

Towards a Provincial Strategy

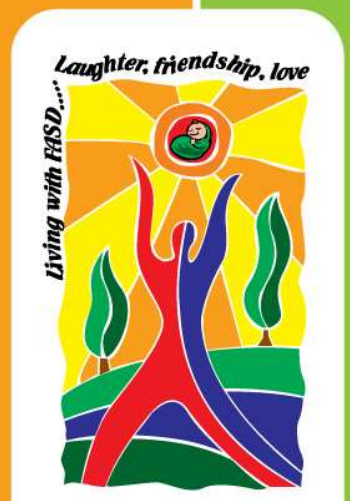
Advancing Effective
Service Provider
Practices in Fetal Alcohol
Spectrum Disorder
(FASD)

2010

FASD | ONE

Fetal Alcohol Spectrum Disorder
Ontario Network of Expertise

Intervention and Support Working Group



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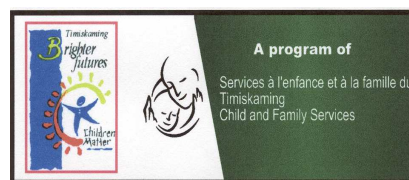
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FASD ONE (Ontario Network of Expertise, formerly known as the FASD Stakeholders for Ontario) is an unincorporated collaboration of diverse provincial and local stakeholder groups working to better serve children, youth, parents, pregnant women, and families affected by FASD in communities across Ontario. In order to better educate the public on issues facing people with FASD, the Intervention and Support Working Group of FASD ONE commissioned three research papers in 2009/2010 (of which this paper is one) on effective practices, education, and respite.

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Executive Summary

Fetal Alcohol Spectrum Disorder (FASD) is an umbrella term that refers to a range of outcomes that have been observed among individuals with prenatal alcohol exposure (Streissguth & O'Malley, 2000). These outcomes include mild to severe disturbances of physical, behavioural, emotional and/or social functioning. Each year, FASD affects 1 in every 100 live births in Canada (Public Health Agency of Canada, 2007). Most of the children affected go unrecognized and undiagnosed.

A lack of knowledge prevails among the general and professional population regarding the nature and treatment of FASD. These factors result in the application of inappropriate support strategies and the development of secondary disabilities in the person affected by FASD.

The purpose of this report was to explore standard practices that are effective in supporting people affected by FASD, and to determine if any effective service providers can be found in the province of Ontario. The researchers conducted a review of literature, consisting of conference presentations and published books or papers from recognized FASD experts who spoke to promising or effective practice. Two factors—early diagnosis, and increased education and training—act as a foundation for all effective practices with this population. Overall, the literature review revealed that the following general practices are essential for effective intervention with people affected by FASD:

- Emphasis on early diagnosis
- Training and education in FASD
- A paradigm shift to a positive, strength-based approach
- Collaborative services
- The need for life-long interdependent supports
- Structure, routine and supervision
- Effective communication approaches
- Awareness of and supports for Sensory Processing Disorders

After sending letters to Ontario ministries and finding only one available FASD-related service, geared to the Ontario Aboriginal population, the researchers conducted a survey of parents and caregivers asking them to identify effective service providers. A group of thirty service providers were identified from the data collected for the entire province—not an exhaustive list of FASD-related service providers in Ontario, but one that served the study. The approaches these service providers used for success, mirror and support the eight main practices presented in this paper.

To improve cost-effectiveness and the provincial capacity to successfully support people with FASD, the following actions are critical:

1. The Ontario Government assign a lead ministry to work with other ministries and create a provincial FASD strategy to ensure that effective practices are utilized.
2. The FASD diagnostic capacity in the province of Ontario be increased.

3. Education, training and increased awareness of FASD be prioritized.
4. Policy makers, service providers, legislators and funders utilize and build on the current effective practices to develop services for people and families affected by FASD.

Case Study

Liam was born in 1983. His mother drank in secret. He was undersized and had an “odd appearance.” He experienced chronic high fevers as a young baby, being hospitalized three times for fever, seizures, and life-threatening heart rates. Medical professionals were at a loss to explain these occurrences. Liam was slow to develop, reaching his developmental milestones late. He was uncoordinated and had no sense of balance. He was easily startled, impulsive and would go into rages when upset.

Once Liam started school, his problems with poor attention, hyperactivity and learning became apparent. He was placed on a list for assessment and was considered learning disabled. Two years later, his assessment confirmed that Liam was delayed, had poor memory and poor concentration. Although it was not written, he also had some mental retardation, of which his parents were informed. He was placed into modified programs. However, he continued to be unsuccessful at school and home. In addition, he suffered from bowel problems, which increased his social isolation.

When Liam was seven, his parents divorced, leaving Liam with his mother. His behavioural rages continued. At 10-years-old, Liam was abandoned by his mother, and he went to live with his father and stepmother. At the age of 12, he was put on Ritalin to control his impulsivity and was diagnosed with Attention Deficit Disorder. This re-assessment made it clear that Liam was not advancing; in fact, the gap between him and his peers was widening. However, his parents began to have some success during this time. They had put Liam on a routine, provided regular coaching regarding social awareness, provided repetitive supports and worked hard to reduce the impact of the bowel problems. He responded well to these changes and the medication improved his ability to attend.

When Liam was 13, his stepmother gave birth to a new daughter. Liam became violent, assaulting his stepmother repeatedly and was found shaking the new baby in a rage. The parents went to the Children’s Aid Society (CAS). The CAS refused to support them with Liam, and stated that the new baby would be taken into custody if they did not find a way to separate the children. This led to Liam’s placement in a series of residential programs. The family was unable to pay, so Liam became a ward of the CAS.

At 18, Liam was placed into supportive housing and put on the Ontario Disability Support Program (ODSP). Liam was expected to be independent but instead drained the staff with his constant need, and he became sexually inappropriate. He was placed in another home where his behaviours became even worse. He was threatened with eviction four separate times. The staff insisted Liam receive counselling. Liam went to see a local therapist and physician.

At the age of 21, Liam was finally diagnosed with Fetal Alcohol Syndrome (FAS). However, supports continued to fail until Liam was placed into a new home. Here, Liam is not expected to be independent. There is a regular routine and structure each day, and there are few rules—to eat, to take medication and to be kind to one another. Residents are encouraged to support one another interdependently creating a caring environment where people are treated as an important part of the “family.”

Liam is finally successful and happy within this structured and caring environment, and he sees his family regularly. To improve the staff's knowledge and ability to support people like Liam, training in FASD has been prioritized.

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Introduction

FASD ONE—Ontario Network of Expertise—(formerly the FASD Stakeholders for Ontario) is a group of service providers and caregivers/parents who work to address issues related to FASD in the province. There are five sub-committee working groups, of which the Intervention and Support Working Group is one. Its mandate is to “focus on building capacity within service sectors and systems and the general community to be able to respond appropriately to the unique and diverse needs of those living with FASD” (*Moving Forward and Supporting Families Affected by FASD* [Intervention and Support Working Group, 2008], p. 2).

Effective support and intervention are essential for individuals who have Fetal Alcohol Spectrum Disorder (FASD) and the families who support them. Knowledgeable people and successful supports are critical in preventing the development of the damaging and costly secondary disabilities of FASD (Streissguth, Barr, Kogan & Bookstein, 1996). These tools are equally important in the effective management of any secondary disabilities that may have already developed, usually in an individual with suspected or unsuspected, and hence undiagnosed, FASD. Most practices and all strategies must be individualized based on the person’s needs, abilities, and developmental stage and/or age. Exceptions to this include emphasis on early diagnosis, prioritizing education and training in FASD, and making the paradigm shift to a strength-based approach.

The Intervention and Support Working Group of FASD ONE embarked on a project to describe what effective practices for supporting people with FASD look like, and to assess whether caregivers and individuals with FASD can find such services in Ontario. This report is a review of prominent general practices that are reported to be effective. This report will not provide detail regarding specific strategies; however, a sample checklist of effective strategies (based on *FASD Strategies Not Solutions* by the Edmonton and Area Fetal Alcohol Network, 2004) is included in Appendix D.

Fetal Alcohol Spectrum Disorder

FASD is an umbrella term describing a range of disabilities that may affect people whose mothers consumed alcohol while pregnant. Included under the umbrella are the following diagnoses: Fetal Alcohol Syndrome (FAS), Partial Fetal Alcohol Syndrome (pFAS), and Alcohol Related Neurodevelopmental Disorder (ARND) (Public Health Agency of Canada, 2007). Confirmed alcohol consumption by the birth mother is an element of two of these diagnoses (pFAS and ARND) (Chudley, A. E., Conry, J., Cook, J.L., Looock, C., Rosales, T. & LeBlanc, N., 2005).

Those with FAS have characteristic physical (small in stature and small head circumference) and facial features (small eyes, long and flat philtrum, and a thin upper lip). They also have learning and behavioural difficulties implicating central nervous system damage or brain damage. With a diagnosis of pFAS, individuals show some of the physical and facial characteristics accompanying FAS (two of the three facial features, and they may or may not have smaller stature). They also demonstrate central nervous

system damage. Individuals diagnosed with ARND do not exhibit any characteristic physical features, but demonstrate central nervous system damage (Alberta Learning, 2004).

Prenatal alcohol exposure affects each person differently, presenting a variable level of disability for each individual. These disabilities are lifelong and restrict a person's ability to grow and mature into an independent and productive adult (Streissguth, Barr, Kogan & Bookstein, 1996). Some terms within the spectrum have fallen out of use, such as Alcohol Related Birth Defects (ARBD) and Fetal Alcohol Effects (FAE). For the purposes of this report, FASD includes any of the above acronyms.

Individuals with FASD share certain primary and secondary disabilities. Primary disabilities are those that a child is born with, and are the result of the damage done to the brain by alcohol. (See Appendix A for characteristics of FASD.) They reflect differences in brain structure and function (Manitoba Education, Training and Youth, 2001, p.1.6).

Primary disabilities include the following:

- physical and health conditions (e.g., issues with oral palate, kidneys, heart, spine and sensory systems);
- delays in meeting developmental milestones;
- difficulties in 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; and
- problems with adaptive skills.

(Alberta Learning, 2004; Saskatchewan Learning, 2004)

In the area of adaptive skills, an individual with FASD often shows the greatest decline, relative to their peers, as they grow older (Alberta Learning, 2004). While there are deficits associated with any disability, there are multiple, individualized strengths as well. Recognizing and building on these strengths minimizes weaknesses.

While the primary effects of prenatal alcohol exposure are permanent, the development of secondary effects (or *disabilities*, as they are called) is variable. These secondary disabilities can include mental health issues, drug and alcohol addictions, school failure, chronic difficulties with employment, frequent involvement with the justice system, and homelessness (Public Health Agency of Canada, 2007). Children, adolescents, and adults with FASD often experience a rise in secondary disabilities when there is a discrepancy between external expectations and their own ability to perform (Streissguth & Kanter, 1997). Research demonstrates that the presence of effective early intervention, diagnosis and family stability can minimize or altogether prevent secondary disabilities, and can reduce the impacts of the disorder (Streissguth et al., 1996; Public Health Agency of Canada, 2007). However, secondary disabilities are prevalent in approximately two-thirds of the individuals with FASD who are diagnosed with ARND (Rich, 2005). The lack of characteristic physical features in ARND makes it invisible, often resulting in no diagnosis or a misdiagnosis.

FASD is considered to be the leading cause of developmental disability in Canada (Public Health Agency Canada, 2007). One per cent or approximately 300,000 Canadians are currently FASD affected (Public Health Agency of Canada, 2007). However, this number is likely an underestimate considering that a diagnosis falling under the FASD spectrum may be delayed or missed altogether (Sokol, Delaney-Black, & Nordstrom, 2003). In Ontario, this outcome is especially likely with national guidelines for diagnosis not released until 2006 and very limited diagnostic services (FASD Stakeholders Diagnostic Working Group, 2006).

Method

The first objective of this report—to describe basic effective practices for people with FASD—was achieved through a review of existing literature that addressed the subject. Using evidence-based research methodology, the researchers were unable to find any peer-reviewed journal articles or post-secondary research on effective practices for people affected by FASD. Consequently, the researchers reviewed conference presentations and published books or papers from recognized FASD experts who spoke to promising or effective practice. Based on repeated themes within these documents, a list of effective practices was generated.

To determine whether effective services do exist in Ontario and where parents and caregivers might find them, the researchers sent letters to various ministries of the provincial government asking them to identify any FASD-related services. Letters were sent to the following ministries:

- Children and Youth Services
- Community and Social Services
- Education
- Health and Long-Term Care
- Community Safety and Correctional Services
- Training, Colleges and Universities
- Health Promotion

With the exception of one early childhood development initiative offered through the Ministry of Children and Youth Services —the Aboriginal Fetal Alcohol Spectrum Disorder and Child Nutrition Program, serving 180 aboriginal communities—, no programs supported individuals with FASD. (See Appendix B for copies of responses to the letters.) The representative of the Ministry of Children and Youth Services who responded to our inquiry acknowledged that more work needs to be done in the area of FASD. The Ministry of Community and Social Services provided the researchers with a list of the types of services available for people with a developmental disability.

Understanding that the majority of people affected by FASD do not have a developmental delay (or that they have an IQ above 70) is critical to providing sufficient supports to these

individuals (Kellerman, 2002). Bill 77, the Services for Persons with Developmental Disabilities Act, 2008, generated by the Ministry of Community and Social Services, may support the shift from IQ score to adaptive functioning when determining individual needs for long-term support. The Ministry of Education reported that the role of individual school boards is to generate specific programs and services based on local needs, and that local boards could “share effective practices in the field of FASD.” However, the majority of school boards in Ontario do not provide training and education in FASD to their staff or specialized supports to those affected. (See companion report, *Towards a Provincial Strategy: Advancing Effective Educational Practices in Fetal Alcohol Spectrum Disorders (FASD)* [Duquette & Orders, 2010]).

In the absence of any provincial government-supported programs for people affected by FASD, the Intervention and Support Working Group of FASD ONE conducted a survey. Parents were asked to identify service providers in their communities who they felt were effective in supporting their child or children affected by FASD.

Instrument

The questionnaire was field-tested with the Hamilton Parent Support Group in April 2008 and revised. Using Zoomerang, an online survey tool, the questionnaire was formatted so that it would be accessible electronically. A recruitment notice with links to the questionnaire was prepared. The survey consisted of demographic items, followed by some multiple-choice questions and, mostly, open-ended questions related to effective service providers for their children affected by FASD. The survey included parents who had children with a confirmed diagnosis, as well as those who suspected their children were affected.

Data Collection Procedures

The survey was launched in June 2008. The recruitment notice was sent electronically to the email contact lists for the 27 FASD Ontario parent support groups, various FASD committees in Ontario, through some electronic mailing lists such as FASlink, and to all members of FASD ONE. Paper copies of the survey were provided upon request. Additionally, all recipients of the recruitment notice were asked to forward it to others so that the number of respondents could be increased. Due to the limited response, the survey was launched again in fall 2008, which again resulted in a limited response.

Based on many of the comments by the parents who did respond and the response levels to similar surveys conducted by the Support and Intervention Working Group, the researchers concluded that the low response rate might be due to the very limited and, in some cases, complete lack of services specifically geared to people affected by FASD. Therefore, parents and caregivers had little to report. However, the forty-four parents and caregivers who did respond to the survey identified thirty service providers in total as effective in their approaches to supporting individuals with FASD. (See Appendix C for survey results.) Seven service providers were unavailable and two declined participation as they felt they did not provide enough direct support or services. This report bears the results of the interviews with twenty-one identified service providers as they pertain to the effective practices captured in the literature review. (See Appendix D for raw data from the identified service providers.)

Effective Practices for People with FASD

Emphasis on Early Diagnosis

Why is an early diagnosis critical? What purpose does it serve? Dr. Ann Streissguth, a renowned FASD specialist, notes in *Fetal Alcohol Syndrome: A Guide for Parents and Families* that people with FASD almost always have some kind of behavioural disabilities because of damage to the central nervous system. This does not mean that they are disabled “for all of life’s activities—they often run like the wind, laugh with gusto, sing like birds, and work hard” (1997, p.187). However, their patchwork strengths and disabilities coupled with frequently dysfunctional behaviour are very perplexing to them and their families. Streissguth notes, “As my patients with FAS/FAE tell me over and over again in their own words and with their actions, it is hard enough having these disabilities. It is even harder living up to the totally unrealistic expectations of others” (1997, p.188).

Streissguth stresses that an early diagnosis helps to prevent these misunderstandings and unrealistic expectations. In addition, an early diagnosis allows for creative lifelong planning to support this individual appropriately for the rest of his or her life. It is critical to effectively serve a person with FASD (Streissguth, 1997, p.189). The lack of identifying facial features in the majority of those affected makes early recognition of this disability even more challenging (Rich, 2005). In order to ensure clients with FASD get an early diagnosis, Streissguth advocates that professional care-providing agencies and services have a dedicated process for identifying clients with potential FASD (Streissguth, 1997, p. 229).

Identifying clients who potentially have FASD starts with the intake procedure. The intake interview should establish the family’s history of alcohol use and identify any signs of central nervous system dysfunction, growth deficiency or other birth defects in the identified individual. In addition, the intake interview should be supplemented with information from other “family” members if possible (Streissguth, 1997, p.229). Intake identification of potential clients with FASD can start with the use of tools as identified in *Practice Guidelines: Early Childhood Development – Addictions* from the Jean Tweed Centre in Toronto (2007). This paper identifies as a “best practice” staff administering tools such as TWEAK or T-ACE in the intake process to identify women who are or were at risk for heavy drinking in the prenatal period. This practice may identify children who have FASD and even the mother who might have FASD herself. Hence two clients in one family might be considered for a FASD workup followed by prevention for any future pregnancies.

Tools such as TWEAK, T-ACE and NET have been shown to be particularly sensitive in detecting heavy prenatal drinking, according to Best Start in Ontario (2001). Identifying (during intake) women who might drink heavily or have trouble stopping drinking during the prenatal period is important. The potential is there (even if rare) for diagnosing two clients with FASD (mother and child), and the need for future preventative efforts should there be another pregnancy in those cases is great.

In terms of effective practice, successful practitioners and providers of FASD supports recommend that one should “think FASD first.” Thinking FASD first means identifying on

first contact or at the beginning of treatment a client who shows many of the red flags or primary behaviours of FASD instead of formally identifying them weeks or months later when more damage has been done with ineffective programming. This practice allows suitable interventions to be put in place immediately without an actual FASD diagnosis. (Please see an important note from the authors related to the effective practice of “thinking FASD first” on page 32.)

Ann Streissguth was one of the first experts to write about the importance of getting an early FASD diagnosis. Based on data from the Streissguth and colleagues landmark 1996 study of a large number of clients ranging from 3 to 51 years of age, early diagnosis was found to be “one of the strongest factors associated with fewer secondary disabilities [as adults]” (Streissguth, 1997, p.189).

Streissguth continues, “In our (1996) study of 415 patients with FAS/FAE, those who had a diagnosis before age six had a lower rate of disrupted school experiences, inappropriate sexual behaviour, trouble with the law, alcohol and other drug problems, and institutional care in psychiatric hospitals or prison” (Streissguth, 1997, p.189). From this we may conclude that a diagnosis of FASD obtained at or before the age of six years is a benchmark of effective practice.

In their *Best Practices: Fetal Alcohol Syndrome/ Fetal Alcohol Effects*, which is based on the work of several well-known FASD researchers, Jo Nanson and Gary Roberts provide more evidence of the need for diagnosing FASD as early as possible (2000, p.62). They write:

A great deal of neurological development occurs after birth, and if early child-care, nutrition and environment are adequate, much progress can be made by the affected child, particularly when effects are less severe (Coles and Platzman, 1992). Those with an early diagnosis may have somewhat fewer difficulties later on. Consequently, various researchers (Astley and Clarren, 1999; Streissguth, 1997; Streissguth and Kanter [eds.], 1997) have called for early diagnosis and prompt intervention with families of alcohol-affected children to promote the development of these children and minimize what are termed secondary disabilities.

In their presentation, *Practical Strategies for Managing Behaviours: What We Need to Understand to be Effective*, Dubosky and McKnight saw many benefits for service providers as a result of diagnosis (2007). These benefits include:

- Viewing the individual as having a disability rather than being “bad”
- Developing successful interventions in prevention and treatment
- Improving outcomes for the individual, the family, and for service providers
- Increasing services based on recognition of the extent of FASD
- Sorting out what may be a misdiagnosis and what may be a co-occurring disorder in a particular client
- Figuring out the reasons for behaviour—critical for working with the client

- Increasing the capacity to work together with colleagues and to have more effective case management
- Developing a clearer focus in advocacy efforts

In March 2005, the Public Health Agency of Canada hosted a thematic workshop on FASD. As background material, participants received a FASD literature review. Discussion of the benefits of a FASD diagnosis and early diagnosis are included in that report and pertinent material is included in the text below.

Early diagnosis of FAS, pFAS and ARND is the crucial first step in the timely delivery of effective intervention. In fact, diagnosis before age 6 is recognized as a major factor in preventing the onset of secondary disabilities (Astley and Clarren, 1999). Also, diagnosis in early childhood may "serve as a clinical biomarker for unrecognized maternal mental health and addiction concerns and provide an opportunity to offer interventions, support and counseling for the birth mother." It may also prompt interventions for other affected siblings and help to prevent alcohol exposure during subsequent pregnancies (Loock et al., 2005).

(Public Health Agency of Canada, 2005: Appendix 3.)

There are great difficulties in obtaining a FASD diagnosis in Ontario. Currently, the provincial government doesn't recognize FASD and, consequently, no funding is available to support the diagnosis or the delivery of any services for people affected by FASD. The Diagnostic Working Group of FASD ONE was formed to unify regional efforts in the province to provide diagnostic services in the absence of funding. The challenges encountered by many stakeholders in developing diagnostic services have included "insufficient funding, lack of specific diagnostic services or clinical professionals, and the need for expanding the number of trained clinicians available. Additionally, there is currently no ministry code that allows a physician to bill OHIP for time spent in reviewing assessment documentation or for making the diagnosis" (FASD Stakeholders Diagnostic Working Group, 2006, p.4). It is critical that the Ontario government increase the capacity for diagnosis of FASD within the province.

Of the 21 identified effective service providers in Ontario, 89% either initiated or completed a full assessment of the individual on intake. Early diagnosis was consistently recognized as important for good prognosis. Individual treatment plans or support plans are being developed, in part, based on the results of the assessment, where available. Most service providers talked about the limited access to assessment services as a barrier to assessment and early diagnosis. In many cases it will take years to get the completed assessment. As a result, several service providers (14%) reported they should "Think FASD First" . . . making efforts to identify clients potentially affected and putting supports in place.

Training and Education in FASD

Without diagnoses, we cannot have informed understanding of the nature of the disability. Whether a diagnosis is confirmed or suspected, all individuals supporting the person affected by FASD must have a strong understanding of how alcohol affects the brain and its impact on behaviours.

People with FAS/FAE, because of their inherent brain dysfunction, place certain demands on the environment. When these demands are understood and met, they can function fairly well. When their needs are not understood and met, their behaviours can become out of control, bizarre, impulsive, desperate, and dysfunctional (Streissguth, 1997, p. 242).

A lack of knowledge regarding FASD prevails in our communities and, indeed, in different parts of the world. A national Canadian survey of health professionals found that health care providers require more education and training in the area of FASD. Only 60% of those surveyed recognized that diagnosis includes a combined assessment of growth, brain and facial abnormalities. The findings reflected the need for supports to increase accurate diagnoses and referrals in Canada (Public Health Agency of Canada, 2004). Similar results were found in an Australian survey of pediatricians. Of the 132 Australian respondents, only 18.9% identified all four essential diagnostic features for FAS. Although 78.2% agreed avoiding binge drinking may reduce FAS, only 43.9% believed women should abstain from using alcohol in pregnancy. (Elliott, Payne, Haan & Bower, 2006)

In *Trying Differently Rather Than Harder*, Diane Malbin agrees on the need to increase accurate diagnoses and referrals. She states that often parents go to professionals seeking support and services with the hope that they (the service providers) will have greater knowledge and information on FASD than the parents do, but in fact this is not true. Often the parents have more knowledge since information related to FASD is not yet in most professional curricula (Malbin, 2002, p.67).

While parents in Ontario have difficulty finding medical professionals who can diagnose their children (see sample comments in Appendix C), they have equal difficulty finding service providers and educators who are trained in FASD and are able to provide effective interventions and support. This conclusion is supported in Duquette & Orders (2010). The frustration of parents is illustrated in the two quotations below taken from the effective practices survey. (See Appendix C for survey results).

My adopted son is now 43-years-old. Never was FASD suggested even though we were under the care of physicians, psychologists and social workers from the time he was in first grade.

There is a huge gaping hole in respect to diagnosis, service, support, education etc...we have no educators, mental health practitioners who are up to speed on this topic. We have too few doctors who even know what FASD is, much less are able to diagnose it. This is a crisis.

Dubovsky (2008) and Lauber (2008)—experts from the SAMHSA (Substance Abuse and Mental Health Services Administration) FASD Center for Excellence—have identified one result of the lack of knowledge: high frequency of misdiagnosis for clients affected by FASD. Primary and/or secondary disabilities are often seen as presenting behaviours in isolation, and there is a lack of understanding regarding the nature of the underlying damage to the brain.

Frequently, a person with FASD will present as a client for a service based on one or more serious problems, such as chronic unemployment, homelessness, substance abuse or anger management issues. *Trying Differently: A Guide for Daily Living and Working with FAS and Other Brain Differences*, a handbook from the Yukon, indicates that, “presenting problems may include difficulties with socialization and independence, difficulty with time, money, sensory overload, dealing with free time, depression, volatility, ability to concentrate and panic attacks” (Trudeau, 2002, pp. 2–3).

Mental health issues are often identified as the cause of these problems. The primary disabilities of FASD, such as “difficulty with memory, gaps in linkages, forming associations, predicting, abstract reasoning, cause and effect reasoning, generalization, and slower cognitive and auditory pace,” which are caused by permanent brain damage are not acknowledged, recognized or understood (Trudeau, 2002, pp. 2–3).

Dr. Kathryn Page, the co-founder of the Fetal Alcohol Spectrum Diagnostic Clinic at the county hospital in San Jose, California, notes that some clients appear to have “an alphabet soup” of psychiatric diagnoses attached to their case. The first thing that should be thought as a predisposing factor to all the mental health problems is that the client in question probably had FASD.

In her work, Page identifies and discusses the relationship of the many commonly co-occurring mental health diagnoses found with FASD. They can include one or more of the following: ADD/ADHD, Oppositional Defiant Disorder, Conduct Disorder, Sensory Integration Disorder [currently referred to as Sensory Processing Disorder], Borderline Personality Disorder, Bipolar Disorder and Attachment Disorders (Page, 2003, p.67 ff).

Why does this “alphabet soup” of diagnoses occur? According to Page, it often happens when harried caregivers of the children and young people who have unrecognized FASD go from professional to professional. These caregivers desperately seek solutions to the serious behaviour problems that are caused by the organic brain damage related to FASD. Each diagnosis captures a part of the real problem and tries to address some or all the symptoms currently faced by the family of the person with FASD. However, the real problem—the organic brain damage of FASD—is not recognized as the cause of all the problems (Page, 2003, p.67 ff). Attempts to intervene pharmacologically at this point are

frequently unsuccessful or are only partially successful without the root cause of the problems being understood.

Even if the correct diagnosis is given, lack of knowledge about FASD translates into a failure “to provide the best management strategies and treatment alternatives to these individuals, primarily because they often treat only the behaviours without comprehending the nature of the underlying organic brain damage” (Streissguth, 1997, p.228).

Typically, support people use a behavioural model when trying to modify dysfunctional behaviours in their clients. Nathan Ory notes that tying “privileges to responsibility” doesn’t fit when dealing with people with this kind of brain damage. Increased privileges are often contingent on exhibiting more self-control and self-management of one’s behaviour. For people with FASD this model can lead to endless failure and mutual animosity between a professional and their client. Behavioural models do not work with people with FASD, because their control over impulses and behaviour is often not possible. They are set up for failure when the behavioural model is used. The psychosocial rehabilitation or behavioural management model assumes that the clients will eventually learn from experience and be able to regulate their behaviour to conform to the social norms practised. They are expected to become responsible for their own behaviour and act in their own best interest. This is unlikely with people with FASD (Ory, 2008).

Information and education are especially important when we consider parents and caregivers. As primary support, parents must understand how to better manage their child’s behaviours. As we have noted, many parents and caregivers have found no answers when seeking support and diagnosis. This outcome has many detrimental effects on families—parents and siblings—, such as “stress, depression, divorce, fatigue, desperation, isolation —the isolation is so painful —and burnout” (Kellerman, 2002). Difficulties experienced by parents and caregivers are reviewed in detail in the companion document, *Towards a Provincial Strategy: Advancing Effective Respite Services in Fetal Alcohol Spectrum Disorder (FASD)* (Whyte, 2010).

In June 2009, the researchers interviewed Sharon Pereira and Lynda Westlake, group facilitators for Helping Hands for FASD in Barrie, Ontario. The results of this interview can be paraphrased as follows: being a parent of a child with FASD is a journey filled with pain, self-reflection, and frustration. This journey is often complicated further by the judgment and blame of the uninformed community.

There is a time when parents lack knowledge or acceptance of FASD and often do not reach out to local parent support groups, if available, until they are exhausted, feeling helpless and burnt out. In the absence of informed support services, families are forced to research the facts of FASD themselves and learn all they can to understand their child and advocate for their needs. It is not until the parents learn and embrace the idea that they cannot change their child, instead that they must alter their own response and the environment, before they are able to create successful support strategies.

Not all families have the resources to make this journey successfully and, as a result, continue to utilize inappropriate support strategies. Ineffective strategies that

parents/caregivers use to support their FASD affected child(ren) may result in the ongoing development of secondary disabilities in those children.

Secondary disabilities include mental health issues. Streissguth writes, “Even though diagnoses of FAS and FAE (forms of FASD) are not common in the mental health field, mental health problems are the most prevalent secondary disability that afflicts individuals with FAS” (Streissguth, 1997). Data from her research concluded that mental health issues are the most common secondary disability faced by people with FASD. Over 90% of the study sample (n = 415) had some type of mental health problem (Streissguth, 1997). This study produced many key statistics regarding mental health problems and FASD. For instance, 58% of the sample was diagnosed with ADHD and 30% experienced panic attacks. Also, for persons with FASD in this study the median age of onset of psychiatric problems was seven, while the median age for the first psychiatric hospitalization was thirteen. Lastly, depression and suicide threats/attempts were common problems, and seventy people (17%) in the study had been detained in psychiatric hospitals for these reasons (Streissguth, 1997).

Indeed, the evidence is mounting for the need to recognize that FASD is often behind mental health problems and substance abuse. Kieran O'Malley gave a plenary presentation at the Vancouver National FASD and Mental Health Conference in April 2008 entitled, “Dual Diagnosis, Developmental Disability and Psychiatric Disorder in FASD: The Challenges of Transgenerational Clinical Management.” In his presentation, O'Malley introduced a new phrase and concept into the FASD lexicon when he referred to “the triple threat of FASD.” Understanding this concept is critical to the provision of effective services for people with FASD.

O'Malley describes the triple threat of FASD as follows: “. . . if one were to observe the whole population of individuals with FASD (diagnosed and undiagnosed), a huge proportion of this population would be found to have one or more diagnosable mental health issues. Of this population with mental health issues and FASD, a large portion will also be found to have alcohol and drug use and abuse problems” (O'Malley, 2008, p. 23 ff).

There are hundreds of thousands of Canadians living with FASD. Many of them will exhibit the “triple threat,” which goes a long way in explaining the incidence of mental health and drug/alcohol abuse problems facing North American society. Realizing that FASD is the starting circumstance of the three conditions in the same person is critical.

Reducing FASD misdiagnoses and the presence of secondary disabilities through appropriate supports and intervention, even in those already diagnosed with an FASD, depends on an increase in knowledge of FASD and the effects of prenatal alcohol use. Therefore, making education and/or training available to the community at large, while requiring training for all staff and caregivers supporting individuals with an FASD, is a necessary effective practice.

Educating the person impacted by FASD is considered equally important for long-term success. There are many benefits to diagnosis and increased understanding of the disability for the individual affected. This practice allows the individual to recognize that there is an organic reason for the dysfunctional behaviours, and that he or she is not

“stupid, bad or crazy.” The individual is less likely to resist supportive structure and routine, and reality-based long-term planning regarding housing, education, employment, recreation and social activities. In addition, this increased understanding may help individuals with FASD to self-advocate, to protect themselves and to accept their unique limitations (Dubovsky & McKnight, 2007). The Ontario government needs to prioritize the training, education and increased awareness of FASD.

Identified effective Ontario service providers supported FASD-related education on every level specific to service delivery. Eighty-one per cent used open language and education regarding FASD with a “no shame” approach with clients. Eight-six per cent ensured families were involved and received ample information/education on the disability. Sixty-six per cent prioritized educating the individual affected. Several service providers stressed that educating the individual was sometimes done in an indirect manner focusing on individual needs and strengths, depending on the age/level of functioning of the individual and his or her level of acceptance regarding the disability.

Educating and training service providers regarding FASD, however, was often not part of any professional training or workplace mandate. Fifty-seven per cent of the identified effective individuals were self-taught on FASD. In some cases, this action was necessary due to lack of professional development within the agencies themselves. Overall, twenty-four per cent of the identified agencies failed to provide educational opportunities in basic FASD, and thirty-three percent failed to support education in strategies for effective intervention.

A Paradigm Shift to a Positive, Strength-Based Approach

Once they grow to understand the neurological impairment and its effects on behaviours, professionals and caregivers experience a significant shift in the way they perceive individuals affected by FASD. Feelings of frustration and anger evolve into understanding, increased patience and acceptance (Malbin, 2002). The following chart is adapted from *Trying Differently Rather Than Harder* (Malbin, 2002, p.43). It describes the shift in perception that happened in people once they completed an educational program on FASD.

From Seeing the Individual as Someone Who ...	To Understanding the Individual as Someone Who...
Won't (i.e., someone who is...)	Can't (i.e., someone who is...)
<i>Annoying</i>	<i>Frustrated, challenged</i>
<i>Lazy, unmotivated</i>	<i>Trying hard, tired of failing</i>
<i>Lying</i>	<i>Confabulating, filling in the blanks</i>
<i>Fussy</i>	<i>Oversensitive</i>
<i>Acting younger, babied</i>	<i>Being younger</i>
<i>Trying to get attention</i>	<i>Needing contact and support</i>
<i>Inappropriate</i>	<i>Displaying behaviours of a younger child</i>

From having feelings of...	To having feelings of...
<i>Hopelessness</i>	<i>Hope</i>
<i>Fear</i>	<i>Understanding</i>
<i>Chaos, confusion</i>	<i>Organization, comprehension</i>
<i>Power struggles</i>	<i>Working with</i>
<i>Isolation</i>	<i>Networking, collaborating</i>
From professional behaviour of...	To professional behaviour of...
<i>Stopping behaviours</i>	<i>Preventing problems</i>
<i>Behaviour modification</i>	<i>Modeling, using visual cues</i>
<i>Changing people</i>	<i>Changing environments</i>

In an e-mail to one of the researchers, Malbin notes the following:

I usually preface "Think FASD First" by establishing that FASD is a brain-based physical condition ... (and being aware of this)... guides exploration of the relevance of program design and practice by first determining whether techniques are informed by research and encompass the neurobehavioral dimension. Most programs (and research projects) fail to explicate that brain-based piece and are typically still based on the assumptions of learning theory and behavioural interventions (Malbin, e-mail, September 8, 2008).

Effective programs for FASD reflect the understanding that dysfunctional behaviour is brain-based and caused by permanent brain damage. The paradigm within the program shifts from "won't to can't." Primary behaviours are not seen as wilful. In addition, staff/caregivers should think FASD first when they see the highly identifiable primary behaviours.

Trying Differently with FASD means to expand your range of options and move from punishing behaviours to understanding them and changing the environment and your expectations of the affected individual. It also means shifting from trying to fix or change peoples' symptoms to changing the way that we react. *Trying Differently* also means that when something doesn't work, don't give up, and don't try harder, try something different (Trudeau, 2002, p.3).

Eric Bontogon, as referenced in Nathan Ory, shares the advice to have no negative carry-over into the next day. People with FASD do not connect today's and tomorrow's experiences. Every day is a new day. Today's bad moments should not affect tomorrow's reality (Ory, 2008, p.203).

With respect to arguments, which will inevitably erupt, a service provider or caregiver should try to find a way to back off and disappear during an argument. Again, don't let today influence tomorrow. Back off and distract the person. The support person could also give up on their side of the argument for a short while or until a new day dawns.

Memory is often short. Tomorrow the individual with FASD will be a new person again, and the issue that caused the argument may be viewed differently (Dubovsky, 2007).

Nathan Ory discusses effective practice regarding fairness to other clients in “General Guidelines for Supporting Adults with Fetal Alcohol Spectrum Disorder (in a Mental Health or Forensic Setting)” (2008). A professional, he discusses, will often have to treat a person with FASD differently than clients without this kind of brain damage. This treatment looks unfair and may seem to give the person with FASD an unfair advantage. Like a diabetic who needs different food from time to time to meet metabolic requirements, a person with FASD needs different treatment to make his brain work better. “They often need what they need 24/7” (Ory, 2008, p.203).

Dubovsky believes that service providers should have a “no-eject” policy for individuals with FASD. In other words, services should never expel or suspend clients for brain-based behaviour or have “zero tolerance” policies. He writes, “We must move from viewing the individual as failing if s/he does not do well in a program to viewing the program as not providing what the individual needs in order to succeed” (Dubovsky, 2007, p. 6). Effective practices include preventing aggressive or unmanageable behaviours (Edmonton and Area Fetal Alcohol Network, 2004). This practice includes thoroughly assessing the individual to determine triggers for behaviours and/or problematic situations, and providing the structure and support to optimize capabilities and prevent behaviours. Preventing aggressive behaviours will reduce the need for zero tolerance policies.

Dan Dubovsky queries how and why individuals with FASD are often steered towards inappropriate standard aptitudes and skills as they become adults. (An example is any job involving several steps with no one there to tell them what the next step is.) He advises that the individual strengths of each client with FASD be assessed instead. People with FASD are not all alike and should not be treated as such (Dubovsky, 2007).

According to Dubovsky, individual strengths can be found in many areas of each client’s life. He recommends an examination of the following:

- The individual
 - What do they do well?
 - What do they like to do?
 - What are their best qualities?
 - What do you like about them?
 - What were your funniest times with them?
 - Their family members; what is each family member able to bring to this situation?
- (Dubovsky, 2007)

Family and service-agency strengths should then be inventoried so that they can be put in plans and used to fulfill client needs. Perhaps most importantly, for adult or adolescent clients, strengths in the individual’s community can then be assessed. At this point, families and service providers can identify a positive role or roles that the client could play in his or her community (Dubovsky, 2007).

After the client’s strengths and favourite activities have been inventoried, programming can be developed that makes use of these aptitudes. A client may love small animals,

cooking or framing houses, and no one had realized it beforehand. People always do better at activities they enjoy, so programming should centre on favoured activities. Strength-based activities particular to any client with FASD should never be used as treats or rewards, and never be withheld as “punishment.” Dubovsky indicates that families and service providers need to find something the person enjoys and does really well, and support the person doing it, regardless of his or her behaviour (Dubovsky, 2007).

Identified effective Ontario service providers overwhelmingly demonstrated a positive approach to service delivery. One hundred per cent stated that all supports must be dependent on a full assessment of strengths and weaknesses. One hundred per cent of those interviewed displayed calmness, patience, empathy and focused on strengths. Ninety per cent reported using positive phrasing and acknowledging the smallest achievements. One hundred per cent reported that they manage unacceptable behaviours and don't terminate service. Ninety-five per cent stated that services are available to the individual as long as they are needed or are re-opened quickly should services be needed again. The only exceptions are when the individual exceeds the age mandated for the service.

Collaborative Services

The research from Streissguth and her colleagues shows that individuals with FASD will need to access many supports over their lifetimes. Due to the nature of this brain-based condition, most individuals with FASD will not be able to coordinate all the services they need. They may thus encounter staff who want to help but do not realize that many other colleagues are already involved in their particular case.

Often, what individuals with FASD most need from their service providers is service coordination. Effective practice for service providers means that they are able to “establish and maintain collaboration and constructive liaisons or relationships with a variety of individuals and groups including families, diagnostic and assessment teams, schools and other agencies” (Ministry of Children and Family Development, Government of British Columbia, 2008, p.8).

Streissguth devotes much effort to describing “guidelines for human services.” Secondary disabilities are more effectively dealt with when all professionals on a particular case collaborate. The three most common secondary disabilities are (1) mental health problems, (2) alcohol and other drug problems and (3) trouble with the law. Effective service provision will often require contending with these three weighty problems. Frequently, one client will be affected by all three of these factors. His or her situations are complex and difficult to manage. For people with FASD, this reality means that service providers have to manage effectively (Streissguth, 1997, p. 228).¹

¹ See Chapter 12 of Streissguth's *Fetal Alcohol Syndrome* (1997) for specific suggestions on providing collaborative and effective services to deal with clients who have FASD in addition to mental health problems, alcohol or drug problems and trouble with the law.

On September 9, 2005, the Public Health Agency of Canada launched a modified version of an existing document called *Fetal Alcohol Spectrum Disorder (FASD): A Framework for Action*. “Moving forward calls for commitment, leadership and collaboration” is the call to action grounding this framework. The framework is designed to inspire and guide the planning, implementation and coordination of policies and procedures in the delivery of services to people affected by an FASD across Canada and thus support the need for collaborative services.

The ultimate goal of collaborative work is to build and maintain an effective system of supports and services to both prevent FASD and meet the needs of people already affected. Developing such a system represents many challenges, which include

- widening the circle of interest in and commitment to preventing FASD and supporting those affected by it— through ongoing education and discussion;
- establishing measurable goals and objectives for prevention, support and services;
- forging and strengthening partnerships within communities and across the country to share resources, expertise, experience and ideas across all sectors;
- developing action plans for prevention, support and services at the community, provincial/territorial and national/federal levels; and
- identifying, securing and integrating funding from a variety of sectors to support action to prevent FASD and improve the quality of the life of those with the disorder.

Dubovsky also includes service collaboration in his discussion of effective strategies for people with FASD. Most caregivers, he notes, usually know what interventions work with and for their children even if they can’t provide these supports for their child. Service providers, on the other hand, can look at their own agency and the other agencies in the community that serve the client. Most have services that could be adapted for people with FASD and have the ability to network with other services. Furthermore, local agencies are familiar with interagency networking and methods of increased funding.

Agencies working together synergistically tend to increase the effectiveness of services provided to clients with FASD. Dubovsky advises professional service providers in particular to ask themselves, “What does this person with FASD need and how can I get it for them?” Dubovsky is also a great proponent of community-based social support for individuals with FASD. He identifies the community in which a person with FASD lives as an ideal collaborator for the provision of effective services. The community must be educated on FASD to cultivate the necessary understanding for effective supports. Agencies should include a profile of the community in their strengths assessment of the individual to better develop long-term social and vocational roles (Dubovsky, 2007).

Knowledgeable and collaborative case management is an essential part of effective service provision. However, an assigned case coordinator is often not utilized or available. Frequently, a service agency will find that the only advocate for a new client with diagnosed or suspected FASD is a family member or friend. This is a stressor for the

family members who are often weary from the day-to-day care of their child, and it must be remedied. (Please see Whyte, 2010.)

However, Streissguth has suggestions for working effectively with this person until a more comprehensive circle of support can be formed. She notes that this advocate (or advocates) should always be involved after s/he (or they) have been identified. Advocates, particularly parents, often have valuable insights in ways to deal with these clients, and their input should be immediately considered (Streissguth, 1997).

Streissguth describes an advocate for someone with FASD as an invaluable ally who can work to change the system to better accommodate the individual, and who can negotiate plausible controls and compromises (Streissguth, 1997). An effective practice for the agency or service provider is to take on the role of advocate. This reduces the stressors on the family.

For other families and in some communities, the case manager or advocate role may be played by *wraparound* support, when a group of agencies work together to provide more effective support for their clients. Wraparound programs have proven to be helpful in the long-term support of people affected by FASD. A wraparound example is described on the Web site of the National Organization on Fetal Alcohol Syndrome. “The family also was accepted into a wraparound program, a strengths- and family-based, holistic approach to wrapping supports around families who have children with behavioural needs. The wraparound team, which consisted of friends who know, love, and understand Sam; wraparound professionals; a therapist; and school personnel, gave the family the hope, support, and expertise they needed to become more stable and to begin planning for Sam's future” (National Organization on Fetal Alcohol Syndrome, 2007).

Professionals in the field of FASD concur that the contributions made by case managers, advocates and wraparound systems are basically similar in their ability to assist the individual who had FASD. A complete description of each type of service is not the intent of this paper. Suffice it to say that the client with FASD must have one or more of these services/systems to be in place for effective servicing to happen.

In the absence of formalized funding and services for people affected by FASD, a large number of coalitions and committees have formed in Ontario to begin to address the lack of services and collaboration in the province.² One community working hard on this development is Toronto.

The Children's Aid Society (CAS) of Toronto has initiated, supported and provided leadership on developing a large local FASD coalition. In addition, the CAS of Toronto has sponsored the development of a community FASD Training, Consultation and Mentorship Leadership Team—a floating community service of specially trained professionals, from various agencies, who provide education, training and case management consultations throughout the Toronto region.

² A complete listing of provincial coalitions and committees can be found in FASD Ontario News, Edition 4 April 2008, p.7 (available online at http://www.beststart.org/fasd/FASD_newsletter_08_rev.pdf).

In collaboration with Catholic Children's Aid Society of Toronto, Native Child and Family Services, Alliance Youth Service, and Bridgeway Family Homes, the CAS of Toronto, through funding from the Ministry of Children and Youth Services, also provides respite services to biological, foster, kinship and adoptive families. The impact on families receiving respite has been evaluated and proven to be a significant stress reducer, enabling families to provide permanency for their children and for youth affected by FASD.

Identified effective Ontario service providers experienced challenges regarding service collaboration. Service providers tend to work in isolation from one another, each focused on different or competing mandates, and fail to understand the complexity of services often utilized by persons affected by FASD and the need for case collaboration. This tendency is the result of lack of knowledge regarding FASD, the prevalence of secondary disabilities and FASD's impact on our communities.

Only 66% of the identified service providers prioritized the development of collaborative services. In some cases, collaboration is replaced by multi-disciplinary supports within an agency. In other cases, collaboration is avoided altogether as referrals to other community agencies, due to their lack of knowledge of FASD, "just make the situation worse."

However, other communities have worked hard to develop this potential. In addition to the Toronto initiatives stated above, Barrie, Ontario has also developed their collaborative efforts. Patty Radford in Barrie states, "In the past twelve years, we have put an emphasis on collaboration, pulling people out of their silos."

Barrie acts a model for the development of collaborative services. Tonya Millsap is the FASD Project Manager for Barrie. She has been funded through the in-kind contributions of the community who agree they all have a vested interest in FASD. "There is a synergetic quality anchoring the work of the FASD Initiative in Simcoe County. We are rooted in the premise that FASD cannot be addressed effectively by single sectors, by single organizations or service providers alone. During this first year of our Simcoe County Initiative in FASD, we have achieved and accomplished significant outcomes because of our collaboration and partnerships. The process of collaboration requires a significant investment of time and nurturing at the outset in order to build sustained, informed and collaborative systems of care for children, youth, adults and families affected by FASD" (Tonya Millsap, June 23, 2009, email to the researchers).

The Need for Lifelong Interdependent Supports

At the same time as this planning and implementation is undertaken, service providers and caregivers should teach people with FASD how to be interdependent or to accept that interdependence is good for them and will ensure they will be more successful as adults. This message must begin at an early age. When their peers look forward to moving away from home and starting their own lives independently, people with FASD should not have the same hope reinforced in them. Instead interdependence is a reasonable and desirable goal.

One of the most promising effective practices is that of developing an interdependent support network for adolescents and young adults with FASD. An interdependent

relationship is defined as “a relationship in which both persons are valued, respected and each one contributes equally; and where no one person is required or expected to have all the answers. It is a relationship in which a belief in the validity of each person’s perspective, skills and insights allow us to collectively make good decisions” (Whitecrow Village, Nanaimo, British Columbia, FASD Interdependent Living programs for Adults).

Many experts recognize that clients with FASD will need lifelong support (Dubovsky & McKnight, 2007; Streissguth, 1997; Ory, 2008; Kellerman, 2003). They will always need some anchoring or external support from outside themselves. Often persons with FASD will not absorb the strategy, and it will need to be applied over and over again (Dubovsky & McKnight, 2007). The most severely affected individuals with FASD will need full-time support for the rest of their lives.

Ann Streissguth writes that most agencies expect their clients to improve with service and get better permanently. The situation for clients with FASD is counterintuitive to the norm, and this can cause significant problems for service providers until they understand the reasons for what they are seeing. “Somewhere around the time of adolescence, they [the clients with FASD] seem to be “treading water” in their development—suddenly their peers are becoming independent and turning into adults while they’re stuck in child-like patterns of behaviours” (Streissguth, 1997, p.189).

Streissguth continues, “In comparison with their peers, people with FASD seem to have more and more difficulties as they grow older, rather than more and more competencies.” Effective services mean lifelong planning for the inevitable dependencies of a client with FASD (Streissguth, 1997, p.189).

Teresa Kellerman talks about the need for lifelong interdependent support in her short 2003 article, “Crossing the Bridge to the Future” (retrieved from the Internet):

Build a Circle of Support: As the child grows into adulthood, there will be a reluctance to depend on immediate family. Because they will not be able to succeed entirely on their own, and because parents can’t live forever, there has to be a time to let go. But hopefully that time does not come until there is a safety net ready to replace the security afforded by having 24/7 supervision at home. The Circle of Support will include informed relatives, job coach, mentor, church members, social workers and others.

Nathan Ory provides more suggestions and another expert opinion on providing lifelong support for adults with FASD in mental health and forensic settings. Professionals in the psychosocial community tend to feel positive when adults with FASD ask to have more independence; they see it as an opportunity to use a psychosocial rehabilitation model of therapy. Ory warns against this response and indicates that people with FASD are better off with functional dependence or “interdependence” (Ory, 2008, p.200). “Some adults with FASD and mental health issues are often only able to be responsible when their essential dependence on the external structure (provided by others) is recognized and continually provided.” In order to stay even relatively organized they will need to be dependent on others (Ory, 2008, p. 202).

In *The Meaning and Use of Structure*, Ory notes that people with FASD often display disruptive behaviours because they are frequently unable to organize their own time, keep focused and/or busy. They must have external structure instead. Without this structure they may react impulsively or perseveratively to random external stimuli. They may become over-focused on their own internal fears and get stuck in an altered or psychiatric state. Thus, “external brains” help prevent disruptive behaviours. Rather than react to the disruptive behaviour, arrange environments so proactive interactions are encouraged (Ory, 2006, p.203).

Furthermore, Ory states that, “Adults with FASD tend to not be internally organized;” they can be easily influenced by others in their environment. People with FASD tend to be accepting and friendly. Ory reports that adults with FASD (and other similar handicapping brain dysfunctions) are likely to be unsafe when they are expected to function independently in the community. They have limited capacity to exercise good judgment and to anticipate the consequences of their own decisions. In order to live a safe and somewhat effective life, adults with FASD need to be functionally dependent on a person or persons acting as an “external brain” who remind them what needs to be done and when (Ory, 2008, p.200).

Many programs in western Canada have developed mentorship programs to support individuals affected by FASD. Examples include the Whitecrow Village and the Cowichan Valley FAS Society in British Columbia who provide FASD mentorship programs. The FASD Cross Ministry Committee in Alberta promotes mentorship by providing both rural and urban mentoring programs. Participants benefit directly from friendship, guidance and role modelling of a trained mentor.

As previously mentioned, none of the Ontario ministries contacted for this paper identified any FASD-specific programs, including those pertaining to the concept of interdependence. As a result, Ontario parents and caregivers are left alone to worry about lifelong support for their child, both during and after the parents’ lifetime. Parents work very hard to plan for their children through wills, trust funds, power of attorneys, disability pensions and involvement with various wraparound programs. Many families, however, are in crisis with limited income, limited access to programs and limited options.

One hundred per cent of the identified effective Ontario service providers did not expect independence from clients but instead, positive interdependence. Where applicable, one hundred per cent developed a support team for their clients’ interdependent living as adults. Ninety-five per cent utilized natural community supports to act as interdependent supports, whenever possible.

One hundred per cent adjusted external supports to increase success for the individual. Additionally, a small number of respondents (14%) indicated their efforts to create mutually supportive environments where clients support clients in their personal goals. This low percentage is explained by the fact that this practice was specific to group programming/living support service providers, which in most cases did not apply to the services identified.

Structure, Routine and Supervision

Many resources and authors who discuss FASD interventions pertaining to children, youth and adults, such as Della Maguire (2002), the Victorian Order of Nurses (2005) and Edmonton and Area Fetal Alcohol Network (2004), note the importance of structure and routine. In her book, *Living with FASD: A Guide for Parents*, Sara Graefe notes that Maureen Murphy first formulated this effective practice idea in 1991 as the 4 S's + 1C—Structure, Supervision, Simplicity, Steps and Context (Graefe, 2006, p. 39 ff). Jan Lutke and Deb Evenson expanded on similar ideas in their 1997 *Eight Magic Keys*. This included emphasis on routine, structure, supervision, a concrete approach, consistency, simplicity, use of specific language (saying exactly what you mean) and repetition.

In *The Meaning and Use of Structure* (2006), Nathan Ory suggests that structured environments substitute for understanding, so that even when the individual with FASD does not know what to do or encounters a change in the routine, the repeated structure of the day takes over and acts as a scaffold. This allows the individual to know what is coming next and what behaviour is expected with the activity. In short, structure assists in overcoming neurodevelopmental difficulties in sequencing and organizing their own actions.

Eric Bontogon, as referred to in Nathan Ory, suggests that the following are effective practices or philosophies related to instances when service providers develop a critical need for immediate solutions to behaviour problems. For instance a person with FASD may be unable to wait for the “reward” and will become agitated and impatient. They seem “childish” in this regard and frequently positive rewards will not work. Try to avoid the word “wait.” Set up structures where reward is built in frequently and automatically so there is little or no waiting (Ory, 2006).

Graefe defines structure as an “environment for children with FAS which includes choices within clear and predictable routines” (Graefe, 2006, p.39). Trudeau explains, “Provide structure not control—control generates power struggles; structure organizes the environment so success happens and is respectful. Structure means having the same patterns each day or every time you do something. Structure also means using the same words for the same instructions” (Trudeau, 2002, p.8).

Providing structure also means eliminating free time. Free time can be difficult for individuals with FASD to handle because they do not know what to do and often get into trouble. This is not to say that a structured day will be “go-go-go;” rather, the down time is built into the day and has a focus with a beginning, middle and end. In other words even free time can be structured for success (Edmonton and Area Fetal Alcohol Network, 2004).

Structure includes altering the environment to support routine. Malbin discusses environment, stating that moving from trying to change the child's behaviours to focusing on changing the supporting environment provides a different perspective for choosing interventions. “The paradox is that if we use the behaviours as cues for recognizing an

underlying neurological condition, and then modify environments to create good fit, many challenging secondary disabilities are resolved or even prevented.”

Assessing the fit between people and their environment includes “considering the role of the brain in behaviours and acknowledging neurologically based differences.”

Environmental conditions to consider include the elements detected through the senses, such as sight, taste, sound, as well as elements that are invisible, such as attitudes, culture, assumptions and values (Malbin, 2002, p.38–39). Previously, we discussed the importance of visual cues as a method of effective communication. Including visual cues within the environment is also a necessary modification under support and structure strategies.

The symptomatic and challenging behaviours that result from this brain-based condition should be viewed as a poor fit between the person with FASD and his or her environment. Changing the individual’s environment, which includes the approach of the service provider, can “improve functioning and reduce challenging behaviours” (Government of British Columbia Ministry of Children and Family Development, 2008).

David Gerry, as mentioned in Nathan Ory, suggests that the following effective practices establish routines and rituals that may be required for success for individuals with FASD: Understand that doing the same thing the same way everyday may be required for comfort. Just do it or let the individual do it, and make creative solutions when the behaviour seems very bizarre. For example, getting ready for and driving to school throughout a holiday period may keep a student with FASD calm. It may seem like a waste of time or gas, but it is not when compared to the results of not performing the ritual (Ory, 2008).

Trying Differently (2002) has several suggestions regarding routine and structure. Essentially, the caregivers need to be organized themselves, getting ready for morning the night before. Free time should be avoided as it is “unstructured and dangerous.” Making plans for unplanned times or having a “bag of tricks” ready to implement is advised along with providing a lot of extra support and understanding when regular routines must change. Examples here include holidays when there is no school, a snow day or summer holidays when the regular, comforting routine evaporates (Trudeau, 2002, p. 9).

Lastly, the role of direct supervision cannot be overlooked in preventing behaviours. “When a child with FASD is not supervised, she can frequently get into trouble” (Edmonton and Area Fetal Alcohol Network, 2004). The problem is that we can become satisfied when we think they have shown us that they can do something independently and so we think that they do not need to be supervised. “It is the unreliability that fools many of us” and the reason for direct supervision all the time (Edmonton and Area Fetal Alcohol Network, 2004).

Supervision sets up people with FASD for success. Some level of supervision will always be required. “Supervision cannot be decreased in adolescence. Although a child may be chronologically fifteen, their mental/emotional functioning may be at a lower level.” (Graefe, 2006, p.83).

Increased structure, routine and modification to the environment will reduce the amount of emotional/behavioural outbursts and allow for the development of self-monitoring or self-regulating skills (Streissguth, 1997). Developing self-regulating skills assists the individuals affected to manage themselves better as adults.

Identified effective Ontario service providers actively supported the use of structure, routine and supervision in the intervention with people affected by FASD. Ninety-five per cent set up simple structures and stuck to them. One hundred per cent of the respondents provide structure and supervision for free time, generally use active supervision, develop regular set routines for various activities such as meal times and promote consistency. One hundred per cent adjust the environments to increase organization and structure. Fifty-nine per cent kept routines consistent from one environment to another. Lastly, one hundred per cent established set morning and evening routines.

Effective Communication Approaches

Early language development is often delayed in individuals with FASD. Dubovsky reports that as children and young adults these individuals tend to be very verbal but with little content. Receptive language is more impaired than expressive language. The client with FASD can talk a “good game” but is unable to process or use all that they hear. This is a greater problem when we consider that verbal reception is the basis of most of our interactions with people. Many situations rely on receptive language for successful outcomes. These situations include

- Parenting techniques
- Elementary and secondary education
- Child welfare
- Judicial system
- Treatment
 - Motivational interviewing
 - Cognitive behavioural therapy
 - Group therapy
 - Alcoholics Anonymous/Narcotics Anonymous Groups
- FASD awareness campaigns
(Dubovsky, 2008, p.9)

Understanding the emphasis on receptive language skills and a modified approach to communication with persons impacted by FASD is an essential element of effective practice.

Effective communication strategies with clients stem from respecting the individual and understanding the nature of FASD. Similar to all intellectual disabilities, respecting the individual with FASD in language always involves speaking about the person first rather than addressing his or her disability. Very few people wish to be defined by their

challenges, and individuals with FASD are no exception. In fact, a person with FASD is often especially sensitive to being identified with their diagnosis or disability.

Dubovsky is clear in his advice. Effective communication practices with an individual with FASD sound like “a child with FASD, not a FASD child, a mother with FASD not a FASD mom, or she has developmental delay, not she is developmentally delayed. Most professionals would never consider saying ‘a cancer person’ and yet we often fall into the trap of saying ‘a FASD person’ which is completely unacceptable” (Dubovsky, 2007, p. 5).

Person-first language is especially important when talking about a person with FASD, because many people with FASD have multiple diagnoses with multiple secondary disabilities. Focusing on these labels and problems rather than on the individual’s strengths can hinder the delicate self esteem of someone with FASD. Dubovsky notes the correct format as: “You are a person with strengths and abilities who has FASD, OCD [Obsessive Compulsive Disorder] and bi-polar disorder” (Dubovsky, 2007, p. 5).

In addition to person-first language, effective communication includes using clear language that is simple with step-by-step instructions. Many individuals with FASD develop a large vocabulary but are, nevertheless, still unable to comprehend what is said to them. Therefore, they appear to participate in the conversation but often do not follow through with what they said they were going to do because they really didn’t receive the message (Streissguth, 1997).

In order to maximize understanding, all staff/caregivers who deal with a client with FASD should perform the following (based on Edmonton and Area Fetal Alcohol Network, 2004):

- Use *repetitive*, simple, clear phrases that state what the individual is supposed to do
- Use as few words as possible
- Use concrete language (for example, instead of saying, “Go get ready and I’ll meet you at the door,” say “Get your coat and wallet and meet me at the door.”)
- Exaggerate body and facial language
- Avoid telling the client what not to do; state directions in the positive only
- Slow down and allow time for processing. Check for concrete understanding of instructions. (Just because the person can repeat the task back does not guarantee understanding. Asking the individual what the instructions mean versus what the instructions were will verify understanding.)

Individuals with FASD often have a difficult time with abstract concepts. Tone of voice, sarcasm and jokes fall under the category of abstract concepts and should be avoided. Individuals with FASD may not fully comprehend that a staff person is just fooling around or teasing and may become unnecessarily upset (Edmonton and Area Fetal Alcohol Network, 2004). Including humour in an approach requires additional efforts to explain and ensure understanding.

It is important to match the instructional language with the level of the person’s functioning. If the person is having a hard day and functioning like a young child, list off tasks one by one and repeat if needed. On a better day, less supervision may be required

(Edmonton and Area Fetal Alcohol Network, 2004). Unfortunately, part of having FASD means that depending on the day (or time of day), the individual may be functioning at different ages. Often the functional age is younger than the chronological age. Dan Dubovsky recommends that staff or caregivers ask themselves, “What age of development does this behaviour feel like?” (Dubovsky, 2007).

Diane Malbin (2002) agrees with Dubovsky and refers to this as developmental dysmaturity, where people with FASD frequently do not act their age. Malbin advises that, in general, caregivers and programs should “think younger” when working with clients with FASD. Developmental dysmaturity occurs when children do not learn about how they feel and how to deal with and/or regulate their good and bad feelings. The result is that older children can become “locked into” an immature way of expressing their feelings and aggression. Malbin suggests figuring out where the client is developmentally and responding at that level rather than responding at where he or she is chronologically (in terms of age).

Visual cues are a form of non-verbal communication and are equally important to consider. These cues can be used to communicate physical boundaries, rules, personal routines, schedules/routines, anger management plans, etc. Visual cues are concrete and allow the support person to use as few words as possible. Examples of visual cues are: taped lines on the floor to indicate boundaries; pictures of what the correct finished task looks like; calendars and *Post-It* notes for daily agendas; and pictures of shoes above where outdoor shoes should go when coming inside. Of particular importance is the mistaken notion that, at some point, individuals with FASD will no longer need visual supports. Adults need these supports as much as children and should always be provided for them (Edmonton and Area Fetal Alcohol Network, 2004).

Identified effective Ontario service providers unanimously supported many effective communication strategies. One hundred per cent of the respondents indicated that they do the following: use repetitive prompts and phrases, use as few words as possible, always tell clients what to do versus what not to do, use concrete language, provide time for processing verbal information and match their communication to the functioning level of the client. Ninety-five per cent made good use of eye contact, exaggerated their facial and body expressions and provided visual cues. Lastly, eighty-one per cent checked for concrete understanding.

Awareness of and Supports for Sensory Processing Disorders

Malbin describes people affected by FASD as having disorganized brains that may have difficulty prioritizing and filtering stimuli. “Normal” environments may be overstimulating and overwhelming. Many people affected by FASD seem to have sensory sensitivities to sight, sound, touch, smell or taste. Malbin describes a child who consistently yelled “Shut up!” to his mother whenever she talked while the car was moving. His mother was offended and felt he was rude. She had lectured him about manners, but with no results. She began to notice he would not yell at stoplights. She stopped talking while driving. When the child was asked what it was like when mom talked while driving, he responded, “I see everything mom, everything.” He was unable to tell her that her talking during the

drive was overwhelming to him. Initially his mother was offended, feeling his behaviour was rude and wanted to stop it. However, once she stopped her behaviour, observed his behaviour and asked how it felt, she understood and could teach him appropriate ways to meet his needs and hers (Malbin, 2002, p.59).

Malbin notes that behaviours are cues to think further and determine their causes rather than target them as the thing to change. Understanding the cause allows for different and more effective options to be utilized while still meeting the needs of both parties. Ask people to describe their experience in varying environments in order to identify their sensitivities (Malbin, 2002, p.59).

In order to provide effective services for individuals with FASD, caregivers and service providers have to assess, understand and address Sensory Processing Disorders. Sensory Processing Disorder (SPD), formerly known as Sensory Integration Disorder (SID), is a neurological disability in which the brain is unable to accurately process the information coming in from the senses. Individuals with FASD can often be overwhelmed with sensory information that completely takes over and makes it nearly impossible for them to attend to the task at hand. Symptoms include increased agitation, irritability or aggression. People affected can also be hyposensitive, experiencing such responses as decreased reaction to temperature. In addition, they may not complain of earaches, broken bones and may be unable to experience painful stimuli (FASD Interagency Workgroup, 2008, p.9).

In *The Out-of-Sync Child: Recognizing and Coping with Sensory Integration Disorder* (1998), Carol Kranowitz provides an expert analysis of SPDs and a handbook for dealing with children with SPDs. She notes that ordinarily, as a child grows older, he or she builds new skills upon the ones already acquired. However, for a person with information processing deficits, “growing older does not always mean getting better at many physical and intellectual tasks, because the basic foundation for efficiently organizing sensory information isn’t solid enough” (p.147).

She continues, “If growing older doesn’t help, what does? Early interventions. The most appropriate intervention for Sensory Integration Dysfunction is occupational therapy, which helps the child develop his nervous system” (p.147). She notes that prior to starting occupational therapy, the child will need a professional evaluation and diagnosis; he or she will also need an occupational therapist who is familiar with sensory processing (Kranowitz, 1998).

Kranowitz notes that early interventions by experienced and qualified occupational therapists can reduce the severity of SPDs in children with FASD, and thus modify the dysfunctional behaviour produced by overwhelming stimuli. Additionally, Kranowitz suggests documenting both positive and negative behaviour rigorously for several days, including day, time, the behaviour and the circumstances. This should be done until patterns of behaviour and inciting stimuli can be determined. This knowledge allows a caregiver or service provider to steer the client clear of inciting stimuli, determine effective calming mechanisms, ideally added to regular routine, and thus prevent dysfunctional behaviour (Kranowitz, 1998).

Although an occupational therapy assessment is preferred, some simple strategies can be implemented at no harm to the individual with FASD if the assessment is not immediately available. Malbin recommends the following:

- Tone down the environment to be less stimulating in terms of colour.
- Where possible, use blue and pale blue-greens, which are calming. Depending on the individual, the colour red may be too exciting.
- Turn shelves sideways so the frontal view of everything is not “in their face.”
- Limit the number of pictures on the walls. (No pictures at all may work well.)
- Eliminate annoying sounds, e.g., the hum of a fish tank, which can be bothersome.
- If you cannot calm the environment, consider having the individual with FASD use headphones and/or wear dark glasses.
- Have regular, predictable quiet times with no television or music, or allow the person to be calmed by his or her own music. Be aware that some people with FASD may be calmed by music that will really annoy you, the care provider!
- Consider a minimalist lifestyle and reduce the amount of furniture and knick-knacks. (Malbin, 2002)

Ory provides advice on “sensory overload” from David Gerry, an experienced caregiver and the Executive Director of the FASD Community Circle in Victoria, British Columbia. Gerry echoes many of Malbin’s ideas above when he suggests that the following are effective practices related to sensory overload in people with FASD:

- Reduce visual clutter and simplify environments.
- If a client seems overstimulated in one environment, try a different environment.
- Recognize that smells and sights can be hugely overstimulating and/or annoying even if they don’t bother you.
- If the client seems bothered, ask them what could be done to fix this room or setting—they will often be able to tell you (Ory, 2008, p. 204).

Identified effective Ontario service providers gave supports regarding the presence of Sensory Processing Disorders (SPDs). Almost all respondents (89%) attempted to secure an assessment to confirm the presence of SPD. One hundred per cent of the respondents reduced exposure to overwhelming environments, allowed for activities of deep pressure/intensity (shovelling, jumping or climbing) and minimized stimulation/busyness in the environment through heightened organization and order. Eighty four per cent reduced sound disruption. Fifty-six per cent of applicable respondents made use of neutral colours and chose natural lighting. A small number noted the importance of documentation and of journaling behaviours to remain sensitive to potential SPD.

Recommendations

Based on the results of this literature review, the foundation of effective practices for people impacted by FASD is early diagnosis as well as education and training on the effects of prenatal exposure to alcohol. Currently, neither is promoted nor readily available.

It is cost-effective to proactively address the issues of FASD. Evidence was presented at a national roundtable, "Development of a Canadian Model for Calculating the Economic Impact of FASD," on March 21–22, 2007. Data were presented on the cost-burden of FASD in Canada. Presentations were given by Jan Lutke ("Inconvenient Economics: What's the Real Cost of FASD Systems Interface?"), Brenda Stade ("Revised Estimate of the Cost Burden of Prenatal Exposure to Alcohol in Canada") and Brian Grant ("Measuring the Economic Impact of FASD in Canada: Criminal Justice Issues"). The adjusted costs for maintaining a child with FASD were found to be just over \$24,000 per child annually. Although the study was not designed at the population level, the data were extrapolated for a "very conservative" national FASD cost of nearly \$600 million. (A 2009 study by Stade et al. puts the total adjusted annual costs associated with FASD at the individual level at \$21,642 [95% CI, \$19,842; \$24,041]; the same study totals the cost of FASD annually to Canada of those from day of birth to 53 years old at \$5.3 billion [95% CI, \$4.12 billion; \$6.4 billion].) The data did not include costs for individuals in the judicial system (incarceration costs were reported as \$72,000 to \$150,000 per year, per person), the homeless, and children in institutions.

The question is whether to pay now to put the necessary systems and safety nets in place or to pay later, when the costs to society in all these areas will be much higher. It is extremely likely that the costs of paying later will be many times the cost to the system of paying now. It is a question of funded interdependence versus the "bottomless pit" of high-cost failure for both the system and the adult with FASD (Public Health Agency of Canada, 2007, p.12).

The following recommendations are considered first steps in developing the provincial capacity to better support families and persons affected by FASD.

1. The Ontario Government needs to assign a lead ministry to work with other ministries and create a provincial FASD strategy.
 - Currently, no ministry of the provincial government is formally responsible for FASD in Ontario. As a result, FASD has become an "orphan" issue. Without some ownership and support, movement towards any further meaningful timely change will not be possible. Given the prevalence of the disability and the impact of secondary disabilities on our communities, FASD must be considered a priority.
 - In addition to assigning a lead ministry, specific staff need to be assigned to the

FASD file and receive designated funding to propel their work.

- A provincial inter-ministerial and cross-sectoral FASD committee needs to be formed to create the provincial FASD strategy to address the needs of people affected within each sector. The group FIANO (FASD Intergovernmental Action Network of Ontario), currently operating, provides a model for inter-ministerial cooperation of this type; however, the network needs to be supported by a lead ministry.
- Ministries need to work with FASD ONE and parents/caregivers to develop this provincial strategy, to enhance existing programs and to strategize effective implementation. Additionally, dialogue and involvement with the Canadian Northwest Fetal Alcohol Spectrum Disorder Partnership (<http://www.cnfasdpartnership.ca/>) and the Atlantic Intergovernmental Fetal Alcohol Spectrum Disorder Partnership are strongly recommended. This collaboration would allow for the development of national standards pertaining to both diagnosis and service provision.

2. Increase the diagnostic capacity in the province of Ontario so that all regions have access to services.

- Expand OHIP codes to include assessments for the diagnosis of FASD.
- Promote diagnostic training to medical professionals already in practice across the province.
- Include detailed and current information on FASD in the curricula for physicians, psychologists, psychiatrists, social workers, nurses and all other related professionals.
- Set up and support diagnostic services across the province.
- Include questions on prenatal alcohol exposure in existing mandated pre-screening tools. Promote training on the use of these tools.
- Make funding for psychological, occupational therapy and speech therapy assessments readily accessible to the parents and caregivers of children affected by or suspected of having FASD. Improve the effectiveness of assessments and reduce misdiagnosis by supporting the training of psychologists.
- Prioritize psychological assessments, especially in the early years of childhood.

3. Prioritize the education, training and increased awareness of FASD throughout the province of Ontario.

- To reduce the incidence of FASD, begin a permanent awareness campaign on FASD.³
- Mandate that detailed and current information on FASD be included in the curricula for physicians, psychologists, psychiatrists, educators, social workers, nurses and all other related professionals.

³ See What We Have Learned: Key Canadian FASD Awareness Campaigns at <http://www.phac-aspc.gc.ca/publicat/fasd-ac-etcaf-cs/index-eng.php>

- Make funding available, province wide, in order to encourage all service provider executives to mandate the training and education on FASD for all staff who support affected individuals and families.
4. Policy makers, service providers, legislators and funders need to utilize and build on the current effective practices in the development of services for FASD.
- A response to the first three recommendations will, in turn, increase knowledge regarding FASD incidence in Ontario. Based on the confirmed prevalence of FASD, consultation with FASD ONE and the plan developed by the inter-ministerial and cross-sectoral committee, funding needs to be designated for the further development of support services for those affected across the province and across all sectors. These services must demonstrate the use of effective practices. In addition, any existing effective services for people affected by FASD need to be recognized and funded accordingly.

Conclusion

Much of what is known about effective interventions for people with FASD has been gained through the experiences of biological, adoptive and foster parents who are raising affected children, as well as through community workers, who have been meeting the challenges of FASD management one situation or crisis at a time. Effective supports include the following: an early diagnosis (preferably before the age of six); stable placement in a family that is supported with respite and trained to help the child manage behaviours; and placement in a school program that understands and provides supports for the primary disabilities of FASD (Public Health Agency of Canada, 2005). These supports address the foundation for effective intervention: early diagnosis and increased education and training to support people affected by FASD.

Early diagnosis, and increased education and training pave the road for success when they are used in conjunction with the remaining recommended approaches to effective service delivery. Once parents, service providers and the community understand an individual has FASD and learn how this disorder impacts his or her behaviours, a paradigm shift to a positive strength-based approach can take place. In turn, these support people will understand the person's needs and plan for lifelong interdependent supports, structure, routine, supervision, alternative communication approaches and an increased sensitivity or awareness of potential sensory processing issues. Lastly, parents, service providers and the community will come to understand the need for case management and community collaboration, across various sectors, to most effectively serve these often complex individuals.

In the absence of government-mandated directives related to FASD, parents, individual service providers, stakeholders and communities bear the responsibility to come together and develop appropriate support plans. This task is far from easy. Appropriate service planning requires education, the development of case management standards, shared

information as well as reconciling often competing mandates and demands of agencies charged with child safety, community safety and family preservation.

Communities can learn from successful models of community collaboration, such as the FASD Initiative in Barrie, Ontario. These models can assist individual communities to create guidelines, increase knowledge of FASD, develop standards for case management and resolve conflicts. The many FASD committees and coalitions that have developed across the province continue to strive toward this end.

In addition, communities that are informed about FASD can provide social supports. Dan Dubovsky, who is a great proponent of community-based social support for individuals with FASD, identifies the community in which a person with FASD lives as an ideal collaborator for the provision of effective services. "If communities recognize the issues that people with an FASD and their families experience they can provide much support to the person, the family and the provider systems." Perhaps best of all, communities that understand FASD can advocate for increased prevention and intervention if they are "onboard" (Dubovsky, 2007, p. 3).

Dubovsky advises agencies to look to the community and evaluate cultural and other factors in a community strength overview. Individuals with FASD can fit into a variety of existing community cultures. Who in the community understands FASD? Communities that understand FASD can advocate for people with the disability. Advocacy leads to increased prevention and intervention as well as mentors, coaches and others who can act as part of wraparound supports. After the strengths of a community are evaluated, effective programming can seek out meaningful, "permanent" strength-based roles in the community for older clients with FASD. It is essential that communities be educated and ready to support a person or people with FASD in order for this approach to work (Dubovsky, 2007).

In Ontario, the various ministries were unable to identify any service providers for people affected by FASD. The one exception was a program geared for the Aboriginal population. Only thirty effective service providers were identified through a provincial survey of parents and caregivers—not an exhaustive list of FASD-related service providers in Ontario, but one that served the study. However, those that were identified consistently supported the basic effective practices outlined in this paper. This is an impressive and remarkable accomplishment considering the lack of provincial governmental recognition for FASD and the many barriers to effective services this creates.

Accessibility to effective service delivery across the province of Ontario relies on a proactive response and an action plan from the provincial government. Adoption of the orphan issue of FASD is critical in the support and long-term success of the individuals and families affected by the disability.

[Please see authors' note on the following page.]

Authors' note (from page 6):

In cases involving persons where FASD is suspected (as yet undiagnosed) it is frequently necessary to get effective supports and strategies in place as quickly as possible to ensure stability and not wait for a diagnosis. Waiting for a diagnosis without implementing effective supports and strategies could jeopardize the safety of everybody involved and completely derail efforts to give the client some success and feelings of accomplishment on which to build in the future. It should also be remembered that FASD strategies will not hurt any client and will support most other neurobiological conditions quite effectively.

Getting a program in place that works for persons suspected of having FASD does not mean that an accurate diagnosis should not be pursued. When pursuing an assessment and diagnosis, one should not “think FASD first.” This practice works well for effective interventions and supports but categorically *does not* work in the diagnostic arena where diagnosticians need to be open to all possibilities and potential causes of the client's presentation.

Service providers should also remember that just because FASD strategies work well for the client it does not necessarily mean the client has FASD or only FASD. A complete assessment and diagnosis must be done after which the intervention strategies will be adjusted to reflect the new information gleaned from an accurate assessment and diagnosis. It is also important when “thinking FASD first” that this information be kept confidential until FASD is diagnostically confirmed.

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Additional Resources Suggested by Identified Ontario Service Providers

"Once Upon a Time: Therapeutic Stories that Teach and Heal" and "Once Upon a Time: Therapeutic Stories to Heal Abused Children (revised edition) by Nancy Davis PhD.

Saskatchewan FASD Tip Sheets www.skfasnetwork.ca

<http://www.skfasnetwork.ca/Network%20Resources%20&%20Materials.html>

<http://www.come-over.to/FAS/faslinks.htm> Best FASD Sites

Fetal Alcohol Spectrum Disorder, by Toronto FASD Coordinating Network 2008

<http://www.torontocas.ca/wp-content/uploads/2008/09/FASD.pdf>

Strategies Parents find Helpful in Raising Children Living with FASD, prepared by Czaee Rajwani. Toronto: St. Michael's Fetal Alcohol Spectrum Disorder Clinic, 2007.

<http://come-over.to/FAS/PDF/TorontoStrategiesParents.pdf>

FASlink Discussion Forum is an Internet mail list for individuals, families and professionals who work with FASD. This provides support and information 24/7. To join FASlink go to <http://listserv.rivernet.net/mailman/listinfo/fas-link>

Olderfas is a support group and discussion list for parents only. They welcome family members/parents/caregivers supporting for older teens with FASD who are transitioning to adulthood. Diagnosis is not required. To join go to

<http://groups.yahoo.com/group/Olderfas/>

Picture This: Life as a Parent of Children with FASD (podcast):

<http://citizenshift.org/picture-this>

Appendix A—Common characteristics of people diagnosed with FASD

Research shows that people with a diagnosis on the FASD spectrum can show any of the following characteristics. A minority of people have many of these characteristics and qualify for a diagnosis of FAS or pFAS. The majority (95%) of people have fewer characteristics and qualify for the diagnosis of ARND on the FASD spectrum. These represent the “invisible majority” of people who have FASD. All people with FASD are individuals. No two persons with FASD are exactly the same.

Characteristics at birth can include:	<ul style="list-style-type: none"> • Abnormally small head circumference • Underdeveloped or damaged brain – (fMRI detectable) • Low muscle tone • Less fatty tissue • Identifiable facial features (philtrum, palpebral fissures, upper lip) • Major organ malformations • Vision problems • Hearing problems, repeated ear & respiratory infections • Seizure disorder and/or Tremors • Infantile Irritability
Cognitive characteristics can include:	<ul style="list-style-type: none"> • Mild to moderate developmental delays • Speech and language disorders • Expressive and receptive language deficiencies • Mathematical deficiencies • Difficulty with abstraction and comprehension • Problems generalizing one situation to another • Poor attention\concentration skills • Memory deficits • Impaired judgment
Motor characteristics can include:	<ul style="list-style-type: none"> • Motor delays • Poor coordination/Clumsiness • Fine motor impairment • Poor core strength
Behavioural characteristics can include:	<ul style="list-style-type: none"> • Hyperactivity with or without Attention Deficit Disorder • Impulsivity • Lying • Stealing • Stubbornness & Oppositional behaviour
Psychosocial characteristics can include:	<ul style="list-style-type: none"> • Delayed socialization and communication skills • Show inability to consider consequences of actions • Inability to interpret social cues, sullenness • Lack of reciprocal friendships • Socially withdrawn • Mood lability • Display teasing or bullying behaviours • Periods of high anxiety and/or excessive unhappiness • Mental illness

(Adapted from: *Knowledge and attitudes of health professionals about fetal alcohol syndrome: Results of a national survey*. Public Health Agency of Canada, 2004, p. 25, Retrieved from the Internet on July 16, 2009.)

Appendix B—Responses from various Ministries regarding FASD supports

Ministry of Education

Special Education Policy
and Programs Branch
18th floor
900 Bay Street
Toronto ON M7A 1L2

Ministère de l'Éducation

Direction des politiques et des
programmes de l'éducation
de l'enfance en difficulté
18^e étage, 900, rue Bay
Toronto ON M7A 1L2



August 12, 2008

Ms. Nancy Hall
The Hamilton Task Force on FASD
447 Main Street East, Unit 201
Hamilton, ON L8N 1K1

Dear Ms. Hall:

Thank you for your letter to the Minister of Education dated May 16, 2008 regarding programs in the field of Fetal Alcohol Spectrum Disorder (FASD). I am pleased to respond on behalf of the Minister.

As you are aware, the Ministry of Education provides funding for special education in Ontario's publicly funded schools; however, school boards develop and provide special education programs and services based on local needs. This includes the provision of programs and services for students with FASD.

School boards develop special education programs that primarily consist of instruction and assessments that are different from those provided to the general student population. These may take the form of accommodations to the learning environment (e.g. specific teaching strategies, preferential seating, and adaptive technology) and/or an educational program that is modified from the Ontario curriculum. School boards also provide special education services that typically refer to supports such as assistance with instructional programming, personal care and behavioural management, and may involve additional human supports such as teachers' assistants. Each school board determines the range of special education programs and services that are required to meet the needs of its students with special education needs.

I suggest you contact school boards directly to inquire if they could share effective practices in the field of FASD with you. School boards profiles, including their contact information can be accessed at: < <http://esip.edu.gov.on.ca/english> >.

The government is committed to ensuring successful outcomes for students with special needs, including those with FASD. Thank you for writing.

Sincerely,

A handwritten signature in dark ink, appearing to read "Barry Finlay".

Barry Finlay
Director

**Ministry of Training,
Colleges and Universities**

Minister

Mowat Block
Queen's Park
Toronto ON M7A 1L2
Telephone (416) 326-1800
Facsimile (416) 326-1656

**Ministère de la Formation
et des Collèges et Universités**

Ministre

Édifice Mowat
Queen's Park
Toronto ON M7A 1L2
Téléphone (416) 326-1800
Télécopieur (416) 326-1656



September 12, 2008

Ms. Nancy Hall
Intervention and Support Working Group of
FASD Stakeholders for Ontario and
The Hamilton Task Force on FASD
nhall@cfshw.com

Dear Ms. Hall,

Thank you for your letter about services for individuals with Fetal Alcohol Spectrum Disorder (FASD). As Minister of Training, Colleges and Universities, I am pleased to respond.

I applaud you and your team for the important work that you are doing to help individuals and families affected by FASD.

The Ministry of Training, Colleges and Universities does not offer programs or services related to FASD. For information about Ontario programs please contact Anne Bowlby at the Ministry of Health and Long-Term Care.

The contact information is:

Ms. Anne Bowlby
Manager, Mental Health and Addictions
Health Program Policy and Standards Branch
Ministry of Health and Long-Term Care
9th Floor – 56 Wellesley Street
Toronto ON M7A 2J9
416-212-2877

Thank you again for writing. I wish you success in your research, and in your day to day work with people with FASD.

Sincerely,

A handwritten signature in black ink, appearing to be 'J. Milloy'.

John Milloy
Minister

**Ministry of Community
and Social Services**

Minister's Office

Hepburn Block
Queen's Park
Toronto ON M7A 1E9
Tel.: (416) 325-5225
Fax: (416) 325-3347

**Ministère des Services
sociaux et communautaires**

Bureau de la ministre

Édifice Hepburn
Queen's Park
Toronto (Ontario) M7A 1E9
Tél. : 416 325-5225
Télééc. : 416 325-3347



AUG 18 2008

Ms. Nancy Hall
Fetal Alcohol Spectrum Disorder
Stakeholders for Ontario
The Hamilton Task Force on
Fetal Alcohol Spectrum Disorder
c/o 201-447 Main Street East
Hamilton, Ontario
L8N 1K1

Dear Ms. Hall:

Thank you for your letter regarding services for individuals affected by prenatal alcohol exposure.

My ministry funds a number of services and supports for adults with a developmental disability through community agencies to enable them to live, work and participate in a wide range of activities within their communities, thereby improving the quality of their lives. As part of these contractual arrangements, agencies must comply with ministry legislation, policies and guidelines, including quality of care.

A “developmental disability” is defined in the current *Developmental Services Act* as “a condition of mental impairment, present or occurring during a person’s formative years, that is associated with limitations in adaptive behaviour”. This definition is used by service providers to determine whether a person is eligible to access ministry funded developmental services.

Services and supports funded by the ministry and delivered through community agencies include:

- in-home and out-of-home respite;
- specialized community supports which assist people with a developmental disability to remain in their community;
- community participation supports, including the Passport initiative, which provide people who have a developmental disability with exposure to a wide range of activities such as work, volunteer, leisure and recreation opportunities. Assistance with personal development is also provided so that individuals can achieve their goals for living as an adult in the community; and
- community living supports and residential services, which include supports to assist individuals to live independently, as well as 24-hour group living situations and family home arrangements.

.../cont'd

-2-

My ministry also administers the Special Services at Home (SSAH) program, which can help individuals with disabilities live at home with their families. This program is available to children and adults with a developmental disability, and children with a physical disability, who are residents of Ontario.

The SSAH program provides funding directly to families so that they can purchase services to provide personal development and relief support to a child or adult with a developmental disability or a child with a physical disability.

Strengthening supports for adults who have a developmental disability is at the heart of our government's plan for positive change in Ontario's developmental services system. In September 2004, we announced our plan to transform services for people who have a developmental disability to create an accessible, fair and sustainable system of community-based supports. As part of the transformation of developmental services, my ministry has worked with experts and stakeholders to clarify eligibility. The criteria to be met to access supports and services, including services for individuals with fetal alcohol exposure, have been set out in Bill 77: *Services for Persons with Developmental Disabilities Act, 2008*.

Bill 77 passed Second Reading on June 2, 2008 and was referred to the Standing Committee on Social Policy for further review. The Standing Committee on Social Policy held public hearings on Bill 77 in Toronto, London, Timmins and Ottawa on August 5, 6, 7, and 8, 2008. Once the committee completes its public hearings, it will study the bill further and present any amendments to the bill to the House to vote on during Third Reading. If passed, the proposed legislation would come into effect upon proclamation.

Our government will continue to work with individuals, their families and community agencies across the province to build a developmental services system that provides the right supports and helps foster community participation.

Once again, thank you for writing.

Sincerely,



Madeleine Meilleur
Minister

**Ministry of Community Safety
and Correctional Services**

Office of the Minister

25 Grosvenor Street
18th Floor
Toronto ON M7A 1Y6
Tel: 416-325-0408
Fax: 416-325-6067

**Ministère de la Sécurité communautaire
et des Services correctionnels**

Bureau du ministre

25, rue Grosvenor
18^e étage
Toronto ON M7A 1Y6
Tél.: 416-325-0408
Télééc.: 416-325-6067



CU08-02922

AUG 15 2008

Ms. Nancy Hall
Intervention and Support Working Group
of FASD Stakeholders for Ontario
The Hamilton Task Force on FASD
c/o 447 Main Street East, Unit 201
Hamilton ON L8N 1K1

Dear Ms. Hall:

Thank you for your correspondence requesting information on programs provided through the Ministry of Community Safety and Correctional Services (MCSCS) that identify and support the needs of those affected by prenatal alcohol exposure. I am pleased to respond.

The MCSCS is responsible for maintaining and operating provincial correctional institutions for adult offenders, 18 years and over, who are serving a sentence of up to two years less a day or who are awaiting criminal proceedings. The ministry also provides community supervision of persons on probation, conditional sentence or provincial parole. Responsibility for all children and youth programs and services now rests with the Ministry of Children and Youth Services. Therefore, I have forwarded a copy of your letter to the Honourable Deb Matthews, Minister of Children and Youth Services, for her consideration.

Although the MCSCS does not currently have programs and services which specifically target victims of Fetal Alcohol Spectrum Disorder (FASD), life skills and orientation core programs are developed in recognition of numerous cognitive deficits experienced by our offender population. As well, the classification process considers individual risks and needs in determining placement and programming. Community agencies are also engaged to provide specialized services and programs to offenders, where appropriate and available.

You may be interested to know that, in January 2007, the Ministry of Government Services' Ideas and Innovations Fund provided financial support to develop and deliver FASD training to Correctional Services staff. Peer trainers were taught the basic facilitation skills, content knowledge and background information necessary to deliver FASD training. The peer trainers subsequently delivered 46 sessions across Ontario, which provided new learning to 459 staff. FASD training is being incorporated into the basic correctional officer and probation and parole officer training.

.../2

Ms. Nancy Hall
Page two

In addition to dedicated FASD training, additional training about FASD is included in most of the core program training. This is to alert staff about the need to educate offenders about FASD, as well as to sensitize staff to the needs of any participants in the core programs who may be affected by FASD.

Should you require further information, you are welcome to contact Ms. Susan Cox, Manager (A), Offender Programs Unit, Strategic and Operational Initiatives Branch, MCSCS, 5-1780 King Street East, Kitchener, Ontario, N2G 2P1, cell (647) 883-5350.

I trust this information will assist you. Again, thank you for writing.

Sincerely,

A handwritten signature in black ink, appearing to read "Rick Bartolucci". The signature is fluid and cursive, with the first name "Rick" being more prominent than the last name "Bartolucci".

Rick Bartolucci, MPP, Sudbury
Minister

c: The Honourable Deb Matthews
Minister of Children and Youth Services

Ms. Susan Cox

**Ministry of Children
and Youth Services**

Minister's Office

56 Wellesley Street West
14th Floor
Toronto ON M5S 2S3
Tel.: (416) 212-7432
Fax: (416) 212-7431

**Ministère des Services
à l'enfance et à la jeunesse**

Bureau de la ministre

56, rue Wellesley Ouest
14^e étage
Toronto (Ontario) M5S 2S3
Tél. : 416 212-7432
Télec. : 416 212-7431



AUG 18 2008

Ms. Nancy Hall
FASD Stakeholders for Ontario and
The Hamilton Task Force on FASD
c/o 201-447 Main Street East
Hamilton, Ontario
L8N 1K1

Dear *Nancy* Ms. Hall:

Thank you for your letter regarding Fetal Alcohol Spectrum Disorder. I appreciate your commitment to the health and well-being of children and youth affected by prenatal alcohol exposure.

As you may know, Ontario has funded the Aboriginal Fetal Alcohol Spectrum Disorder and Child Nutrition Program as part of its Early Childhood Development Initiatives since 2001. This program provides \$4.4 million in funding for services related to fetal alcohol spectrum disorder and child nutrition through service contracts with 18 Aboriginal service providers and First Nations that deliver programming to 180 Aboriginal communities both on- and off-reserve land.

Marian Mlakar, Director in my ministry's Children and Youth at Risk Branch, has program responsibility for this work. She can be reached by e-mail at marian.mlakar@ontario.ca.

While our government has accomplished much in the past several years, there is more to be done. I would like to congratulate you for focusing on this important work and I welcome your input as we look for new and innovative ways to build a more accountable and sustainable system.

Sincerely,

Deb Matthews

Deb Matthews
Minister

c: Ms. Marian Mlakar, Director

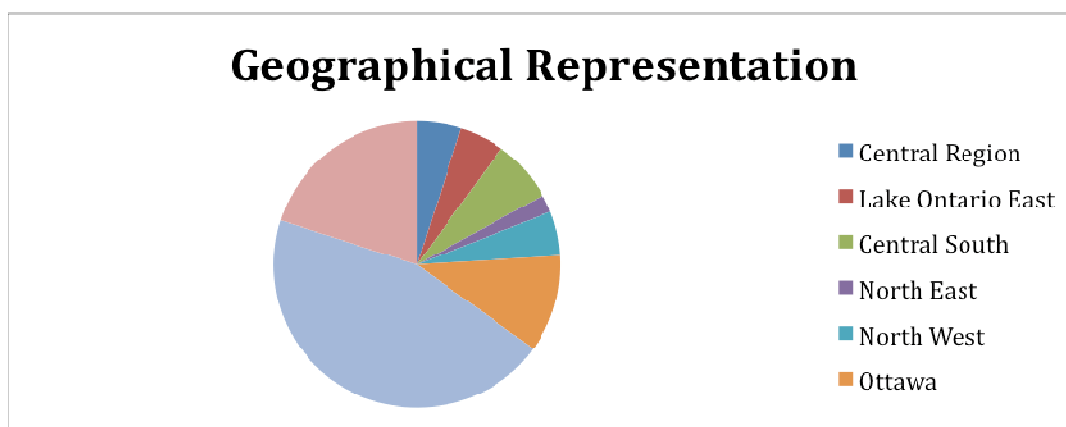
Appendix C—2008 Ontario Parent Survey of Effective FASD Practices: Results

1. Number of respondents

- 44 respondents in total
- Respondents provided information regarding 58 children
- 59% (26 respondents) identified effective service providers

2. Geographical representation of respondents

- 45% **South West** (Brant, Bruce, Chatham-Kent, Dufferin, Elgin, Essex, Grey, Haldimand, Hamilton-Wentworth, Huron, Lambton, Middlesex, Norfolk, Oxford, Perth, Waterloo, Welland, Wellington) (20 respondents)
- 20% **Toronto** (Durham, Halton, Peel, York) (9 respondents)
- 11% **Ottawa** (Grenville, Lanark, Ottawa-Carleton, Prescott-Russell, Stormont-Dundas, Glengarry) (5 respondents)
- 7% **Central South** (Haliburton, Muskoka, Renfrew, Simcoe) (3 respondents)
- 5% **North West** (Kenora, Rainy River, Thunder Bay) (2 respondents)
- 5% **Central Region** (Algoma, Manitoulin, Nipissing, Parry Sound and Sudbury) (2 respondents)
- 5% **Lake Ontario East** (Kawartha Lakes, Frontenac, Hastings, Leeds, Lennox-Addington, Northumberland, Peterborough, Prince Edward) (2 respondents)
- 2% **North East** (Cochrane, Timiskaming) (1 respondent)



3. Number of children per family affected by FASD

- 64% of respondents (28 people) indicated that they had one child affected by FASD.

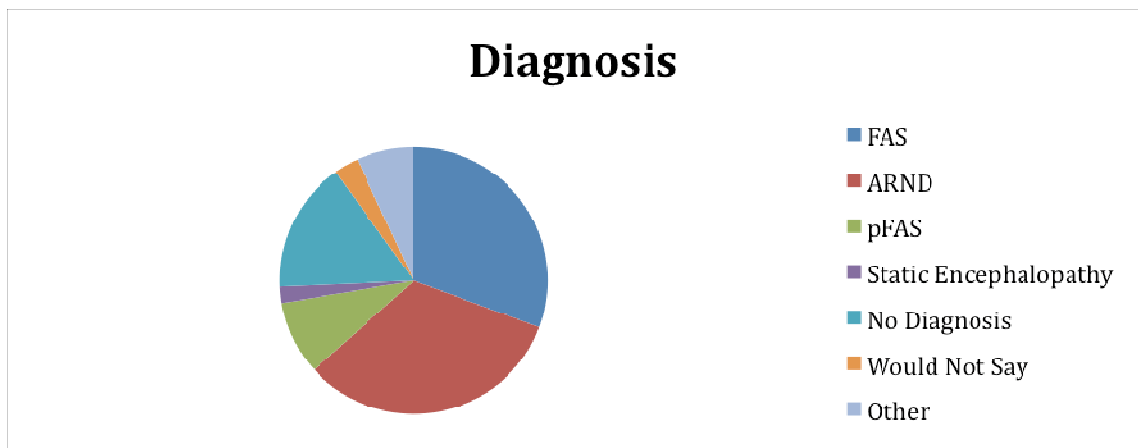
- 36% of respondents (16 people) reported having 2 or more children affected by FASD.

4. Age ranges indicated for families affected by FASD

- 21% were 0–6 years (12 children)
- 38% were 7–12 years (22 children)
- 19% were 13–17 years (11 children)
- 22% were 18+ years of age (13 children)

5. Diagnoses for families affected by FASD

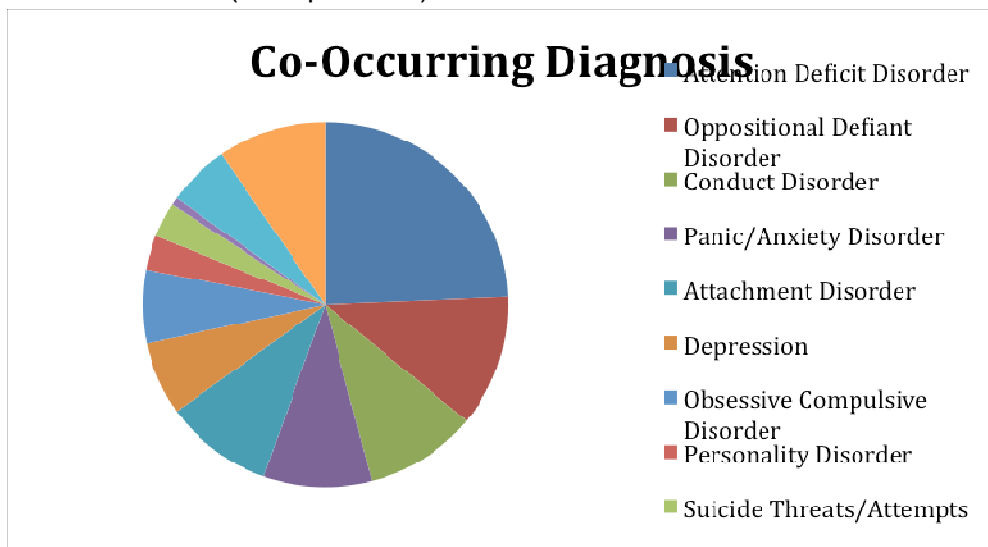
- 33% indicated that their child was diagnosed with **Alcohol Related Neurodevelopmental Disorder** (19 children)
- 31% indicated that their child was diagnosed with **Fetal Alcohol Syndrome** (18 children)
- 16% indicated that their child **did not have a diagnosis** (9 children)
- 9% indicated that their child was diagnosed with **Partial Fetal Alcohol Syndrome** (5 children)
- 4% indicated an '**Other**' diagnosis but FASD is **highly suspected** (4 children)
- 3% **preferred not to reveal** their child's diagnosis (2 children)
- 2% indicated that their child was diagnosed with **Static Encephalopathy** (1 child)



6. Co-occurring diagnoses for families affected by FASD

- Of the 44 people who indicated that they had children affected by FASD, 35 (80%) respondents indicated that their child had co-occurring diagnoses, sometimes multiple co-occurring diagnoses. In total, 168 responses were provided for 58 children.
 - 71% - attention deficit disorders (41 respondents)
 - 34% - oppositional defiant disorder (20 respondents)
 - 29% - conduct disorder (17 respondents)

- 28% - panic/anxiety disorder (16 respondents)
- 28% - attachment disorder (16 respondents)
- 19% - obsessive/compulsive disorder (11 respondents)
- 19% - depression (11 respondents)
- 9% - personality disorder (5 respondents)
- 9% - suicide threats/attempts (5 respondents)
- 2% - preferred not to say (1 respondent)
- 28% listed “other” co-occurring diagnoses which included (16 respondents)
 - 7% - Sensory processing disorder/sensory integration dysfunction (4 respondents)
 - 5%- Addiction problems (e.g. drugs, alcohol, sex) (3 respondents)
 - 3% - Tourette’s Syndrome (2 respondents)
 - 2% - Developmentally Challenged (1 respondent)
 - 2% - Epilepsy (1 respondent)
 - 2% - Noonan Syndrome (1 respondent)
 - 2% - Profoundly deaf (1 respondent)
 - 2% - CAPD (1 respondent)
 - 2% - PTSS (1 respondent)
 - 2% - LD (1 respondent)



7. Identified effective service providers for people affected by FASD in Ontario

- 30 Service Providers in total were identified by parents completing this survey (Please Note: Specific Staff are noted where identified in survey)
- 7 Service Providers were no longer available and 2 declined to participate as they felt they did not provide enough direct supports to families or people impacted by FASD
- 2 Service Providers declined formal identification in this document
- **Catholic Family Services, Hamilton**

- **Melanie McLeod, West Elgin Community Health Centre- Brake Shop, West Lorne**
- **Margot Staley, A Child First- The Livingstone Centre, Tillsonburg**
- **Elspeth Ross, FASD Group of Ottawa, Ottawa**
- **Bethesda, Vineland**
- **Sue Whaley, CAS Cornwall, Cornwall**
- **Charlene McNabb, Child and Family Counseling Centre, St. Thomas**
- **Niagara Youth and Children Services, St. Catharines**
- **Vera Lapczak, Blue Balloon, Toronto**
- **Helping Hands for FASD, Barrie, Ontario**
- **Patty Radford, Simcoe Community Services, Barrie**
- **Marsha Rennie, Kawartha Haliburton CAS, Peterborough**
- **Pam Beacock, Catulpa Community Support Services, Barrie**
- **Maureen Parkes, NorWest Community Health Services, Thunder Bay**
- **Chris Margetson, FASD Consultant, Guelph**
- **Treatment Foster Care Programs, Cobourg**
- **Sheila Burns, FASD Consultation and Training, Ajax**
- **Margarette Guerra, Brampton Caledon Community Living, Brampton**
- **Bethany Residence, Burlington**

8. Ages served by identified service providers

- **2 (10 %) provide Service to 0–18 years of Age**
- **10 (48 %) provide Service to Adults 18+ years of age**
- **9 (43 %) provide Service to All Ages**

9. Number of clients on caseload with an FASD diagnosis

- **<5 Clients- 11 (52%)**
- **>5 Clients- 3 (14%)**
- **>10 Clients- 0 (0 %)**
- **>15 Clients- 0 (0 %)**
- **>20 Clients- 6 (29%)**
- **Provides support and intervention through 1:1 parental education only- 1 (5 %)**

10. Number of clients on caseload suspected of having FASD

- **<5 Clients- 10 (48%)**
- **>5 Clients- 4 (19 %)**
- **>10 Clients-0 (0 %)**
- **>15 Clients-0 (0 %)**
- **>20 Clients- 6 (29%)**

- Provides support and intervention through 1:1 parental education only- **1 (5%)**

11. Number of agencies trained in ‘basic FASD’

- Yes- **11 (52%)**
- No- **5 (24%)**
- Not Applicable- **5 (24%)**

12. Number of agencies trained in ‘Strategies For Effective Intervention’

- Yes- **9 (43%)**
- No- **7 (33%)**
- Not Applicable- **5 (24%)**

13. Number of identified service providers who were self-taught

- **12 (57%)** identified service providers sought their own information on FASD

14. Geographical representation of identified Ontario service providers

- 48% **South West** (Brant, Bruce, Chatham-Kent, Dufferin, Elgin, Essex, Grey, Haldimand, Hamilton-Wentworth, Huron, Lambton, Middlesex, Norfolk, Oxford, Perth, Waterloo, Welland, Wellington) (10 Service providers)
- 19% **Toronto** (Durham, Halton, Peel, York) (4 Service Providers)
- 10% **Ottawa** (Grenville, Lanark, Ottawa-Carleton, Prescott-Russell, Stormont-Dundas, Glengarry) (2 Service Providers)
- 14% **Central South** (Haliburton, Muskoka, Renfrew, Simcoe) (3 Service Providers)
- 5% **North West** (Kenora, Rainy River, Thunder Bay) (1 Service Provider)
- 0% **Central Region** (Algoma, Manitoulin, Nipissing, Parry Sound and Sudbury) (0 Service Providers)
- 5% **Lake Ontario East** (Kawartha Lakes, Frontenac, Hastings, Leeds, Lennox-Addington, Northumberland, Peterborough, Prince Edward) (1 Service Provider)
- 0% **North East** (Cochrane, Timiskaming) (0 Service Providers)

Geographical Representation of Identified Service Providers



15. Sample comments from the parent survey respondents in Ontario regarding the lack of FASD support services available in local communities

- “I had difficulty completing this survey, there are so few services or support staff who even know what FASD is!”
- “I am ashamed that the government does not recognize the need for a full-time support person for families in this area. Every community or at least region should have a FAS/E specialists/coordinators.”
- I really think there is no help out there, there are no real solutions, the system seems to only frustrate the child but the parent as well. My son is now grown and recently charged with uttering threats, we tried through the court to get a mental health diversion. The courts ruled that ADHD and FASD is a childhood illness and has no bearing on a case involving a 20 year old.”

“I should like to note that there is nothing in our area for anyone to access. There is a huge gaping hole in respect to diagnosis, services, support, education etc. It is a huge problem. My only service as I noted is a very small support group that is currently struggling to survive at London CAS. This is very sad. My child has nothing to access at all—there is no camp; there is an appalling lack of information in schools. We in southwestern Ontario have fallen so far behind it is basically a crisis situation for many families here. We are in many cases adoptive and foster families doing the very best we can with very difficult behaviours and very hard children. We have no support—and what’s more than that we have no services. The schools here typically react to our children as behavioural and send them home to be home schooled—adding another stressor to the family. This is not okay. There is a

huge failure to address FASD in any way other than prevention. Dollars are spent educating about prevention, which is important, but when it comes to how we handle and support families who are raising children with FASD, there is absolutely nothing available. We are stressed, burned out and exhausted. We have no educators, mental health practitioners who are up to speed on this topic. We have too few doctors who even know what FASD is, much less are able to diagnose it. This is a crisis.”

- “We use weighted vests with some and heavy pressure exercises during body breaks. Recently, I made weighted quilts—top and bottom layers of flannelette with double natural cotton quilt bat between. Positive results—four of the boys demonstrated better/improved sleeping habits.”
- “I have more negative than positive feedback about how our system is inadequately handling our children. Our system FAILED my son and will fail his 5-year-old brother. I sit on the FASD Advisory Committee and our family will be the case study for Simcoe County.”
- “We need a funded support group such as the Autism Ontario group. There are no supports for FASD, no seminars or education programs for caregivers.”
- “The high maintenance required by these youngsters usually results in them being dropped or ignored.”
- “I have had my children to psychologists, special need teachers, board of education specialists, pediatric doctors, in the end, after many visits and miles, these people have one answer—put them on medication. They also diagnose them with learning disabilities; they offer no assistance other than more sessions which don’t work or only work for a short time.”

Appendix D

FASD Effective Practices Project:
Raw Data from Identified Service Providers

Record of 2008 Interview Responses

* Items in black represent strategy ideas from “Strategies Not Solutions”, Edmonton and Area Fetal Alcohol Network, 2004

* Items in red represent additional suggestions from the Identified Service Providers

Strategy	Used Y-N-N/A
IN GENERAL	
Individualized supports based on assessed strengths and weaknesses- strategies needed will depend on this	21-Y
Open language/education and 'no shame' approach to the topic of FASD	4-n 17-y
Use of regular routine/structure to activities and/or programming	20-y 1-na
Utilizes natural community supports to act as interdependent supports, wherever possible	19-y 1-na 1-n
Support play/ playfulness despite chronological age	18-y 2-na 1-n
Prioritizes family and/or support people involvement with all aspects of assessment and support training	18-y 3-n
Services are unlimited as long as client needs them OR file can be re-opened quickly should services be needed again (within agency mandate i.e., 18 and under only or Developmental Delay only)	19-y 1-n 1-na
Unacceptable behaviours are managed- does not terminate service	20-y 1-na
Service/treatment plans are client centred	16-y 1-n 4-na
Completes/Initiates a full assessment (Psych., OT, speech, medical)	17-y 2-n 2-na
Support person identified is calm, patient, empathetic and sees strengths first	21-y
Individual is free to opt out of program, responsibilities or routine if they choose to	10-y

Creates a mutually supportive environment between all clients- all supports all	3-y
All staff are prepared to support and can interchange roles when necessary	9-y
Educate person about FASD	14-y
Uses positive phrasing and acknowledges smallest achievements	19-y
FASD is only one aspect of the person, NOT the focus	3-y
Prioritizes respect for client and family	17-y
Stresses agency supported parent groups	5-y
Prioritizes knowledge of community resources and appropriate referrals for service supports- Uses collaboration	13-y
Trains and support parents to act as advocates	7-y
Encourages the use of regular charting and journaling of behaviours for client and caregiver to ensure recognition of progress and concretize what works and what doesn't for each individual	4-y
Provides parents with the support of a trained behaviour therapist who can assist in implementing the strategies more successfully	1-y
Encourages "No Shame, No Blame" as part of FASD education	1-y
ENVIRONMENTAL SUPPORTS	
Reduces distractions in work areas	1-n 17-y 3-na
Considers time of day before planned outings re. less busy times of day	2-n 17-y 2-na
Reduces exposure to environments too overwhelming for the individual	19-y 2-na

Is mindful of number of people dealing with the individual i.e. less is less confusing/overwhelming	18-y 2-na 1-n
Minimizing stimulation/busyness in the environment, heightened organization and order	20-y 1-na
Use of neutral colours	9-y 5-na 7-n
Limits amount of choice re. games, toys (2 or 3 at a time)	15-y 5-n 1-na
All similar items are stored together i.e. all story books together, all dolls together	7-na 12-y 2-n
Concretizes boundaries in the environment i.e. mats for reading time, divided areas	14-y 3-na 4-n
Labels individuals belongings	4-n 12-y 5-na
Uses pictorial/visual prompts (i.e. hot and cold taps, labeled cupboards, green/red dots on VCR buttons etc) and posted visual routines (washing, dressing, morning) as memory supports	5-n 16-y
Chooses to use natural light vs fluorescent lighting	5-na 7-n 9-y
Limit exposure to violence	14-y 6-na 1-n
Limited exposure to stimulating environments	1-y
'De-clutter' visual stimulation AS WELL AS auditory and smells	1-y
Provides external structure/scaffold which addresses weaknesses and allows child to function best	1-y
Does complete environmental assessment of triggers and makes alterations	1-y
SUPPORT/STRUCTURE/SUPERVISION	

Sets up logical simple structure and sticks to it	20-y 1-n
Frequents the same favorite places i.e. restaurants, parks	17-y 2-na 2-n
Meals involve a regular set routine	18-y 3-na
Provide structure/supervision to free time	19-y 2-na
Uses regular cues or repetitive verbal prompts in daily interactions	19-y 1-na 1-n
Teaches skills in all environments/understands failure to generalize	20-y 1-n
External supports are adjusted to improve success of the individual	21-y
Utilizes a full assessment to determine individual needs i.e. OT- sensory issues/learning strengths and weaknesses/ medical concerns and medication use	19-y 2-n
Has made a paradigm shift/ understands behaviours in terms of neurological brain damage	21-y
Uses a blend of alerting and calming activities within routine	1-y
Level of supervision is appropriate to developmental age and abilities not chronological age or stage	1-y
Use of cell phones and walkie talkies to broaden distance without supervision where possible, with check ins	1-y
HYPERSENSITIVE SUPPORTS	
Stands at front or back of lines	7-n 8-y 6-na
Uses sunglasses	7-n

	9-y 5-na
Tinted car windows	8-n 8-y 5-na
New clothing/bedding pre-washed before wearing	12-y 5-n 4-na
Active supervision/limited exposure to crowds	19-y 2-na
Reduce sound disruption	3-n 16-y 2-na
Child does not have to wear socks	1-y
Uses wireless thermometer (Male & Female formats) to show amount of clothing needed	1-y
Sensory diet is provided proactively throughout each day rather than when child is upset	1-y
HYPOSENSITIVE SUPPORTS	
Watch for lack of awareness of pain or cold	17-y 2-na 2-n
Provide oral stimulation i.e. gum, straw chewing	3-n 16-y 2-na
Brush hair before combing	10-n 7-y 4-na
Use weighted blankets and garments	6-n 11-y 4-na
Teaches personal boundaries	2-na 19-y
Allow for activities of deep pressure/intensity i.e. snow shovelling, jumping, climbing, yard work	2-na 19-y
Uses bear hugs*	10-y 8-n

	3-na
Uses/encourages fidget toys	2-n 18-y 1-na
At school, child is placed beside role model and close to teacher	1-y
Sit under large bean bag chair	2-y
*Self Squeezing is taught	1-y
Uses Routine Deep Muscle Stimulation	1-y
REDIRECTION AND RETEACHING-GUIDING BEHAVIOUR	
Understands punishment does not change behaviours	20-y 1-n
Maintains firm rules, no exceptions	15-y 6-n
Promotes consistency	21-y
Uses emotional rewards/values relationship	20-y 1-n
Avoids threats	21-y
Limit Choices and number of choices needed	21-y
Models steps to choice making i.e. pro and con list	16-y 5-n
Allow for time to process verbal information	21-y
Establish a safe place for venting physical aggression	19-y 2-n
Uses one clear consequence for behaviours vs natural or logical consequences	13-y 8-n
Walk away from tantrums until over	2-na 3-n

	16-y
Recognizes triggers for behavior and prevents	21-y
Uses immediate reinforcement	21-y
Posts the rules	3-na 15-y 3-n
Rules are simple and few	20-y 1-n
Avoids Time outs, physical punishments, taking things away, grounding, contracts, loss of privileges, threats, cancelling positive activity because of behavior	14-y 4-n* 3-na
Actively uses time ins	1-y
*Behaviour programs must be individualized- some punitive responses can be effective	3-y
Consequences must follow behaviour and be appropriate to the situation	1-y
Does not use any consequences	1-y
IMPULSE CONTROL	
Allows for active and rest times both (both physical and mental)	20-y 1-na
Teaches and provides positive physical activities i.e raking leaves, snow shoveling	20-y 1-na
Uses strategies such as gum or fidget toys	4-n 17-y
Provides additional down time	20-y 1-na
Acts preventatively if individual steals i.e. locks up valuables	17-y 3-na 1-n
Uses observer to monitor, redirect, negotiate and facilitate	1-y

Avoids focus on negative behavior- apologize, make amends and re-focus	1-y
Practice an appropriate response i.e. who to go to or strategy to use	1-y
Considers pharmacologic treatment when indicated	1-y
COMMUNICATION SUPPORTS	
Good use of eye contact	20-y 1-n
Use of exaggerated facial and body expressions	20-y 1-n
Use of visual cues	1-n 20-y
Group instructions are provided individually, using person's name	5-na 15-y 1-n
Use specific people's names vs they or them	19-y 2-n
Uses repetitive prompts and phrases	21-y
Uses as few words as possible	21-y
Always tells individual what to do vs what NOT to do	21-y
Uses concrete language	21-y
Gives directions all at once (if interrupted repeat again)	13-y 1-na 7-n
Provides time to process verbal information	21-y
All instructions are 'now'	5-n 15-y 1-na
Checks for concrete understanding	17-y 4-n

Does not interrupt individual while they are speaking	19-y 2-n
Frames questions in terms of response wanted i.e. Susie where is Mr. Smith? vs. Have you seen Mr. Smith?	4-n 14-y 3-na
Matches level of communication with the functioning of the individual	21-y
Supports understanding of humour	20-y 1-n
Uses sign language	3-na 8-n 10-y
Has child squeeze something soft in their right hand while communicating	3-na 12-n 6-y
Uses 'talking sticks' (or the like) to demonstrate conversation turns	2-na 10-n 9-y
Uses 'your words are bumping into mine' to concretize interrupting	2-na 14-n 5-y
Uses a lot of humour	1-y
Speaks quietly to set tone	1-y
Accommodates based on assessed verbal and visual skills	1-y
Is aware that disruptive behavior can serve a communication function and assesses for this	1-y
Emphasized work on turn taking, eye contact, pretend play and reciprocal eye gaze	1-y
TIME	
Uses steady routine to emphasize the sequence and structure of time	21-y
Teaches time through associated activities i.e. measured by length of any given activity	18-y 2-na 1-n

Uses the same words when talking about time consistently i.e. fifteen minutes after ten each time vs. quarter after ten sometimes	4-na 5-n 12-y
Uses simplified face clocks to emphasize the hour an activity starts and ends (clock modified with less numbers)	6-na 5-n 10-y
Uses both face and digital side by side to allow for comparison	6-na 8-n 7-y
Concretizes the passage of time i.e. removes links of a chain on regular intervals to show time passing, uses hour glass or specialized clocks *	3-na 7-n 11-y
Uses digital watches with alarms as prompts for memory regarding routine	5-na 10-y 6-n
Supports individual to make appointments on time	5-na 14-y 2-n
Uses colour coded system in day timer to support older individuals to keep track of things that occur over larger periods of time i.e. paying rent, irregular appointments with dentist, doctor etc.	8-na 5-n 8-y
*Concrete passage of time also demonstrated with timers, veggie steamers with timers, crock pots, bread makers, recorders with displayed time, phones with time/minute displays	1-y
'X' off calendar days	2-y
Schedules short sessions, allowing client to choose if they want to continue or not	1-y
MONEY	
Understands life long support is needed	19-y 1-n 1-na
Money is distributed in smaller payments vs. monthly amounts	15-y 6-na
Supervises spending and praises good spending decisions	16-y 1-n 4-na

Teaches how to find a deal or bargain	6-na 14-y 1-n
Supports a joint account to allow for direct payments	3-n 9-na 9-y
Teaches spending in each likely location i.e. grocery store, Laundromat, department store	8-na 11-y 2-n
Uses routine to teach grocery shopping i.e. same store, same order	13-y 7-na 1-n
Teaches value of money through product and price associations (uses real money and products to teach)	6-na 14-y 1-n
Monitor and distribute cigarettes based on agreed budget	1-y
Encourages earning concrete items (money/tokens) for effort to normalize and support problem solving regarding how to get needs met	1-y
Providing a budget for collaborative group activity 'theme dinners' work well and encourage use of creativity (includes meal planning, shopping, preparation, theme decorations, clothing, music etc.)	1-y
OWNERSHIP	
Calmly points out if individual has things belonging to others and then returns item (removes if owner unknown)	14-y 5-na 2-n
Watches for new and unexplained acquisitions	16-y 5-na
Assigns a colour coding system or labeling to indicate who owns what	6-n 11-y 4-na
Valuable items are kept locked up	16-y 5-na
Asks 'how' and 'where' to allow for return of items NOT 'why?' (refrains from blame)	16-y 3-na 2-n

Uses pants without pockets for shopping	9-n 5-y 7-na
Teaches and reinforces understanding of borrowing	2-na 4-n 15-y
No borrowing allowed	2-y
Supports families and clients to set boundaries re. personal space and ownership within the home	1-y
Use of hands in pocket when shopping if client is adamant about wearing pants with pockets- giving opportunity for choice whenever possible	1-y
STORY TELLING	
Avoids asking redundant questions i.e. Are you sure that is what happened? Or ones you know the answer to	17-y 3-n 1-na
Provides positive opportunities for story telling to help distinguish between lying and story telling	16-y 4-n 1-na
Promotes the use of drawing stories in sequence of events	7-n 3-na 11-y
Does not punish lies	16-y 3-n 2-na
Listens attentively, clarifies stories	21-y
Uses therapeutic stories during care and at home to reinforce understanding and generalization	1-y
Provides insight to teachers/parents regarding what story telling is for and how to respond	1-y
Uses modeling and interpretation to support story telling	1-y
CALMING TECHNIQUES	

Stays calm during outbursts	21-y
Avoids/anticipates overwhelming situations	21-y
Does not touch armpits	10-n 4-y 7-na
Has a comfy corner set up	17-y 3-n 1-na
Wraps child in a blanket to reduce anxiety	5-na 10-y 6-n
Teaches self regulation and stress reducing techniques	21-y
Uses back rubs	7-n 11-y 3-na
Uses preventative foot rubs	11-n 7-y 3-na
Uses oral stimulation to calm i.e. crunchy foods*	9-n 11-y 1-na
Uses the game 'foot wars' as a stress reducer	14-n 4-y 3-na
Uses a thinking chair with timed intervals for calming	11-n 9-y 1-na
*Uses oral stimulation to calm i.e. making of tea AS WELL AS a set routine for the tea time and preparation process	1-y
Provides space and quiet	1-y
Uses 'Time Away' vs time outs	1-y
FEELINGS AND EMOTIONS	
Teaches emotions in concrete ways	2-n

	19-y
Uses emotional 'check-ins'	5-n 16-y
Connects physical response to stress/upset to feelings	1-n 20-y
Creates feeling dictionary with individual	10-n 10-y 1-na
Clearly labels all emotions and then uses associated slang i.e. angry and then use 'pissed off'	9-n 12-y
Teaches appropriate response to identified feelings i.e. tired- lay down	18-y 2-na 1-n
Teaches the emotions of others (doesn't assume transfer of knowledge)	20-y 1-na
Treats each day as new	20-y 1-n
Model labeling own emotions and strategies to calm down	1-y
Social Stories	1-y
Uses coloured emotion charts that are matched to situations	1-y
Encourages a diary to identify emotions/moods and contributing factors	1-y
Use of 'feeling faces chart' for emotion identity and journaling feelings	1-y
TRANSITIONS	
Uses routines to anchor time and place i.e. same parking spots, store bags in same place	18-y 2-na 1-n
Uses role modeling to encourage transition i.e. put coat on and say see I am ready	18-y 1-n 2-na
Uses a timer or other methods to provide transition warnings	17-y 3-n

	1-na
Uses rehearsal to teach appropriate response to transition i.e. if child has outburst, practice alternate response repeatedly	3-n 16-y 2-na
Uses books or photo albums to prepare for transition i.e. moves, trips	14-y 3-na 4-n
Keeps routines the same from one environment to another i.e. same seat, same colour coding, arrange furniture in similar ways	7-n 10-y 4-na
If travelling, uses same hotels when possible	5-n 6-y 10-na
Prepares for special holidays or anniversaries in advance	18-y 3-na
Special event decorating and take down happens slowly to allow for easier transition	5-n 10-y 6-na
Makes routine changes/transitions known, using open communication and planning/practice for how to handle it	1-y
Schedules simplified by breaking down into morning and afternoon binders and applying colour coding	1-y
Uses picture stories to provide transition warnings	1-y
PERSEVERATION	
Uses prevention to avoid perseveration/problem behavior	18-y 2-n 1-na
Considers reason for perseveration and adjust expectations for the next task to reduce anxiety	18-y 1-n 2-na
Watches for patterns of perseveration and interrupts	19-y 1-na 1-n
Creates routine to ease with transition i.e. uses colour coding to connect clothing choices to calendar days to support changing clothes from day to day	5-n 12-y

	4-na
Uses re-direction	2-y
Takes time to identify triggers for behavior first	1-y
TRANSITIONING FROM CHILDHOOD TO ADULTHOOD	
Does not expect independence but positive interdependence	15-y 6-na
Develops a transition team for individual	2-n 7-na 12-y
Assesses life skill/training needs	16-y 5-na
Assesses vocational strengths and abilities	1-n 5-na 15-y
Develops a support team for interdependent living	13-y 8-na
Considers all aspects of the individual i.e. health, mental health, spirituality, vocational, social etc.	16-y 5-na
Planning is done in advance and includes family doctor	1-y
Application and regular reporting to ODSP must be done by parent/caregiver or service provider	1-y
Supports parents/caregivers to investigate estate planning, wills, trusts, guardianship and power of attorney	1-y
Ensure parent/caregiver has permission to speak with doctors, social workers and other professionals	1-y
CRIMINAL JUSTICE SYSTEM INVOLVEMENT	
Ensures all involved are aware of the disability as soon as possible in the process	15-y 5-na 1-n

Ensures external supports are aware of the risk for criminal involvement	14-y 6-na 1-n
Provides identification for the individual to use should they get arrested	3-n 7-na 11-y
Supports supervised social interactions and activities	14-y 7-na
Advocates for shorter more frequent interviews	10-na 10-y 1-n
Advocates for routine appointments	11-na 10-y
Ensures all orders are provided in writing and verbally to both the individual and the primary support team	11-na 10-y
Supports specific court instructions to successful completion	9-na 12-y
Avoids open ended and why questions	10-na 11-y
Ensures individual understands probation orders (set boundaries and schedule)	1-y
Advocates with probation to reduce breaches and increase support strategies for judges and probation officers	1-y
Age Specific Strategies	
FEEDING - Babies	
Prepares foods with neutral flavor, heat and texture	10-na 9-y 2-n
Holds infant upright while feeding	10-na 8-y 3-n
Feeds baby slowly and burps often	10-na

	9-y 2-n
Provides smaller, more frequent meals	9-na 9-y 3-n
Feeds baby as soon as signs of hunger are shown	10-na 9-y 2-n
Uses consistent bottles, nipples, cloth and bibs	11-na 9-y 1-n
Reduces external distractions	10-na 11-y
Gradually introduces new foods	11-na 10-y
Watches for sensory responses	12-na 9-y
Baby on feeding tube- developed routine and provided oral stimulation to develop sense of hunger	1-y
FEEDING - Children	
Uses routine to lead into meals i.e. exercise before meals each time	3-n 15-y 3-na
Food is not used as reward or punishment	18-y 3-na
Meals are provided same times each day, 3 per day	14-y 3-n 4-na
Provides repetitive menus matching days of the week i.e. chicken on Mondays	10-n 7-y 4-na
Supports consistent meal time rules	18-y 3-na
Provides meal in short time frames to reduce distraction	6-n 12-y 3-na
Avoids meal time interruptions/distractions	17-y

	3-na 1-n
Provides regular scheduled snacks	16-y 4-na 1-n
Provides a consistent seat for the individual	15-y 4-na 2-n
Uses stools if the child's feet do not touch the floor	6-na 6-n 9-y
Uses exercise balls as chairs when needed to increase attention	4-na 8-n 9-y
Allows standing at the table	5-na 7-n 9-y
Uses placemats to outline individual boundaries	4-na 14-y 3-n
Uses tennis balls on chair legs to reduce noise	5-na 7-n 9-y
Allows individual to eat early if people at table are disruptive to them	5-na 3-n 13-y
Allows for breaks during meals	5-na 2-n 14-y
Portions are controlled	15-y 4-na 2-n
Uses plates with separations	5-na 7-n 9-y
Puts food right on plate to reduce choice making	4-na 12-y 5-n
Experiments with food preferences	16-y 3-na 2-n

Reminds individual to chew and swallow	5-na 15-y 1-n
Considers individual needs i.e. specialized spoons to increase independence, pre cut meat when needed	4-na 2-n 15-y
Desserts are not available until after meal	14-y 3-na 4-n
Provides oral/gum stimulation to strengthen muscles	1-y
Encourages families to use drive thru and eat at the park vs eating in a restaurant	1-y
Uses felt bottoms or carpet pieces on bottom of chair legs to reduce noise	1-y
FEEDING - Adolescents	
Supervises food prep and clean up	7-na 13-y 1-n
Utilizes successful strategies from childhood	7-na 11-y 3-n
Provides practice support to follow package directions	6-na 13-y 2-n
Provides practice support using a microwave	6-na 14-y 1-n
Does not use metallic wrap in the kitchen	8-na 7-y 6-n
Supervises food consumption when needed	6-na 13-y 2-n
Considers external support i.e. meal on wheels	10-na 8-y 3-n
SELF CARE - Babies	

Uses same environmental conditions for all diaper changing i.e. lighting, temperature, diaper brand and location	11-na 8-y 2-n
Uses warm cloths on baby's bottom to reduce cold effects once dirty diaper is removed	10-na 10-y 1-n
Keeps diaper wipes where they will stay warm	11-na 8-y 2-n
Changes diapers more often than normal	10-na 10-y 1-n
Uses mild detergents	10-na 10-y 1-n
Reduces external noises and crowds during change times	10-na 10-y 1-n
Massage with scented body lotion (soft tickling or firm rubs depending on child needs)	1-y
SELF CARE - Children	
Uses posted routines with tasks broken down into steps	5-na 15-y 1-n
Demonstrates how to do each task	5-na 16-y
Makes routines part of regular schedule	5-na 15-y 1-n
Uses vanilla scents to reduce anxiety*	5-na 10-n 6-y
Practices and demonstrates shaving skills	8-na 6-y 7-n
*Not restricted to vanilla, if sensory permits	
SELF CARE - Adolescents	
Does not assume routines are mastered...checks in to make sure	17-y

	4-na
Uses posted checklists for morning and evening routines	5-n 5-na 11-y
Uses calendar to prompt and warn for upcoming menstrual cycles	9-na 9-y 3-n
Demonstrates and practices use of menstrual products	9-na 11-y 1-n
Teaches and practices the use of birth control	8-na 12-y 1-n
Uses videos to teach personal hygiene	7-n 6-na 8-y
Develops and supports daily and weekly routines for shopping, cleaning and cooking	12-y 5-na 4-n
Has posted pictures/instructions on household appliances	5-n 5-na 11-y
Uses Public Health to provide in-services to staff and clients	1-y
Ensures hygiene is part of the regular routine/schedule	1-y
TRANSPORTATION – Younger Children	
Uses seat belts that the child cannot undo	10-na 9-y 2-n
Wraps cloth around seat belt to increase comfort	9-na 4-n 8-y
Uses soothing music or sing along nursery rhymes	1-y
Uses window blinds	1-y
TRANSPORTATION – Older Children and Adolescents	

Provides space for the individual in the vehicle i.e. uses front seat or no one beside him in back	5-na 12-y 4-n
Uses games to keep children occupied	5-na 14-y 2-n
Uses headphones and relaxation strategies	6-na 14-y 1-n
Provides an 'Option Card' for individual to carry in case something goes wrong i.e. what to do if you miss bus	7-na 10-y 4-n
Provides bus tickets...not money for bus	7-na 12-y 2-n
Ensures individual is picked up at destination	7-na 14-y
Use of colour coded city bus route maps	1-y
Considers the possibility of car sickness (shown either through nausea or anxiety) and medicates as needed	1-y
RELATIONSHIPS AND SEXUALITY – Younger Children	
Uses constant supervision to eliminate the chance of abuse	5-na 16-y
Teaches and re-teaches personal boundaries	4-na 17-y
Teaches about strangers in a concrete way and in the context where they are encountered	6-na 15-y
If child is a runner, teaches a designated safe spot to run to when upset *or person to call	8-na 11-y 2-n
Teaches private bodies vs. private parts	5-na 15-y 1-n
Teaches proper names of body parts	5-na

	15-y 1-n
Reinforces physical boundaries by teaching one arm's length away from everyone else	4-na 15-y 2-n
Acts as a role model for appropriate social interaction	4-na 17-y
Uses social skill development to teach how to make and keep friends	4-na 17-y
Uses hoola hoops on straps to concretize personal space	1-y
Teaches good and bad touches	1-y
Teaches 'keep no secrets'-won't be in trouble if they tell	1-y
RELATIONSHIPS AND SEXUALITY – Older Children and Adolescents	
Uses high levels of supervision on outings and activities	5-na 16-y
Uses chairs with arms to delineate personal space	7-na 8-y 6-n
Provides cues for boundaries i.e. masking tape on floor or furniture	6-na 8-y 7-n
Includes personal space in house rules i.e. Everyone must be an arm's length away	6-na 12-y 3-n
Arranges for friendships or mentors with peers who are responsible, understanding and patient	4-na 15-y 2-n
Teaches about good friendships and expectations	4-na 17-y
Educates people around the individual on FASD	4-na 16-y 1-n
Provides safe activity options (focuses on what the person CAN do vs. what they cannot)	4-na 16-y 1-n

Speaks openly and willingly about menstruation	7-na 12-y 2-n
Teaches strategies for managing menstrual cramps	9-na 12-y
Keeps books/resources on sexuality available	4-na 5-n 12-y
Gives regular lessons on sex education *short intervals	4-na 5-n 12-y
Provides social teaching and scripting for dealing with sexual situations	5-na 4-n 12-y
Promotes the use of longer acting birth control methods vs. the pill	8-na 10-y 3-n
Uses concrete methods to teach 'consent'	1-y
Prioritizes street safety	1-y
Discourages early dating	1-y
Reviews how to manage break ups	1-y
SELF HARMING – Young Children	
Constant supervision	5-na 16-y
Teaches ways to release the 'mad' that does not include self harm	5-na 2-n 14-y
Teaches safe ways to release frustration	4-na 1-n 16-y
Consults with doctor/psychiatrist	1-y
Determine Causes	1-y

Uses re-direction	1-y
SELF HARMING – Older Children and Adolescents	
Staff or individual understands/has knowledge in suicide prevention	6-na 14-y 1-n
Staff removes articles that could be used for self harm from individual's room	7-na 13-y 1-n
Staff checks for tissue or towels with blood to determine frequency/extent of behavior	8-na 9-y 4-n
Does not ask to see wounds*	9-na 6-n 6-y
Promotes the use of a diary with dated entries	5-na 4-n 12-y
Reduces the number of triggers in environment i.e. pictures of deceased people, unrepaired damage from a previous tantrum	7-na 4-n 10-y
Monitors computer use to ensure individual is not interacting with strangers regarding suicide or self mutilation	7-na 11-y 3-n
Ensures the individual always feel home is a safe place to go	5-na 15-y 1-n
*Treat cuts (checking for infection and severity) while downplaying self harming behavior-focus on feelings	4-n
Determine Causes	1-y
Uses re-direction	1-y
PLAYTIME	
Uses a lap blanket for TV watching/playing games	5-na 11-y 5-n

Provides limited options i.e. two items to play with- nothing else in sight	5-na 12-y 4-n
Teaches turn taking	3-na 18-y
Uses concrete prompts to demonstrate beginning and end of play time i.e. timer	4-na 15-y 2-n
Labels toys so individual understand who owns what	5-na 11-y 5-n
Uses visible boundaries in play area i.e. masking tape to mark the area	3-na 14-y 4-n
Plans social outings in advance and teaches about expectations in advance	3-na 17-y 1-n
Uses a routine to ensure clean up	2-na 17-y 2-n
Provides play to allow for sensory exploration	2-na 18-y 1-n
Provides play that works core body muscles i.e. tug of war, especially if individual is upset	2-na 18-y 1-n
Uses distraction to avoid outbursts	2-na 19-y
Develops/encourages activities to last a lifetime i.e. working out	1-y
Acts preventatively regarding difficulties with transition to avoid initiating activities that will increase stressors regarding time needed to complete or difficulty ending activity from perseverative behaviours	1-y
Colour coded and separate boxes for toys	1-y
Use of specific activity areas i.e. painting centre, table/cut and paste centre, reading area	1-y
Uses playing on a large therapy ball to develop core body muscles	1-y

SLEEP/WAKE TIME	
Minimizes stimulation in bedroom	18-y 3-na
Establishes set morning and night routines	18-y 3-na
Ensures individual uses same bed/room each night - established routine	18-y 3-na
Limits number of toys or books in bed - only one or none	14-y 4-n 3-na
Uses small lamp vs. nightlights	13-y 4-n 4-na
Includes bathing in night time routine	18-y 3-na
Considers the use of melatonin to reduce sleep disturbances	6-n 12-y 3-na
Uses fleece throws to increase comfort	6-n 12-y 3-na
Rocks infants up and down vs. side to side	9-na 11-y 1-n
Babies are wrapped tight or loosely depending on individual needs	9-na 12-y
Uses cribs for as long as possible	9-na 10-y 2-n
Uses a rocking or swinging crib	9-na 11-y 1-n
Bedding meets individual needs i.e. some prefer a heavy blanket or same blanket or comforter each night	4-na 16-y 1-n
Establishes rituals for saying good night	4-na 16-y 1-n

Uses 'slow down' activities between dinner and bedtime	16-y 3-na 2-n
Provides a light snack before bed	3-n 15-y 3-na
Uses ticking clock in bed with infant or Mozart/Bach's calming rhythms	6-na 10-y 5-n
Teaches what to do when individual cannot sleep	4-n 14-y 3-na
Residence is child proofed for night wandering i.e. alarms/bells on doors and windows	5-na 3-n 13-y
Wakes individual at the same time and in the same way each day	2-n 16-y 3-na
Considers a sleep disorder assessment as needed	1-y
Avoids stimulating activities or difficult discussions before bed	1-y
Soft Hair brushing	1-y
Use a Soother, if appropriate	1-y
CLOTHING	
Removes all clothing tags	14-y 2-na 5-n
Washes all new clothing repeatedly before wearing	13-y 6-n 2-na
Staff considers clothing they choose i.e. simple soft colours or no patterns	4-na 8-n 9-y
Teaches dressing in the same way each day i.e. using a left to right, bottom to top approach	5-na 5-n 11-y
Avoids fabrics that exert pressure i.e. avoid turtlenecks and denim	5-na

	12-y 4-n
Uses curtain weights in hems	8-y 9-n 4-na
Uses Velcro when needed	13-y 4-na 4-n
Teaches buttoning clothes bottom to top	6-na 5-n 10-y
Rotates non-seasonal clothing out of bedroom until needed	15-y 3-na 3-n
Uses open shelving for clothing storage if necessary	13-y 4-na 4-n
Uses visual prompts of hand drawn thermometers inside window (with real one outside)- when it matches it shows when warmer clothing is needed	5-na 8-n 8-y
Uses visual prompts for dressing in warm outdoor clothing	15-y 3-na 3-n
Establishes a place for everything so individual knows where everything goes	18-y 3-na
Uses rules about putting all dirty clothes in hamper each day	17-y 2-na 2-n
Uses routine to set out clothing for next day, in advance	5-n 14-y 2-na
Allows the use of hoodies for anxiety reduction	5-n 14-y 2-na
Uses 'Zip Laces' as an option for velcro	1-y
Lays out PJs and removes day clothing for laundering each night to avoid wearing clothes again and again	1-y

RECREATION	
Teaches use of swings/slide when park is not busy	5-na 4-n 12-y
Encourages sensory recreation activities i.e. picking up marbles with toes, swinging arms like windmills	2-na 4-n 15-y
Tapes metal nut to pencil or pen	4-na 8-y 9-n
Uses thicker crayons	4-na 11-y 6-n
Uses a binder taped to the table to assist with drawing	4-na 7-y 10-n
Plans for regular recreation and supports participation	2-na 19-y
Discourages recreation linked to aggression i.e. martial arts	3-na 12-y 6-n
Encourages interaction with animals	1-na 19-y 1-n
Plans birthday parties each year with the same repetitive activities to reduce anxiety	4-na 11-y 6-n
Supervises attendance at all parties	4-na 14-y 3-n
Teaches use of equipment as needed and turn taking (particularly for older children utilizing public recreational facilities)	1-y
Plans parties with family only or low numbers attending	1-y
Purchases heavier, thicker, weighted pens and pencils	1-y
Encourages parents/caregivers to choose strength based activities and only share information about the person's special needs with program staff, if absolutely necessary	1-y

Encourages parent/caregiver to look for appropriate and carefully selected camps, prepared to support an individual with FASD	1-y
Encourages parent/caregiver to attend all of the child's games and events	1-y
Promotes action activities	1-y