

Towards a Provincial Strategy

Summary:
Advancing Effective
Service Provider
Practices in Fetal Alcohol
Spectrum Disorder

2010

FASD | ONE

Fetal Alcohol Spectrum Disorder
Ontario Network of Expertise

Intervention and Support Working Group

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***Towards a Provincial Strategy:
Advancing Effective Service Provider Practices in
Fetal Alcohol Spectrum Disorder (FASD)***
(Summary)

What we seek

A provincial strategy to address Fetal Alcohol Spectrum Disorder (FASD) developed in collaboration with FASD ONE, parents/caregivers, service providers, and other stakeholders. We invite the provincial government to become the leaders in Advancing Effective Practices, and to address the need for the life-long supports required by children, youth, and adults affected by FASD.

Why?

Ontario is one of the only provinces without a provincial strategy to address the disorder, yet FASD is considered to be the leading cause of developmental disability in Canada (Public Health Agency Canada, 2007). One percent or approximately 300,000 Canadians are currently FASD affected (Public Health Agency of Canada, 2007). In Ontario, that number translates into 30,439 children and youth under the age of 19 who would be affected by the disability.

In spite of this number, much remains unknown about FASD because it is most often an invisible disability. Most people with FASD do not have distinguishing facial characteristics, appear normal, and are of average to above-average intelligence. In addition, Ontario currently has limited diagnostic capabilities.

The result of this ignorance is costly in terms of the secondary disabilities that people with FASD develop without proper support. These may include: mental health issues, poor academic or employment outcomes, addictions, and involvement with the child welfare system and/or the law.

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

What exactly is FASD?

FASD is an umbrella term describing a range of disabilities that may affect people whose mothers consumed alcohol while pregnant. While there are different diagnoses included in the FASD spectrum, all individuals with FASD have brain damage. This brain damage can cause a range of disabilities including mild to severe delays in cognitive, physical, emotional, social, and behavioural skills.

Who We Are

FASD ONE (Ontario Network of Expertise, formerly known as the FASD Stakeholders for Ontario) is a group of stakeholders working together to address issues related to FASD in Ontario. Our membership includes experts and specialists in the following areas:

health	child welfare
children's mental health	research
addictions	justice
early learning and development	Aboriginal services
developmental services	

It also includes family members, who have an intimate knowledge of the practical needs of individuals living with this disability.

FASD ONE is an unincorporated collaboration of diverse provincial and local stakeholder groups. We work to promote, plan, facilitate, and support the coordination, enhancement, and expansion of services and initiatives. Our aim is to better serve children, youth, parents, pregnant women, and families affected by FASD in communities across Ontario.

In order to better educate the public on issues facing people with this range of disabilities, the Intervention and Support Working Group of FASD ONE commissioned three research papers in areas of critical importance: effective practices, education, and respite.

About Effective Practices—Findings from the Research

The Intervention and Support Working Group of FASD ONE embarked on a project to explore standard practices that are effective in supporting people with FASD and to determine if any effective service providers can be found in the province of Ontario. The literature review and full findings of this project can be found in the report *Towards a Provincial Strategy: Advancing Effective Service Provider Practices in Fetal Alcohol Spectrum Disorder (FASD)* (Hall, Cunningham & Jones, 2010), of which this paper provides a summary.

There is a prevalent lack of knowledge among the general and professional population regarding the nature and treatment of FASD. This lack of knowledge extends to ministries of the Ontario provincial government.

Of seven ministries approached for this study, only the Ministry of Children and Youth had a designated provincial service addressing FASD: the Aboriginal Fetal Alcohol Spectrum Disorder and Child Nutrition Program, geared to the Ontario Aboriginal population. On this finding, the researchers of this project conducted a survey of parents and caregivers asking them to identify effective service providers, of which a group of thirty service providers were identified from across the 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 following eight main practices presented that are summarized under the following four headings.

Importance of early diagnosis and education

Overall, a number of general practices were identified that are essential for effective intervention with people affected by FASD, emphasis on early diagnosis being the most critical.

Given that many people with FASD do not have identifying facial features, early diagnosis prevents misunderstandings and unrealistic expectations and can prevent the onset of secondary disabilities. It also emphasizes the importance of professional care-providing agencies and services having a dedicated process for identifying clients with potential FASD: they should “Think FASD First.”

Training and education in FASD—for caregivers, schools and service providers, the communities in which FASD affected people reside, and the general population—are also critical effective practices. 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, its impacts on behaviours, and how to support effectively.

Lack of knowledge contributes to

- high frequency of misdiagnosis for clients affected by an FASD;
- failure to provide the best management strategies or alternative treatments through support services that address dysfunctional behaviours rather than understand or treat underlying brain damage;
- ineffective supports for parents/caregivers, which can result in family breakdown, the high cost of having individuals affected by FASD being put into permanent care, and the ongoing development of secondary disabilities.

FASD-oriented education and training for service providers, however, was often not part of any professional training or workplace mandate. Fifty-seven percent of identified individuals in the survey were self-taught on the subject of FASD. In some cases this was necessary due to lack of professional development opportunities within the agencies themselves.

Strength-based approach and collaborative services

Another effective practice is a paradigm shift to a positive, strength-based approach in the way that professionals and caregivers perceive and serve individuals affected by FASD. Once service providers and caregivers understand the neurological impairments of FASD and its effects on behaviours, feelings of frustration and anger evolve into understanding, increased patience and acceptance. Programs would do best to reflect this understanding and shift the underlying perception of the person affected by FASD from someone who “won’t” to someone who “can’t.” Service providers with a “no-eject” policy for individuals with FASD are often the most successful in serving individuals with FASD.

Collaborative services are another effective practice. Individuals with FASD need to access many supports over their lifetimes; due to the nature of their condition, most of them are not able to coordinate all the services they need. An advocate—ideally an agency or service provider—can work to change the system in order to better accommodate the individual and coordinate the many services that are necessary to support the person affected by FASD. This is effective case management.

Interdependent supports, structure, and communication

Life-long interdependent supports are another effective practice for success in dealing with people affected by FASD. Service providers and caregivers should teach people with FASD from an early age not only how to be interdependent, but that interdependence is good for them and essential for their success as adults. This means

- reinforcing this reality as early as possible; and
- service providers no longer expecting that people affected by FASD will become independent over time and, as a result, planning for life-long interdependence.

Structure, routine and supervision are additional effective practices. People with FASD must have external structure to organize their own time and to keep focused and/or busy. Without this structure they may react impulsively or prolong responses to random external stimuli. Structure includes altering the environment to support structure and routine. Routine and supervision are essential in preventing behaviours. Supervision sets up people with FASD for success; some level of supervision will always be required as the brain damage is permanent.

Effective communication approaches are another effective practice. Early language development is often delayed in individuals with FASD. Receptive language is more impaired than expressive language. An understanding of the emphasis on receptive language skills and a modified approach to communication with persons impacted by FASD are essential elements of effective practice. Effective communication includes using clear language that is simple with step-by-step instructions. In general, caregivers and programs should “think younger” when working with clients with FASD.

Awareness of and supports for Sensory Processing Disorders

The last effective practice identified by this research to successfully deal with people affected by FASD is awareness of and supports for Sensory Processing Disorders or SPDs (formerly Sensory Integration Disorders [SIDs]). Sensory Processing Disorders are neurological disabilities in which the brain is unable to accurately process the information coming in from the senses. Everyday environments may be overstimulating and overwhelming for people affected by FASD whose brains cannot prioritize or process stimuli. Many of these people seem to have sensory sensitivities to sight, sound, touch, smell, or taste. In order to provide effective services for individuals with FASD, caregivers and service providers *must* assess, understand, and address Sensory Processing Disorders.

Recommendations

Based on the results of the literature review in *Towards a Provincial Strategy: Advancing Effective Service Provider Practices in Fetal Alcohol Spectrum Disorder (FASD)* (Hall, Cunningham & Jones, 2010), the most effective practices to deal with people impacted by FASD must be founded on early diagnosis, education, and training, as well as life-long supports for those affected and their care providers. Currently, these services are neither promoted nor readily available.

To improve cost effectiveness and the provincial capacity to successfully support people with FASD, it is critical that

- the Ontario government assign a lead ministry to work with other ministries to create a provincial FASD strategy and ensure that effective practices are utilized.
- staff within the service sector be assigned to the FASD file and receive designated funding to propel their work using effective practices.
- a provincial inter-ministerial and cross-sectoral FASD committee be responsible for addressing the needs of individuals affected by FASD who are either currently receiving services or are in need of services. The existing operating group FIANO (FASD Intergovernmental Action Network of Ontario) provides a model for inter-ministerial cooperation of this type; however, the network needs to be supported by a lead ministry.
- the diagnostic capacity for FASD in the province of Ontario be increased.
- education, training and increased awareness of FASD throughout the province of Ontario be prioritized.
- policy makers, service providers, legislators, and funders utilize and build on the current effective practices in the development of services for people and families affected by FASD.