.
- Use behaviours and reactions of those with FASD as cues to underlying sensitivities in order to adapt and fit the environment and approaches to the individual.
- Be aware of accommodations and practices needed to support Sensory Processing Disorder. This neurological disability causes the brain to have challenges in accurately processing information coming in from the senses. Evaluation and diagnosis early on by occupational therapists is important to improving outcomes of those with this disorder, and helps to understand what strategies can better accommodate the behavioural needs of the individual.

The Fetal Alcohol Syndrome/Fetal Alcohol Effects Outreach Project (FASEout) provided an *Implementation Guide* to help organizations create an action plan and assess their readiness to address FASD, which reflects the best practices identified by experts in prevention, diagnosis and intervention: [http://www.faseout.ca/eng/training.htm](http://www.faseout.ca/eng/training.htm). Resources are also available from FASout to help train professionals to support clients with FASD and increase awareness on the nature of the disorder. *Best practices for addressing FASD* were identified by experts from FASout, who developed three important phases (Produski, 2008): prevention, identification, and intervention.

**Needs assessment pilot in the Toronto public school system**

The Motherisk Program in Toronto conducted a qualitative needs assessment pilot on the school capacities and education practitioner capabilities for supporting children with FASD in the Toronto public school system (Koren, Fantus and Nulman, 2010).

The Motherisk program demonstrates a general process of special needs intervention in Toronto public schools for children with a diagnosis or for children with apparent academic progress concerns. Program elements include:
1) A special needs team (core team) is established, including parents, caregivers, teacher, vice principal and other available special needs staff (i.e. speech/language, occupational therapist, psychologists).

2) The primary teacher and the special needs team develops an Individual Education Plan (IEP) if the child has been diagnosed before or during the school year, which enables the teacher to follow-up with the necessary support. For example, students with two or more developmental deficits might go to a resource teaching classroom for a few hours a day, while in-class support is provided to those requiring less support.

3) Educational assessments depend on the context of the school. Throughout and after the waiting period, the special needs team can support the learning needs of the child who may or may not yet have a diagnosis.

4) The team will refer the child to a family physician for medical diagnosis and other necessary support systems. This depends on the context of school learning objectives in terms of addressing the behavioural needs of children.

The study found that all schools were adamant in maintaining an inclusive system for children with special needs. They also found that IEPs are at times developed for children who have not yet been diagnosed, but still require extensive support. Without a formal diagnosis, the special needs team in the school can continue to support the individual under concern and can place the individual on a waiting list for educational assessment. This can either lead to a diagnosis or be used as a guide for the child’s learning needs. Many of the schools prioritize children based on level of need due to lack of resources available to address all learning needs of the school population. Also, educational practices for FASD were not likely to be informed by a medical diagnosis. Rather, the academic assessment would be more likely to determine practices and would help improve outcomes for the children by enhancing the teacher’s knowledge of the child’s needs.

4.11 Collaborative services

Job and colleagues (2013) and Pei and colleagues (2010) conducted a large qualitative analysis of perspectives of caregivers, administrators, teachers and allied professionals in order to establish an evidence base for service planning needs of children in schools. The analysis by Pei and colleagues (2010) revealed that assessments need to be ongoing and timely with integrated and meaningful perspectives from all stakeholders addressing the “whole child”. Also, recommendations and strategies that are easy to understand, practical and specific are important, especially for psychological recommendations. Finally, each stage in the process needs to be supportive of learning and development of all stakeholders.

Job and colleagues (2013) found overall that it is important to have a mutual and open understanding of how different stakeholders contribute to collaborating on developing programs, sharing information and improving educational outcomes for the child. A few main findings emerged, including fostering relationships through respecting the caregiver’s role in having a significant contribution to the education of the child with FASD. In particular, this means ensuring that strategies are implemented in a consistent manner in home and school environments along with relationship building, meaningful engagement, and early and frequent communication. School staff, especially special education teachers, need to be more informed of the nature and characteristics of the disorders, and need more assistance in understanding specific strategies and resources to support their work. Another theme was accessing supports, which includes awareness by all roles of who to go to and where to find appropriate supports and information.
to help in the assessment and to connect to community resources. A major concern was the focus needed on transitional support, such as kindergarten years and into adolescence and adulthood.

4.12 Planning and implementing interventions

There are limitations to many of studies assessing intervention planning and implementation, including small sample sizes and challenges with identifying clear results (Bertrand, 2009; Peadon et al., 2009; Premji et al., 2007; Ryan, 2009). However, Peadon and colleagues (2009) cited seven studies being undertaken with more rigorous study procedures and larger sample sizes, while Bertrand (2009) found five interventions that are promising for improving the developmental outcomes for children with FASD. Ensuring that the family is involved and engaged throughout the entire process is a key element to fostering life-long and stable support (Hall et al., 2010; Job et al., 2013; Pei et al., 2010), and has shown to have very beneficial outcomes for children with FASD (Bertrand, 2009).

Planning the program or intervention that is unique to the child’s comprehensive learning profile can be done by the core team after all information is collected and assessments are completed (Chudley et al., 2005; Kalberg & Buckley, 2009). Studies assessing the efficacy of interventions show that interventions should be targeted and individualized, and they achieve more improvements when focused on specific deficits and learning needs (Bertrand, 2009). For intervention in childhood, FASEout suggests multidisciplinary case management and addressing medical, education and psychological support as best practices (Produski, 2008). The learning environment can be adjusted to be structured, routine, calm and quiet with a curriculum that focuses on functional skills for independent living, behaviour management strategies and coming up with realistic expectations. Integrating a more practical life-skills program into the classroom should also be considered (Produski, 2008).

A neurodevelopmental framework

Kalberg & Buckley (2007) state that intervention planning can be informed by two pieces of information: understanding the evidence-base for interventions and the neurological implications of FASD. Based on the evidence, Kodituwakku (2010) recommends a neurodevelopmental framework for developing interventions for children with FASD and ultimately leading to an improvement in performance. O’Malley and Rich (2013) also propose this approach as an effective way to develop multimodal and multisystem intervention strategies and psychopharmacologic management, especially in consideration of co-occurring mental illnesses. From these two studies, this approach or framework largely focuses on understanding a “direct brain-behavior relationship” (Kodituwakku, 2012, p.722) and evaluating the interaction between the social-cultural environments to cognitive development in a holistic way.

- In terms of co-occurring mental illness, intervention planning should include evaluating which symptoms might be attributed to brain-based or to environmental factors to lead to psychopathology.
- Support and training consists of responding to functional impairments and deficits as early as possible, such as attention-focused and self-regulation training.
- Assisting the individual to be able to reach their potential toward independence and generalizing skills to different situations should be key factors through supportive guidance and environmental and structural adjustments.
- When it comes to medication use, O’Malley and Rich (2013) approach this component of treatment with caution and acknowledge the lack of clinical trials and studies to assess effectiveness. They suggest general guidelines
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that should be combined with the multi-system and multi-modal approach, including “targeting medications, lower doses and gradual increase in dosage” (p.469). Effective case management from a psychiatrist is also important for medication management in consideration of co-occurring mental illness. The CDC briefly summarizes medication use: [http://www.cdc.gov/ncbddd/fasd/treatments.html#Medication](http://www.cdc.gov/ncbddd/fasd/treatments.html#Medication).

Emerging interventions

Cognitive control therapy was identified by Kalberg and Buckley (2007) as an intervention with promising evidence to improve the behaviour of children with FASD. This therapy focuses on metacognitive thought processes, or having awareness of one’s own processes and strategies. It focuses on five key thought patterns or controls: body movement and self-regulation, scanning information, selective attention, comparing past and present information, and categorizing and conceptualizing information. One study involving children with FASD (Adnams et al., 2003) showed positive improvements in behaviour, but with a small sample of 10 children.

On behalf of the [Interventions for Children with Fetal Alcohol Spectrum Disorders Research Consortium](http://www.cdc.gov/ncbddd/fasd/research-intervention.html), Bertrand (2009) summarized five intervention trials with adequate sample sizes that show promising findings and significance in individualized and targeted interventions. The development and evaluation of the interventions was based on known deficits of the children and the evidence base for existing programs or intervention with similar populations or targeting similar deficits (e.g. interventions for children with ADHD who have similar attention deficits, see Kerns et al., 2010). In assessment and intervention planning, studies considered population-specific characteristics such as living in foster care or parent-child relationship that could impact the health of the child (Bertrand, 2009). The studies are described in Appendix A. A few core elements emerged:

- Parent education or training was involved in all interventions. For two studies, this was the main focus of the intervention (Parent-Child Interaction Therapy (PCIT) – Eyeberg & Boggs, 1998; Parent Support and Management (PSM) – based on behaviour programs from Barkley, 1997; Webster-Stratton, 2001). Across all five studies, parents or caregivers improved knowledge of FASD and practical challenges with parenting. The Families Moving Forward (FMF) intervention showed considerable improvements and results in meeting the needs of parents and family members ([http://depts.washington.edu/fmffasd/](http://depts.washington.edu/fmffasd/)).

- Explicit instruction, also explained in the parent training, was more beneficial to learning new skills than observation and following an abstract process used for typical childhood development.

- The studies demonstrated the importance and feasibility of integrating the targeted interventions for children with FASD into existing frameworks and services available in special education, therapy, counseling or other community-based services.

- Collaboration and parent involvement (targeted or supplementary training) throughout the entire process were identified as major strengths to the success of the programs, especially in addressing issues and finding solutions.

- Funding was a major limitation to these studies, which made it challenging to increase effectiveness, validity and reliability of the interventions in terms of longer-term follow up of changes in behaviours and skills, and the generalizability of these to other situations.

Peadon and colleagues (2009) conducted a systematic literature review to identify interventions for children with FASD. Most of the 12 studies found did not report many of the necessary standards to include in the study design, such as
procedures and reporting of results to make replication and conclusions as reliable or valid. Many of the studies had small sample sizes, study designs that were not scientifically well-established and short-term follow-up. However, their findings suggest a few important intervention targets (sample sizes included), including improving knowledge in mathematics (Kable et al., 2007; n=61), skills in spelling, reading and pre-literacy through a language and literacy intervention (Adnams et al., 2005; n=65); improving attention and non-verbal reasoning through Attention Process Training (Vernescu, 2007; n=20); facilitating learning through Virtual Reality Training (Coles et al., 2007; n=32), possibly improving behaviour though Cognitive Control Therapy (Adnams et al., 2003; n=10); and improving social skills and behaviour at home from social skills training (O’Conner’s et al., 2006; n=100).

Although the study by Kerns and colleagues (2010) has a small sample size (n=10) with no comparison group, the significant results have important implications for supporting the use of virtual reality training, and combining meta-cognitive strategies (a component of Cognitive Control Therapy). It also includes attention specific training for improving independence in a child’s ability to plan and organize behaviour around a task across different settings. This intervention made use of positive reinforcement through a computer game and prompting from a learning assistant until the participant could perform on their own. An important element of the program was the feedback given by the computer game itself, which seems to increase motivation in terms of self-control and regulation.

4.13 Education and training needs of staff
FASout developed a Provincial Outreach Program for Fetal Alcohol Spectrum Disorder (POPFASD) which is a professional development program to help educators build capacity in developing strategies for meeting the learning needs of students with FASD and helping integrate these students into mainstream classrooms (http://www.fasdoutreach.ca/). The program is tailored to the teachers’ needs in interactive workshops and mentorship (e.g. group discussions, meetings, mentorship on accommodations in the classroom and observation/follow-up on progress).

Professional development opportunities and specific strategies for implementing educational practices are required for all stakeholders who support children with FASD, especially for teachers in the classroom and for parents (Bertrand, 2009; Hall et al., 2010; Job et al., 2013; Koren et al., 2010; Pei et al., 2010). Caley, Kramer & Robinson (2005) also emphasized the importance of education and training for school nurses, who are involved in all levels of preventing further disability for children with FASD in many school systems. Job and colleagues (2013) found that learning and developing capacities to support children with FASD in the home and school environment is an ongoing process which requires attention and effective collaboration throughout all stages of planning and delivering services.

Guidelines for screening, assessment and diagnosis of children with FASD helps respond to the training and education needs in the school system and in community settings (Hall et al., 2010; Koren et al., 2010). School staff need education and knowledge that will reframe the way their beliefs and perceptions guide how they manage and teach students with FASD (Job et al., 2013). All those involved in supporting children with FASD require education on the nature of the disorders and the underlying brain damage that results in learning and behavioural difficulties, especially special education teachers (Job et al., 2013; Koren et al., 2010). These can be gained through attending workshops, conferences or involvement in mentoring (Job et al., 2013). Teachers require specific strategies and resources to work with these students in order to implement and adapt educational programming in a population-specific way, clearly stated in the recommendations reports.
Learning and behavioural strategies

According to Kalberg & Buckley (2007) an instructional plan which outlines the needs of the student for the teacher is developed following a “functional routine” (p. 282). This plan involves specific strategies and objectives to create clear expectations and organizational practice early on. This information can be useful for parents, teachers and other stakeholders involved in supporting children with FASD. Strategies and objectives in the plan include:

- location of the activity
- materials required
- steps to completion
- cues to identify the start of a routine
- how to respond to performance in a way that reinforces independence.

Structure and systematic teaching are methods that are potentially effective, including visual structure, environmental structure and task structure (Kalberg & Buckley, 2007). Similar strategies are described in reports published by Ministries of Education across Canada (Alberta Learning, 2004; British Columbia Ministry of Education, 1996; Saskatchewan Learning, 2004; Yukon Education, 2007). However, Kalberg & Buckley (2007) state that it is important for the teacher to understand the difference between controlling the child as opposed to implementing a structured learning environment.

- Visual Structure: Fosters more ability to understand how needs of the environment requires change and flexibility in thinking. This includes reducing the visual and auditory distractions in the environment by adjusting the physical environment, implementing daily schedules and routines for each individual and visually structuring tasks for organization, clarity and instructions.
- Environmental Structure: Conditions can be modified to support learning and to establish clear expectations of what will happen in different locations. Simplicity and clarity are important in the environment, for example, visually defining different places to work on specific topics or tasks.
- Task Structure: Systems are put in place to understand the steps of the task (beginning, middle, and end), the ordering and expectations of tasks, and possibly what a completed task looks like.

5. Next steps and other resources

Additional resources provided on the FASout website include PowerPoint presentations, print resources, a list of national trainers and a forum of information sharing in order to support professionals in the training of best practices of FASD: [http://www.faseout.ca/eng/home.htm](http://www.faseout.ca/eng/home.htm)

Alberta Learning in Alberta, Canada developed a resource entitled Teaching Students with Fetal Alcohol Spectrum Disorder: Programming for Students with Special Needs Series: [https://education.alberta.ca/media/377037/fasd.pdf](https://education.alberta.ca/media/377037/fasd.pdf)

The Special Programs Branch of the Ministry of Education, British Colombia, developed a resource guide for teaching students with Fetal Alcohol Syndrome and the associated effects: [http://www.bced.gov.bc.ca/specialed/fas/](http://www.bced.gov.bc.ca/specialed/fas/)


The Centers for Disease Control and Prevention (CDC) and the National Organization on Fetal Alcohol Syndrome (NOFAS) Training and Education resources: [http://www.cdc.gov/NCBDDD/fasd/training.html#EducationalResources](http://www.cdc.gov/NCBDDD/fasd/training.html#EducationalResources)

**Other organizations and programs**


FASD Clinical Services, Peel Region, ages 6 years and under: [http://peel.cioc.ca/record/CDR0924](http://peel.cioc.ca/record/CDR0924)

Lutherwood Community of Practice for Clinical process development: [http://www.fasdwaterlooregion.ca/](http://www.fasdwaterlooregion.ca/)

CAMH Catch program: [http://www.camh.ca/en/hospital/care_program_and_services/child_youth_and_family_program/Pages/catch_program.aspx](http://www.camh.ca/en/hospital/care_program_and_services/child_youth_and_family_program/Pages/catch_program.aspx)


FASEout, Fetal Alcohol Spectrum Outreach Project: [http://www.faseout.ca/eng/home.htm](http://www.faseout.ca/eng/home.htm)


Knowing what works and receiving training on an evidence-informed practice or program is not sufficient to actually achieve the outcomes that previous evaluations indicate are possible. A program that has been shown to improve mental health outcomes for children and youth but that is poorly implemented will not achieve successful outcomes (Fixsen et al, 2005). In order for a program to be evidence-informed, it needs to be applied with fidelity to the design and it needs to be implemented using supportive “drivers” related to staff competency, organizational leadership and organizational capacity. These drivers include assessing and monitoring the outcomes of your practice using evaluation or performance measurement frameworks, which are particularly important when there is insufficient evidence in the literature to guide clinical decisions. Choosing a practice is an initial step toward implementation, but the implementation drivers are essential to ensure that the program reaches appropriate clients, that outcomes are successful and that clinical staff members are successful in their work.

The Ontario Centre of Excellence for Child and Youth Mental Health has a number of resources and services available to support agencies with implementation, evaluation, knowledge mobilization, youth engagement and family engagement. For more information, visit:
http://www.excellenceforchildandyou.ca/what-we-do or check out the Centre’s resource hub at http://www.excellenceforchildandyou.ca/resource-hub.

For general mental health information, including links to resources for families:

http://www.ementalhealth.ca
References


Appendix A: Service planning, delivery and interventions for children with FASD in the education system

<table>
<thead>
<tr>
<th>Reference</th>
<th>Study Description(s)</th>
<th>Findings</th>
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<td><strong>6. Screening, assessment and diagnosis</strong></td>
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</table>
| Pei, Job, Poth & Atkinson, 2013 | **Purpose:** Establishing an evidence-base for assessment for intervention of children with FASD  
**Participants:** A sample of 60 key stakeholders who have roles of planning and delivering interventions with children with FASD (teachers, administrators, principals, assistant principals, 1 head of student services, allied professionals, education assistants, caregivers, maternal grandmothers, foster mothers, 1 adoptive mother)  
**Method:** Inductive analysis in 3 phases of the 11 focus groups and 3 individual interviews. | Three key findings emerged, along with sub-themes within each theme:  
1) *The whole child* -- Seeking the big picture; Considering the role of diagnosis  
2) *The assessment process* -- Responsiveness; Finding success  
3) *Building school capacity* -- Information sharing; Meaningful understanding |
| Poitra et al., 2003 | **Purpose:** Evaluating the feasibility of screening for FAS in a school-based setting  
**Participants:** 1,384 kindergarten students were screened over 9 years  
**Method:** The FAS Screen (Burd et al., 2003; 8-11 minutes in length per child) was used annually by school staff, teachers, social workers and psychologists, and was done at the start of kindergarten in the fall. A 4-hour screening training was completed to staff. Diagnostic clinics are held 1-2 times per year and referred to other genetic dysmorphology clinics if the clinic appointment was missed. | 98 percent of the school population was screened over the course of the study, and 5 percent (69) had a positive screen. Positive screens referred to local genetic dysmorphology clinic, and completed assessment reports were shared with the school for educational planning. After being sent to a genetics/dysmorphology clinic for evaluation, 7 were diagnosed with FASD (6 FAS; 1 pFAS) using the IOM criteria and key informants. The results show a prevalence of 1 per 230 kindergarten students. |
| Clarren, Randels, Sanderson & Fineman, 2001 | **Purpose:** Assessing the feasibility of screening for FASD in primary schools by creating and implementing a model for surveillance of FAS  
**Participants:** Two county health departments in Washington State were included. 1,630 children were screened through schools in one county, and 2,110 students were screened in the second.  
**Method:** Counties implemented multidisciplinary, collaborative screening and a diagnostic process: a country coordinator in FAS was available for each school; school and public health nurses were trained on FASD identification; children in 1st grade who met the criteria were referred to a diagnostic clinic | 63 of the first County were positively screened, and 29 attended a specialized clinic, while in the second county 61 were screened positive and around 28 attended the clinic. Many families did not consent to attending a clinic after being screened positively. Four children in the first county were diagnosed with FASD and two were diagnosed with FAS and another syndrome in the other county. |
| **7. Planning and implementing interventions** |  |  |
| Job et al., 2013 | **Purpose:** Establishing an evidence-based for improved collaboration and communication in integrating the voices of key stakeholders for students with FASD  
**Participants and method:** The sample and semi-structured interviews were the same as Pei et al. (2013), as both are a part of a larger research project. | Three key findings emerged, along with sub-themes within each theme:  
1) *Fostering relationships* – Respect; Candid communication  
2) *Reframing practices* – Beliefs; Actions; Preparation |
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The researchers adapted the qualitative analysis to the research questions of this particular study.

Koren, Fantus & Nulman, 2010

**Purpose:** A needs assessment pilot of supporting children with FASD in the Toronto public school system

**Participants:** A sample of 12 practitioners (2 principals, 1 vice-principal, 2 materials and resource teachers, 2 school board psychologists, 2 primary grade teachers, 1 kindergarten teacher, 1 special education teacher) from 5 schools of the Toronto District School Board and one school from the Toronto District Catholic School Board (K-grade 8); ranging from 7 to 34 years of experience in education with exception of the kindergarten teacher

**Method:** Qualitative analysis through semi-structured interviews aimed at sharing their expertise on FASDs and the challenges in addressing special needs in schools

Their study revealed a general process of special needs intervention in Toronto public schools for children with a diagnosis or for children with apparent academic progress concerns:

1) A special needs team (core team) is established
2) The primary teacher and the special needs team develops an Individual Education Plan (IEP)
3) Throughout and after the waiting period, the special needs team can support the learning needs of the child who may or may not yet have a diagnosis.
4) The team will refer the child to a family physician for medical diagnosis and other necessary support systems.

The findings depend largely on the context of the school in terms of access to resources and policies and procedures which exist within the school to address special needs.

Kerns, Macsween, Wekken, & Gruppuso, 2010

**Purpose:** Evaluated the efficacy of an attention training programme in children with FASD

**Participants:** 10 children (8-15 years; FASD diagnosis, IQ 60-107)

**Method:** No control group was used; participants were assessed before and after the Computerized Progressive Attention Training (CPAT) program (16 hr training over around 9 wks at school). The program includes 4 structured tasks targeting attention orientation, sustained attention, selective attention and executive attention, in a hierarchical format based on performance. A learning assistant is available throughout the program.

Findings show most significant improvements in reducing distractibility on the Test of Attentional Performance for Children (KITAP), reducing reaction times on the Attentional Network Test adapted for children (ANT-C), and increasing auditory sustained attention on the Test of Everyday Attention for Children (TEA-Ch). Measures assessing working memory showed non-significant improvements, but that working memory underlies attention abilities. There were also significant improvements in math and reading fluency, suggesting an impact on improving attention processes to better performance on tasks in school settings. Follow-up surveys showed generally positive experiences by parents and teachers.

Bertrand (2009) on behalf of the Interventions for Children with Fetal Alcohol Spectrum Disorders Research

**Purpose:** To identify and summarize interventions that improves the developmental outcomes, secondary conditions and lives of children with FASD and their families.

**Intervention criteria for inclusion:** Target a specific area of deficit or risk; referrals for standard care in both treatment and control groups were guided by multidisciplinary assessments; parents and caregivers receive specific instruction and training on FASD, advocacy skills, and caregiver support.

Five interventions were described in detail, which focused on math skills, behavioural regulation, peer relations and social communication, executive functioning, compliance, learning readiness, and clinically challenging behaviours. These interventions have significant results and promising evidence for implementing interventions for children with FASD and involving their families.

1) Project brun buddies was developed by the University of California at Los Angeles to assess a parent-assisted children's friendship training

1) The Social Skills Rating System Parent Form, the Social Skills scale and the Problem Behaviors Scale were used. Findings show significant improvements in
### Fetal Alcohol Spectrum Disorder (FASD)

<table>
<thead>
<tr>
<th>Consortium</th>
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<tr>
<td>3)</td>
<td>The Marcus Institute evaluated a psychoeducational program targeting core learning deficits and mathematical functioning of children affected by alcohol. 56 children (3-10 years; PAE, excluded with moderate intellectual deficits or below and severe mental health challenges while ADD dual diagnosis was included) completed the study and were randomly assigned to mathematics targeted intervention or standard psychoeducational treatment.</td>
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<td>4)</td>
<td>The University of Oklahoma assessed two group based interventions with the aim of reducing behaviour problems and stress in parents and caregivers. The two interventions (14 weeks, 90 mins/wk) included the Parent-Child Interaction Therapy (PCIT) and the other study evaluated a Parent Support and Management (PSM) program. 46 children (3-7 years; FASD) and caregivers completed the study and were randomly assigned.</td>
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<tr>
<td>5)</td>
<td>The University of Washington developed and evaluated a program for parents, caregivers and families. The Families Moving Forward (FMF) program (16 sessions bi-weekly for 9-11 months) which would help change attitudes and responses of parents to their children’s behaviours, including related stress, through child management and parent training techniques. 52 children (5-11 years; clinical behavioural and severe mental health challenges while ADD dual diagnosis was included) completed the study and were randomly assigned to the FMF group. Very high significance was found between groups for meeting the DTC group, and the parent report showed increase in social skills and decrease in problem behaviours. These benefits were maintained at 3-month follow-up, including further gains in social skills.</td>
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### Table of Findings

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<th>Consortium</th>
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<td>2)</td>
<td>The Marcus Institute evaluated a psychoeducational program targeting core learning deficits and mathematical functioning of children affected by alcohol. 56 children (3-10 years; PAE, excluded with moderate intellectual deficits or below and severe mental health challenges while ADD dual diagnosis was included) completed the study and were randomly assigned to mathematics targeted intervention or standard psychoeducational treatment.</td>
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<td>3)</td>
<td>This intervention by Children’s Research Triangle in the U.S. targeted neurocognitive difficulties in self-regulation for 78 adopted or foster care children (6-11 years; FASD). Strategies and techniques used were adapted from the Alert Program (<a href="http://www.alertprogram.com/">http://www.alertprogram.com/</a>) and assessed (clinical psychologist assessments) then randomly assigned children to the intervention (12 weeks of 75 min group therapy sessions; parents attended education groups) or to being assessed and referred to community or school services and resources (e.g. occupational therapy).</td>
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<td>4)</td>
<td>The University of Oklahoma assessed two group based interventions with the aim of reducing behaviour problems and stress in parents and caregivers. The two interventions (14 weeks, 90 mins/wk) included the Parent-Child Interaction Therapy (PCIT) was used (direct coaching of behavioural parenting skills (12-16 sessions) and the other study evaluated a Parent Support and Management (PSM) program. 46 children (3-7 years; FASD) and caregivers completed the study and were randomly assigned.</td>
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### Additional Information

- The Cognitive Behaviour Checklist (CBCL) showed that knowledge of FASD for parents and caregivers significantly increased, including high satisfaction with the workshops, knowledge of advocacy and behavioural regulation. On four measures of academic outcomes (Test of Early Mathematical Ability 2nd Ed., Bracken Early Concept Scales-Revised; Key Mathematics R/NU; Bayley Scales of Infant Development 2nd Ed.), children receiving the mathematics targeted intervention revealed much higher scores on all measures.

- The Behavior Rating Inventory Executive Function (BRIEF) showed statistical significance before and after the treatment compared to the control; however, subtests of the measure did not show significance meaning that the difference must be attributed to the subtests in combination rather than separate. The Roberts Apperception Test for Children (RATC), which assesses perceptions on interpersonal situations, show significance on adaptive scales with one subtest showing that children in the control group more easily used narratives and could point out when solutions to problems were not realistic.

- Around half of the participants did not complete the study. Around 9 sessions were completed for the PCIT and for the PSM group. None of the tests used show significance between the groups, but results seemed to be better for the PCIT. Despite non-significance between groups, improvements in problems with behaviour were shown over time for both groups. A reduction in behaviour problems for the PSM indicates that training and education only for parents could show improvements, while parents reported feeling positive and satisfied with the program.

- All of the children and almost all of the parents and caregivers completed the baseline and follow-up measures. From the intervention group, caregivers showed significant improvements in self-efficacy for parenting and felt more engaged with behaviours of self-care than those of the comparison group. Challenges with disruptive behaviour were also significantly decreased for the FMF group. Very high significance was found between groups for meeting the
Fetal Alcohol Spectrum Disorder (FASD)

challenges at a young age, neuropsychological impairment, verbal IQ ≥70) were randomly assigned to this intervention compared to a standard community of care intervention.

family needs, found through Multidimensional Assessment of Parental Satisfaction (MAPS). Other measures included the Parenting Sense of Competence (PSOC) Efficacy Scale, the ECBI, and self-report and parent satisfaction scales developed for the study.

Purpose: Conducting a systematic review to identify and evaluate the evidence of interventions for children with FASD

Methods included: Randomized control-trials and other studies including comparisons to control interventions (quasi-RCT, non-randomized control trials) and cohort studies with measurements before and after the intervention.

Outcomes of interest: measures of physical and mental health, developmental and cognitive status, quality of life, educational attainment, employment, contact with the law and substance use.

Pharmacological interventions (2 studies found):

1) Oesterheld et al. (1998) randomly assigned 4 children (5-12 years; FAS or pFAS & ADHD) from a Native American residential school to a sequence of 5-days of methylphenidate and two placebos.

2) Snyder et al., (1997) randomly assigned 12 children (6-16 years; FAS & ADHD) from Canada to usual stimulant medication and placebo for a sequence of 3 days with 1 day between interventions.

Educational and learning strategies (7 studies found):

1) Adnams et al., 2003, randomly allocated 10 children (mean age 8.5 years) with FAS from a previous study in South Africa to Cognitive Control Therapy in one school or a usual classroom in another school (1 hr/wk, 10 months, 1 month follow-up).

2) Adnams et al., 2005, assessed 65 children (9-10 years; FAS or pFAS and a deferred diagnosis category) from a study of 105 South African children randomly assigned to a language and literacy intervention (1 hr/wk, 38 wks over 9 months (follow-up at 9 months).

3) Coles et al., 2007, randomly assigned 32 children from a Fetal Alcohol Clinic in the U.S. (4-10 years, FAS or pFAS, excluded with IQ < 50) to a Virtual reality game of fire safe safety or of street safety (follow-up after 1 week).

4) Kable et al., 2007 randomly assigned 61 children (3-10 years; FAS, pFAS or alcohol-related dysmorphology) from the community and a Fetal Alcohol Clinic in the U.S. to a mathematics intervention (6 wks tutoring) or a standard psycho-educational group (follow-up at 6 wks).

1) Found significant differences between placebo and methylphenidate in hyperactivity and impulsivity, but not attention, using the Conner’s Parent Rating Scale-48 and the Conner’s Teachers Rating Scale-39 at the end of each day.

2) Findings show no significant effect of performance on attention from the stimulant compared to placebo, while hyperactivity scores significantly improved. Measures included an Underlining test, and Abbreviate Symptoms Questionnaire – Parents measuring Hyperactivity.

1) A Cognitive Control Battery showed improvements in behaviour, but were not significant. A Personal Behaviours Checklist showed improvements in behaviour compared to the control group, while a neuropsychological testing battery showed no significant differences.

2) Significant improvements found on a Phonological Awareness and Early Literacy Test for the intervention, while general scholastic tests showed no significant difference between intervention and control group.

3) Significant improvements in knowledge of fire safety and street safety after the intervention. At follow-up, fire safety maintained significance while street safety did not.

4) Compared to the psycho-educational group, children in the mathematics intervention showed significantly greater improvements in knowledge of mathematics and had a greater chance of showing significant clinical gains.
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<td>5) Loomes et al., 2008, did not report allocation of participants, but assessed 33 children (4.2-11.8 years; ARND, Alcohol Exposed Neuro-behavioural disorder or Static Encephalopathy) from hospital and FASD clinics, schools and the community in Canada in a Rehearsal training (follow-up between 6 and 21 days).</td>
<td>5) After the intervention, no significant differences were found between the intervention and control groups. At follow-up, comparisons to the control group showed significant increases in digit span for the intervention group.</td>
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<td>6) Meyer, 1998, assessed 4 boys from primary school in the U.S. (FAE and a learning disability) in a perceptual task that could be used as a teaching strategy.</td>
<td>6) None of the participants were able to model the task, and build the same structure (4 minute video of a boy of similar age using building blocks).</td>
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<td>7) Padgett et al., 2006, assessed 5 children (4-7 years; FAS, pFAS) from a Fetal Alcohol Clinic in the U.S. in a virtual reality game teaching home fire safety (focused on verbal strengths, and challenges with visual-spatial and fine motor weakness; follow-up at 1 week).</td>
<td>7) After the intervention and at follow-up, children increased their knowledge of fire safety in the home shown through their abilities to create a sequence of 3 cards that showed the steps to respond to a fire.</td>
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**Social Communication and Behavioural Strategies (3 studies found)**

1) O’Conner et al., 2006, conducted a quasi-randomized control trial by alternating the allocation of 100 children (6-12 years; FAS, pFAS or ARND with challenges in social skills and verbal and IQ≥70) from a community in the U.S. to a parent assisted child friendship training (CFT) (12 sessions of 90 mins over 12 weeks; parents participated in concurrent information sessions on FASD and social skills; follow-up at 3 months). 1) Significant improvements were found in the intervention group for sustained attention and non-verbal reasoning, while no significant differences were found for executive functioning. 2) Timler et al., 2005, assessed one child (9 years; FASD) from a Fetal Alcohol Clinic in the U.S. in a social communication intervention (2 individual sessions of 1 hr/wk followed by 4 group sessions of 2 hr/wk; follow-up at 6 weeks). 2) Number of strategies increased on how to behave in different situations, including an increase in verbs describing mental states. 3) Vernescu, 2007, used a randomized control trial and allocated 20 children (6-12 years; FASD) of the Inuit population in Canada to an Attention Process Training or to contact sessions (games and academic support included; follow-up at 3 weeks). 4) On a Test of Social Skills Knowledge of CFT participants the knowledge improved significantly compared to the control group, which was sustained at the 3 month follow-up. On the Parent report after the intervention and at follow-up of the Social Skills Rating System, social skills and problem behaviours of the CFT participants improved significantly compared to the control group.