



**Submission to the Select Committee on
Developmental Services**

**Monday, January 13th, 2014
London, Ontario**

**The Registered Nurses' Association of
Ontario (RNAO)**



Good morning,

My name is Kathy Moreland Layte. I am a registered nurse and professor of nursing from Kitchener, Ontario. I am here today representing the Registered Nurses' Association of Ontario (RNAO). RNAO is the professional association representing registered nurses wherever they practise in Ontario. Since 1925, RNAO has advocated for healthy public policy, promoted excellence in nursing practice, increased nurses' contribution to shaping the health-care system, and influenced decisions that affect nurses and the public they serve.

On behalf of RNAO, I'd like to extend our thanks to the Select Committee on Developmental Services for hearing our presentation this morning. Committee members are to be commended for addressing the issues of developmental services, as they impact greatly on the health of many Ontarians, their families, and our communities as a whole. Through review of the minutes of your proceedings, it has been noted that the issues of children and adults with autism and other developmental disabilities have been represented. Thus, I will focus RNAO's remarks on a group of individuals and their caregivers who too often fall through the cracks of the developmental services grid.

I am here to speak with you about children, youth, adults and caregivers living with fetal alcohol spectrum disorder. I will start by sharing some background information, which we have also included in the files before you.

Fetal Alcohol Spectrum Disorder (or FASD) is a brain-based physical disability that is the most common type of developmental disorder in Canada. The brain damage developed in relation to FASD is permanent and cannot be cured. And, because of their brain injury, people with FASD face a wide spectrum of lifetime challenges, from mild to very serious physical, mental and emotional disabilities.

Let me give you a sense of the disorder's key mental disabilities. They include: difficulty with assessment, judgment, impulse control and reasoning; poor memory and language processing; poor emotional regulation; an inability to generalize or think abstractly (or, to put it more specifically: poor transfer of concepts from similar situations); and difficulty with planning and executive function.

The term FASD is, in fact, an umbrella acronym that encompasses four medical diagnoses, including: fetal alcohol syndrome (FAS), partial fetal alcohol

syndrome (pFAS), alcohol-related neuro-developmental disorder (ARND) and alcohol-related birth defects (ARBD).

This disability affects approximately one per cent of the population.

Equally alarming is the fact that FASD prevalence is only expected to rise. Statistics point to troubling trends: for example, binge drinking, defined as four or more drinks within a short period of time, is increasing. According to Health Canada, 20 per cent of women of childbearing age consume five or more drinks at a time, once per month or more often. This is three times the rate a decade ago. Health Canada has determined that women at highest risk of binge drinking are 15 to 19 years of age, followed closely by those in the 20- to 24-year-old age bracket.

Consider this, too: the Public Health Agency of Canada continues to state that no amount of alcohol – of any kind, at any time – is considered safe for women thinking of becoming pregnant or for those who are already pregnant. Yet, the estimated overall rate of unplanned pregnancy is 40 per cent. And, the highest rate of unintended pregnancy is 82 per cent among 15- to 19-year-olds.

Let's get back to the disability itself, which is largely considered invisible. That's likely because those diagnosed with fetal alcohol syndrome, or FAS, are the only people under the FASD umbrella who bear the facial features so commonly associated with fetal alcohol exposure. A birth mother must be binge drinking between day seven and 15 of her pregnancy in order for those facial features to develop. Others, born with the other forms of FASD, go unnoticed until other symptoms appear. However, it is important to note that fetal alcohol syndrome is not indicative of greater or lesser brain injury than the other diagnoses included in FASD.

Children and adults affected by FASD are at a higher risk of developing additional health challenges such as addiction and mental health issues, including anxiety and depression. Difficulties when it comes to learning and staying in school. Long-standing, unsupported attention to a child's FASD or lack of a diagnosis often progresses into tertiary challenges, such as trouble with the law, sexual promiscuity (including teenage pregnancy and sexually transmitted infections), unemployment, homelessness, and other hardships associated with poverty.

In addition to the human cost of suffering for people with FASD, there is great strain on health care, educational, community and criminal justice services.

Until people with FASD have serious behavioural or mental health issues, there are very few community supports available through the lifespan of those affected.

Let me now share the caregivers' perspective.

There is a great deal of stigma associated with obtaining a FASD diagnosis, especially for the biological parent. Because of this, many children are instead diagnosed with attention deficit hyperactivity disorder, oppositional defiant disorder, attachment disorder, or anxiety.

Getting a FASD diagnosis can take years. In Ontario – unlike Alberta, British Columbia and Manitoba – there are difficulties with obtaining a FASD diagnosis for three main reasons:

- There is limited diagnostic expertise. A FASD diagnosis requires psychometric testing, clinical expertise, a speech assessment, and an occupational therapist assessment.
- The birth mother must admit alcohol use while pregnant.
- Except for medical services, the diagnosis of FASD is not covered under OHIP. This means an out-of-pocket expense for the caregiver, with the average cost of a complete assessment being \$3,000 to \$5,000, compounded with the fact that it can take years to obtain.

Caregivers of children with FASD struggle and often lose their children due to the aforementioned challenges. They have few options if they are living with an aggressive child, youth, or adult at home. In fact, many caregivers often surrender children suffering from FASD to family and child services when they have no other support. As the representatives from Peel Region shared, “they are at the end of their rope.” Children are also placed in section 23 schools not specifically geared to FASD issues, juvenile detention centres or group homes. Because of the funding cuts to regional family and children services, many group homes are closing. As a result, many of those living with

FASD are sadly lost to the streets, or families must continue to bear the burden of their child's aggression or needs.

Should their child stay with them, caregivers face a life of chronic stress, financial strain and grief as a result of their child's disabilities and lack of educational and social support. Many caregivers report significant social isolation exacerbated by a frequent lack of understanding of their child's issues from family members, health-care professionals and educators.

Many caregivers give up their jobs and face financial strain to stay home to care for their children, as their children cannot be attended to at school. The high cost and lack of availability of trained caregivers, as well as lack of respite opportunities, is a burden for many. Currently, families pay anywhere from \$15 to 35 per hour for appropriately trained workers – and that's if they can find them. Many of these children do not meet the threshold to qualify for supplemented childcare (such as Extend-a-Family), as they do not fall below the required IQ, which is less than 70, to qualify as intellectually disabled. Special Services at Home funding, while available, is limited to those who qualify. To make matters worse, caregivers of children with FASD have few financial resources available to them other than the Disability Tax Credit.

Let me now address some of the issues related to education for people with FASD.

Most educators are ill-prepared to understand the needs and strategies to identify and assist those with FASD. While the Ministry of Education has already outlined the *Education for All* strategies, each school board must decide how their special education funding is used. The funding formula is based on the 15 per cent special education criteria set out by the Ministry of Education, but does not meet the needs of many communities. In my own community of Kitchener, over 20 per cent of the children are identified with special needs. The board must deal with providing “the best they can” with insufficient funds.

Cuts to educational assistant positions and child youth worker jobs have made classrooms a difficult place for educators and children with FASD to have their needs met. Inclusion philosophies have not considered the inability of many of these children to handle over-stimulating environments.

Children with FASD are often removed from school under the *Safe Schools Act* because of aggression and/or an inability to cope with the sensory inputs of a regular classroom. Because many with FASD “look normal,” educators have more difficulty recognizing these issues as a part of the disability versus defiance. Consequence-based approaches to problematic behavior rarely work with these children, as they have little ability to transfer learning from one context to another.

Individual education plans and the Identification, Placement, and Review Committee processes have many “loopholes” that allow school boards to limit educational assistant help and support, “modified school days,” and/or removal under the *Safe Schools Act* when behavior problems become an issue. This creates a great deal of stress and financial burden on caregivers.

While removed from school, little to no tutoring is provided, and these children are left on long waiting lists for limited and often inappropriate mental health services or classrooms that are often effective, but short term. These waits can last anywhere from months to years. The children are then returned to their regular schools, often for one to two hours per day, repeating the cycle.

Many caregivers eventually remove their children from school permanently, resorting to home schooling because of exasperation and frustration.

It is also important to discuss the transition to adulthood for people with FASD.

It is estimated that those living with FASD may be developmentally one-third to half their biological age in many functions, putting them at great risk during their teen and early adult years. As a result, people with FASD require lifelong care, often in the form of a person or people to negotiate situations and prevent them from getting into difficulties in school, their teens, and adulthood.

At 18, children diagnosed with FASD are eligible for disability, but have few or no social service supports to help them through the processes to get disability support, to find work or become self sufficient. If they are still living with their caregivers, there continues to be no support services available. Aging parents and grandparents fear for their childrens' future in a similar way to those with

other developmental disabilities. Who will care for their children if they become ill or die?

There are also ballooning costs associated with the FASD population. The cost of FASD to the public is difficult to determine, but has been estimated as anywhere from \$1 to 3 million dollars per individual over a lifetime. \$5.3 to 7.6 billion dollars is spent annually in Canada to support those with FASD from birth to age 53.

I would be remiss if I didn't discuss costs without talking about the impact the lack of care of children with FASD has on the criminal justice system. Based on available Canadian data, it is estimated that youth with FASD are 19 times more likely to be incarcerated than youth without FASD in a given year.

Research also indicates it is estimated that there is 10 times greater incidence of FASD in the correctional population than the general population.

The average daily cost for a federal inmate is roughly \$360 per day, or about \$170 per day as a provincial or territorial inmate. Compare these costs to the average cost of an early intervention. A child youth worker costs \$164 per day per student, or \$82 per day for two students. Finally, an educational assistant

costs about \$123 per day, per student, or \$62 per day for two students. Investing early shows greater changes of self sustainability in the future.

Let me now give you a sense of what RNAO is doing to help those affected by this devastating disability.

In 2012, at RNAO's annual general meeting, a resolution was unanimously passed to address the prevention, diagnosis and treatment of FASD in this province. You have in your package a copy of that resolution, as well as some of the follow-up activities that have taken place, including an article from RNAO's bimonthly publication, *Registered Nurse Journal*.

In February 2013, RNAO released its political platform called *Why Your Health Matters* in an attempt to begin a conversation and prompt a call to action to leaders such as yourselves to collaborate and focus your work on matters that will build an even stronger province. Our presence here today is a part of a commitment to educate decision-makers about this vital gap in developmental services for those living with FASD, and advance healthy public policy to serve them, their loved ones and our communities. Lack of attention to people with

FASD impacts two of our key health priorities: accessibility to health care and the reduction of poverty.

So what can you do, as political leaders driving policy in Ontario? Allow me to outline three key points.

1) RNAO is calling for a provincial strategy. Ontario is one of the only provinces without a provincial framework to address FASD through an integrated, interdisciplinary strategy for the prevention, diagnosis and care of individuals and families living with FASD. In 2005, the Public Health Agency of Canada developed a *Framework for Action* on FASD, calling on all provinces to develop an integrated, purposeful approach to FASD. To address FASD and save costly resources, Ontario needs to develop an evidence-based, integrated strategy to address FASD, including: prevention, diagnosis, intervention and support. Such a strategy is currently being drafted for presentation to the provincial government by FASD Ontario Network of Expertise. Such a strategy would reduce the harm created by continued use of alcohol in pregnancy, diagnose those affected by prenatal alcohol exposure early, and provide supports to individuals and families living with FASD through their lifespan.

2) We urge that accessible, affordable diagnostic services be available to children who suffer FASD and their families. And,

3) Caregivers should have the respite and other services they need to be able to work, stay well and have a healthy family life.

In conclusion: FASD is a preventable disability Ontario is not adequately addressing. Spending \$150,000 on prevention saves \$1.6 million in treatment. Prevention is more than just raising awareness about the dangers of drinking in pregnancy. Addressing the inequities that exist in our province with respect to the social determinants of health such as poverty and social exclusion would significantly decrease the incidence of FASD. We need to promote the low-risk drinking guidelines for all people in their childbearing years, develop policies that limit the potential for alcohol abuse and involve all health-care providers in screening for risky alcohol use and education about the dangers of drinking above the low-risk drinking guidelines. FASD impacts the health of Ontarians, their families and communities across all determinants of health. It creates poverty and secondary health issues while increasing costs to associated social services, education, health care, community services, and the criminal justice system. It breaks families and entire communities.

The time for an integrated provincial strategy is now!

With a focus on prevention, early diagnosis and the right supports, we, as a society, can decrease the prevalence and help those living with FASD achieve their potential. Without a provincial strategy, people who suffer from FASD and their caregivers suffer, and the costs to the system in human and financial terms become greater. Individuals and families with FASD need and deserve better.

On behalf of RNAO, I thank you for your time and welcome your questions.

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