

Evidence In Action



February 7, 2014

Profiling knowledge generation, exchange, & implementation activities

Developing a comprehensive system-level approach to FASD in Simcoe County

About the initiative

Fetal Alcohol Spectrum Disorder (FASD) affects over 5,000 individuals in Simcoe County. FASD is an invisible physical disability with behavioural symptoms. Individuals with FASD often have health issues and special needs that require ongoing support. When support is not available, individuals with FASD may face challenges related to mental and physical health, addiction, education, employment, and involvement with the justice system.

The Simcoe County FASD Initiative was started to help the community develop a comprehensive approach to prevention, diagnosis, and intervention for individuals with FASD and their families. Over 25 partners are working together to create a network of shared capacity where service providers and caregivers have access to culturally relevant information and supports in the community.

Development of Comprehensive Approach to FASD

The initiative was interested in adopting an evidence-based model for working with individuals and families affected by FASD. This model

needed to be effective, sustainable, and flexible to work within existing services and programs. The Neurobehavioral Accommodations Model@ (NAM) Process was chosen based on these criteria.

NAM was developed by Diane Malbin, Executive Director of Fetal Alcohol Syndrome Consultation, Education and Training Services Inc. (FASCETS). The model is informed by evidence that supports the recognition of FASD as a brain-based disability. It provides practical tools to help identify the individual's specific brain deficits and supports a process that makes accommodations based on the individual's primary disabilities.

These tools include the FASCETS Neurobehavioural Prescreening Tool and the NAM Grid. The prescreening tool helps identify primary characteristics, strengths, secondary behavioural symptoms, and tertiary characteristics. Both tools are completed by a team that includes parents, teachers, and service providers. Together these tools provide a common language and help to understand the individual in the context of their brain-based disability.

In December 2008, Malbin came to Simcoe County to train 100 multidisciplinary service providers representing 25 agencies. The community then developed an Implementation Protocol for NAM specific to the Simcoe County context.

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Sustaining the Initiative and NAM Implementation

After the training sessions, FASD Leads were identified in each partner agency to act as champions and representatives. The FASD Leads group meets regularly to share knowledge and build capacity and competence. They also provide training for service providers and the community.

The overall initiative has been sustained over time by a well-developed organizational structure, which includes interconnected working groups focused on key priority areas and common long-term outcomes:

- Prevention/Awareness;
- Family Support;
- Diagnosis;
- Interventions;
- Youth Justice.

An FASD advisory group made up of parents, caregivers, and agency managers was also formed to discuss priorities and linkages, coordinate work plans, oversee working groups, and monitor process and progress. The Project Coordinator, currently based out of Catulpa Community Support Services, oversees the entire initiative.

The FASD Prevention and Awareness Committee is chaired by the Simcoe Muskoka District Public Health unit and made up of parents, care-



Simcoe County FASD Leads

givers, and service providers. Their role is to increase awareness of FASD and facilitate development of primary prevention strategies. This committee has created public awareness campaigns, hosted day-long educational events, and developed teaching materials for grade nine students in local high schools.

To meet the needs of the Francophone and First Nations communities, the committee translated educational materials and engaged in cultural partnerships.

Impact of NAM Model

The initiative conducted a preliminary evaluation of outcomes for Simcoe County caregivers, service providers, and youth with FASD. Results showed:

- Caregivers have better understanding of FASD, are better able to cope, and are less stressed.

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- Service providers feel more confident in their ability to support youth with FASD.
- The number of service providers using NAM between Oct 2009 and Aug 2010 increased five-fold.
- Youth with FASD had fewer behavioural challenges and more adaptive behavioural skills.

Next Steps for the Initiative

The Simcoe County FASD initiative plans to undertake the following next steps:

- Continue to build agencies' capacity to provide services more effectively and efficiently to people with FASD and their families.
- Continue to educate both the community and service providers about FASD prevention, diagnosis and intervention.
- Protect and build on the community's investment in staff time and effort. related to services to people with FASD and their families.
- Identify gaps and take advantage of funding opportunities.

EENet perspective

The Simcoe County FASD Initiative has demonstrated the value of using an evidence-based process like NAM as part of an initiative to create a comprehensive system-level approach to care. This approach includes the development of

a network of cross-sectoral partners to support each other and work towards common defined outcomes. Ongoing work to increase education and support families enhances the ability of service providers to provide culturally-relevant information and highly effective supports to individuals affected by FASD.

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