



## Fetal Alcohol Spectrum Disorder - Activities to Address Key Priorities

**Date:** May 30, 2019

**To:** Board of Health

**From:** Medical Officer of Health

**Wards:** All

### SUMMARY

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This report responds to direction from the Board of Health (BOH) in July 2018 to consult with the Toronto Fetal Alcohol Spectrum Disorder (FASD) Network (the Network) and report back on potential measures the City of Toronto could undertake to improve prevention, access to services, and access to supportive housing for people living with FASD. Toronto Public Health (TPH) is an advisory member of the Network and has been working with the Network since the summer of 2018 to address the BOH request.

FASD is a neuro-developmental disability that occurs in individuals who were exposed to alcohol prenatally. There is no cure for FASD and it is a lifelong disability. It can be prevented by avoiding alcohol during pregnancy. As mandated, TPH engages in a wide range of activities to raise awareness about and prevent FASD. Prevention is also supported by ensuring compliance with *Sandy's Law*, a provincial requirement for establishments selling or serving alcohol to post signs warning of the risks of consuming alcohol during pregnancy. Policy measures to mitigate the impacts of alcohol retail expansion can also play a role in preventing alcohol-related harms, including FASD.

Early diagnosis and appropriate interventions improve the long-term outcomes for people living with FASD. Diagnostic, health, and social services for people living with FASD are limited in Toronto or not sufficiently tailored to the specific needs of this population. Supportive housing is also required, as the majority of people living with FASD are unable to live independently. Toronto's current supportive housing options are challenged to meet the specific needs of people living with FASD. Long wait lists for supportive housing spaces pose a further barrier.

To respond to challenges in accessing tailored, adequate, and lifelong services and supportive housing for people living with FASD, the Network has developed a *Case Coordination Model for Adults 16+ Affected by FASD* and a housing model called *Housing to Effectively Support Adults 16+ Affected by FASD*. TPH has connected the Network with City Divisions, in particular, Social Development, Finance & Administration and the Housing Secretariat so that they may engage in further consultation to advance services for people living with FASD in Toronto, where feasible and within the mandates of these divisions.

## **RECOMMENDATIONS**

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The Medical Officer of Health recommends that:

1. The Board of Health forward this report to the Interim Executive Director, Housing Secretariat, the Executive Director, Social Development, Finance and Administration, and the General Manager, Shelter, Support and Housing Administration, for consideration in their ongoing review of programs, policies, and processes in their mandates.

## **FINANCIAL IMPACT**

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There is no financial impact associated with this report.

## **DECISION HISTORY**

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In July 2018, the Board of Health requested that the Medical Officer of Health consult with the Toronto FASD Network and report back on potential measures the City of Toronto could undertake to improve prevention, access to services, and access to supportive housing for people living with FASD.

<http://app.toronto.ca/tmmis/viewAgendaItemHistory.do?item=2018.HL28.11>

## **COMMENTS**

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The Toronto FASD Network (the Network) is a city-wide planning and coordinating body addressing the resource and service needs of children, youth, and adults affected by FASD and the needs of their families. Members include parents, care providers, educators, health and social service professionals, and policy makers. Toronto Public Health is an advisory member of the Network and has engaged with the Network on a number of occasions since the July 2018 Board of Health request to consult with this group and explore opportunities "to improve prevention, access to services, and access to supportive housing for people living with FASD". The Network has written a report summarizing the state of the needs related to FASD prevention and those living with FASD. The Network's report and input from consultation with them have informed this report.<sup>1</sup>

### **FASD: Cause, Prevalence and Burden of Disease**

Alcohol use during pregnancy can lead to FASD, which is a term used to describe a range of physical, mental, behavioural and learning effects that occur when an individual has been exposed to alcohol as a fetus.<sup>2</sup> Alcohol is a known teratogen (i.e. an agent that causes birth defects). Alcohol in any amount and form, used at any point in pregnancy, is unsafe.<sup>3</sup> While there is no safe amount or form of alcohol consumption during pregnancy, consuming a large quantity of alcohol in a short timespan (i.e. five or more drinks at one sitting) or frequent consumption (i.e. more than seven drinks per

week) represents the riskiest drinking habits for the fetus.<sup>3</sup> In addition to FASD, alcohol consumption during pregnancy increases the chance of birth defects, miscarriage, stillbirth, preterm birth, and sudden infant death syndrome (SIDS).<sup>2</sup>

Fetal Alcohol Spectrum Disorder is one of the leading causes of preventable birth defects and developmental delays among Canadian children.<sup>4</sup> Although it is preventable, prevalence rates are not decreasing. Estimates of the Canadian prevalence of FASD range from one to four percent of Canadians. According to the first population-based study in Canada, conducted by the Centre for Addiction and Mental Health (CAMH), an estimated two to three percent of elementary school-aged children (7 to 9 years) in the Greater Toronto Area likely have FASD.<sup>5</sup>

Although characteristic facial features are one indicator of FASD, the majority of people with FASD are not visibly different and, therefore, it is primarily an invisible disability. People with FASD may have average or above average intelligence, but they can experience challenges with executive functioning, communication, and neuromotor deficits.<sup>6,7</sup>

People living with FASD, particularly those who have not received effective early and ongoing interventions, are at increased risk for a range of issues including: disrupted school experiences and early school failure; depression, anxiety, and other mental health conditions; substance use issues; involvement with the law; and, family disruption. The majority of people with FASD are unable to live independently and are at risk for homelessness.<sup>1</sup>

In Canada, the direct and indirect costs of FASD for supportive needs in health, mental health, social services, education, and the negative costs through criminality and the criminal justice system are estimated to be \$4 billion/year.<sup>7</sup>

## **Prevention – Awareness and Practice**

The fact that FASD is preventable and that rates remain high indicates a need for increased public awareness. As mandated, TPH engages in a wide range of activities aimed at raising awareness about the risks of drinking alcohol during pregnancy and the importance of preventing FASD. Toronto Public Health's key message is that there is "no safe amount, no safe kind and no safe time to drink alcohol in pregnancy."

As an advisory member of the Network, TPH collaborates with the Network to plan and implement prevention activities promoting International FASD Awareness Day held annually on September 9. This includes public messaging at Mel Lastman Square and lighting the Toronto sign at Nathan Phillips Square.

Toronto Public Health's prevention activities continue on a year-round basis. Fetal Alcohol Spectrum Disorder information is communicated to the public, including those planning a pregnancy or who are pregnant, through the City's website, social media messages, the *Welcome to Parenting* online prenatal program, and the *Pregnancy to Parenting* blog. In addition, past awareness-raising activities have targeted youth and university students. Toronto Public Health has also worked to develop FASD prevention strategies aimed at specific higher-risk populations. For example, TPH nurses offer

client-centred prenatal education and counselling through the *Homeless and At-Risk Prenatal* program.

Toronto Public Health communicates about the risks of consuming alcohol in pregnancy and FASD to Toronto physicians through articles in the *Communique: Toronto Public Health's Physician E-Newsletter*. The Ontario Prenatal Record, which includes screening questions related to alcohol consumption, is included in the prenatal section of the City's Health Professional's web portal.<sup>8</sup> This document outlines specific messaging emphasizing that there is no safe amount of alcohol, no safe type of alcohol, and no safe time to drink alcohol during pregnancy.

Toronto Public Health staff are well trained through current resources (such as new staff orientation, Prenatal Nursing Practice Guidelines and Canada Prenatal Nutrition Program Curriculum) to incorporate messages about the risks of alcohol consumption in direct interactions with residents and through communication strategies, including those related to International FASD Awareness Day.

## **Prevention – Policy**

As part of a 2004 amendment to the provincial *Liquor License Act, Sandy's Law* requires all establishments in Ontario that serve or sell alcohol to display signs cautioning women who are pregnant about the risks to the fetus (including FASD and birth defects) of consuming alcohol during pregnancy.<sup>9</sup> Non-compliance with *Sandy's Law* may lead to action by the Alcohol and Gaming Commission of Ontario (AGCO). Given the expansion of licensed retail premises proposed in the 2019 Ontario Budget, the AGCO needs to carry-out its regulatory and enforcement mandate, including ensuring compliance to *Sandy's Law*.

There is growing evidence that increasing access to alcohol through greater availability, and longer hours in which alcohol is sold, is associated with increased alcohol consumption and higher rates of alcohol-related harms.<sup>10</sup> There is also a trend to greater alcohol consumption that is particularly pronounced among women – increasing from 1.9 to 3.6 drinks per week between 1996 and 2017.<sup>11</sup> Given the provincial proposals to increase access, it is important to strengthen mitigation measures to prevent alcohol-related harms, including FASD (see Appendix A for the full text version of the provincial changes). A list of potential measures to mitigate the harm of alcohol retail expansion, as proposed by the Ontario Public Health Association, is provided in Appendix B. These measures have additional benefits, including managing economic costs related to municipal enforcement and reducing healthcare costs.

## **Access to Services**

For people living with FASD, early diagnosis provides the opportunity to create an appropriate and feasible intervention plan, which is key to improving outcomes in the long term. The Network and the 2015 FASD Provincial Roundtable Report highlight concerns about limited FASD diagnostic services in Toronto and Ontario.<sup>1,12</sup> Toronto currently has only two FASD diagnostic clinics: Surrey Place and Anishnawbe Health Toronto, with the latter serving the city's Indigenous population. At Surrey Place, there is a six month wait list for diagnostic services.

People living with FASD require lifelong access to services, supports, and resources to help them do well and sustain their progress. Services, supports, and resources need to be client-centred and developed with specific consideration of the impact FASD has on the brain. For example, people living with FASD may have impairments to executive and adaptive functioning that make it difficult to navigate the health and social services sectors. They may not remember appointments, lose appointment cards, misplace documentation, and be unable to complete long and complex forms.

The Network has developed and is seeking funding for a *Case Coordination Model for Adults 16+ Affected by FASD* with the goal of assisting and supporting affected adults to access the services, resources, and supports they require to manage their disability over their life span.<sup>1</sup> For example, as the Network notes, when services, supports, and resources are provided, people with FASD can do well; however, when services are withdrawn, often because of a perception that the desired outcome has been achieved, people regress. Therefore, the Network's model proposes consistent and continuous service delivery that recognizes the lifelong nature of FASD.

With limited diagnostic and other services available for people living with FASD, many are navigating life in Toronto without appropriate supports. City of Toronto staff who provide services to residents should be aware that FASD and other invisible disabilities, including mental illness and addiction issues, may be present.

To advance the City of Toronto's approach to service access for those living with FASD, TPH worked with Social Development, Finance & Administration to ensure that the Network was included in a workshop session about the developmental services sector and care planning for people with a neurodevelopmental disability hosted by the Specialized Program for Interdivisional Enhanced Responsiveness (SPIDER) program on March 22, 2019. Social Development, Finance & Administration and the Network are planning to conduct a FASD-specific workshop session in the fall of 2019, including a panel with those with lived experience of FASD.

## **Access to Supportive Housing**

The disabilities associated with FASD mean that the majority of adults living with FASD have significant challenges living independently and accessing permanent housing. Adults with FASD may access a number of different housing support systems in Toronto, but none are sufficiently tailored to address their specific needs. As a result, people fall into the gaps between services, are more likely to experience homelessness, and to become involved with the criminal justice system.<sup>13</sup> Many are also being housed within mental health and addictions housing programs. While these programs are equipped to address these concurrent disorders, they may not necessarily be able to accommodate the unique needs of people living with FASD.

Housing supports in Toronto are provided through a range of different municipal and provincial program areas. The programs are challenged to provide the ideal combination of supports for people living with FASD. Moreover, the housing programs that are available and may meet the needs of some people living with FASD have long

waitlists for access, which is a substantial barrier. Housing supports currently available within Toronto include:

- The Ministry of Health and Long-Term Care and the Local Health Integration Networks (LHINs) provide housing and support services for people with mental health and addiction issues. The Toronto Mental Health and Addictions Access Point (The Access Point), funded by the LHINs, is the centralized point to apply for individual mental health and addictions support services and supportive housing. The Access Point has substantial waitlists for supportive housing: from 2011/12 to December 2017 the number of people on the waitlist for supportive housing in Toronto increased from 3,574 to 13,645. As of October 31, 2015, 60% of applicants on the waitlist in Toronto had been waiting for two or more years for supportive housing.<sup>14</sup>
- The Ministry of Children, Community and Social Services provides a range of residential and support services for people with developmental disabilities through community agencies. In Ontario, a developmental disability is defined in law as significant limitations in cognitive functioning and adaptive functioning that originated before 18 years of age; that are likely to be life-long in nature; and affect areas of major life activity, such as personal care, language skills, learning abilities, the capacity to live independently as an adult or any other prescribed activity. In 2012, the Ministry estimated there were 62,000 adults in Ontario with developmental disabilities and that about half needed residential services. During the 2013/14 fiscal year, 17,900 people received residential services (98% were adults). Another 14,300 adults were on a waitlist for services at year-end.<sup>15</sup>
- City of Toronto Housing Support Programs provide supports to help people maintain their housing, such as information on tenant rights and responsibilities, neighbourhood orientation, money management, and referrals to health supports. The City also provides housing support services to assist people in accessing and maintaining permanent housing. The services provided are based on an assessment of client needs, prioritization, and connecting people to housing and supports. Housing is provided in market units or through community partners who also deliver ongoing supports. The City of Toronto also provides funding and financial incentives to organizations interested in creating new supportive housing opportunities in Toronto.
- City of Toronto Seniors Services & Long-Term Care, Supportive Housing Services program is a community-based service for people 59 years of age and older promoting independent living to eligible residents in designated buildings. The program offers the stability and safety of intermittent 24-hour support and an on-site Registered Practical Nurse. Services include personal care, light housekeeping, laundry, medication reminders, security checks, light meal preparation, wellness, and health promotion.<sup>16</sup>

According to the Network, there is a current lack of supportive housing tailored to the needs of adults living with FASD. To address this gap, the Network has developed a supportive housing model called *Housing to Effectively Support Adults 16+ Affected by FASD*. This model highlights the need for stable, lifelong housing that emphasizes

interdependence rather than independence. The model proposes supportive housing that is client-centred, strengths-based, comprehensive, family-engaged, provides access to required services across an individual's life span, collaborative, culturally appropriate, and evidence-based. Some of the supports that need to be provided through individualized service plans based on the unique needs of individuals are, life skills, money management, service coordination, and employment supports.<sup>1</sup>

To move toward more appropriate supportive housing options for people living with FASD, TPH has identified the Network as a stakeholder for the Housing Secretariat's (formerly the Affordable Housing Office) consultations related to the development of the *HousingTO 2020-2030 Action Plan*. As such, among other activities, the Network will participate in a supportive housing charrette in the spring of 2019. The Network can also be supported to host its own consultation with its members.

### **TPH Ongoing Activities to Address Key FASD Priorities**

Moving forward, TPH will continue as an advisory member of the Toronto FASD Network and seek ongoing opportunities to prevent FASD and facilitate access to services for people with FASD in Toronto. Toronto Public Health will also continue to work with the Network and City Divisions to identify programs, policies and processes that can be feasibly updated within existing mandates to support the recommended actions of the Network.

### **CONTACT**

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### **SIGNATURE**

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Dr. Eileen de Villa  
Medical Officer of Health

### **ATTACHMENTS**

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Appendix A: Changes to Alcohol Regulation in the 2019 Ontario Budget  
Appendix B: Measures to Mitigate the Harm of Alcohol Retail Expansion

## Appendix A - Changes to Alcohol Regulation in the 2019 Ontario Budget

*Excerpt 1 taken from 2019 Ontario Budget*

Early wins for the people

As the government continues to develop a plan for alcohol reform, it is listening to the people of Ontario and moving forward with a number of initiatives to improve consumer choice and enable opportunities for businesses in the near-term by:

- Creating a tailgating permit for eligible sporting events. Eligible events would include professional, semi-professional and postsecondary sporting events. This change will allow Ontario sports fans to participate in legal tailgating events similar to those permitted in many U.S. states.
- Introducing legislation permitting municipalities to designate public areas, such as parks, for the consumption of alcohol. Ontario would be joining other provinces, including British Columbia, Alberta and Quebec that provide a similar authority to municipalities.
- Providing flexibility for wineries, cideries, breweries and distilleries to promote their products at manufacturing sites by removing the prescribed serving sizes for “by the glass” licences.
- Extending hours of alcohol service at licensed establishments — including bars, restaurants and golf courses — to a 9:00 a.m. start, seven days per week. Hours of alcohol service will also start at 9:00 a.m. for “by the glass” licences, and Special Occasion Permits. The government will continue consulting further on measures related to the additional extension of hours.
- Changing advertising rules to allow for “happy hour” in Ontario. This would allow licensed establishments to advertise their promotions as they do in British Columbia and Alberta.
- Introducing legislation to pause the previous government’s changes to the Wine Tax, which was scheduled to increase on April 1. The proposed change would leave more money in the pockets of Ontario wine consumers.

These changes are expected to be in place by summer 2019.

In addition, the Province is evaluating ways to reduce the cost of beer at the Royal Canadian Legion halls by fall 2019.

*Excerpt 2 taken from 2019 Ontario Budget*

In addition, the government will begin allowing casinos to advertise complimentary alcohol. This change will level the playing field for Ontario casinos and enable them to compete more effectively with those in the United States.

Source: Government of Ontario. 2019 Ontario Budget: Ontario’s Plan to Protect What Matters Most. Available at: <http://budget.ontario.ca/2019/index.html>.



## Appendix B - Measures to Mitigate the Harm of Alcohol Retail Expansion

The following is a list of measures to mitigate the harm of alcohol retail expansion as proposed by the Ontario Public Health Association (OPHA) in their Preliminary Assessment of Alcohol Regulations Proposed in the 2019 Ontario Budget:

- Expanding slowly, with careful attention to evaluating the impact, and addressing health and safety issues.
- Ensuring adequate funding for the Alcohol and Gaming Commission of Ontario such that it has sufficient capacity to enforce the Liquor License Act and regulations in the expanded private retail environment as well as new oversight responsibility inherent with other regulation changes.
- Requiring municipal government endorsement of a retail sales license, including the posting of a public notice of a licence application, to ensure that new access points are in the interest of the community.
- Requiring a site and community safety assessment.
- Requiring minimum site safety and security measures (e.g. interior and exterior lighting, video monitoring). The Registrar's Standards for Cannabis Retail Stores may be a starting point for convenience stores selling alcohol.
- Requiring the same operating parameters as grocery stores that are licensed to sell alcohol, including (a) minimum age of 18 years and SmartServe Training for staff involved in selling or sampling alcohol, (b) prescribed hours of sale, (c) rules for the display of product including securing product outside of prescribed sale hours, (d) restrictions on marketing and financial inducements including agreements with manufacturers and the exchange of loyalty points as payment for alcohol, (e) wholesale purchase from the LCBO, (f) price structure, (g) restrictions on product format and alcohol content (e.g. sales of spirits are not permitted), and (h) posting of signage related to Sandy's Law.

Source: Ontario Public Health Association. Preliminary Assessment of Alcohol Regulations Proposed in the 2019 Ontario Budget. Available at: <https://opha.on.ca/getattachment/Advocacy-and-Policy/Issues/Preliminary-Assessment-of-Alcohol-Regulations.pdf.aspx>.

## REFERENCES

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1. Richards, Sharron. 2019. The Toronto Fetal Alcohol Spectrum Disorder (FASD) Coordinating Network Report to the Toronto Board of Health.
2. Lowdermilk, D. L., Perry, S. E., Cashion, K., & Alden, K. R. 2016. Maternity & Women's Health Care, 11th ed. St. Louis, MO: Elsevier.
3. Best Start Resource Centre. 2016. Prenatal Education Key Messages for Ontario: Alcohol. Available at: [www.ontarioprenataleducation.ca/wp-content/uploads/2016/02/Alcohol.pdf](http://www.ontarioprenataleducation.ca/wp-content/uploads/2016/02/Alcohol.pdf)
4. Canadian Centre on Substance Abuse. 2013. Licit and Illicit Drug Use during Pregnancy: Maternal, Neonatal & Early Childhood Consequences. Available at: [www.ccsa.ca/Resource%20Library/CCSA-Drug-Use-during-Pregnancy-Report-2013-en.pdf](http://www.ccsa.ca/Resource%20Library/CCSA-Drug-Use-during-Pregnancy-Report-2013-en.pdf)
5. Popova, S., Lange, S., Chudley, A., Reynolds, J., Rehm, J. 2018. World Health Organization International Study on the Prevalence of Fetal Alcohol Spectrum Disorder (FASD) Canadian Component. Available at: <https://canfasd.ca/wp-content/uploads/sites/35/2018/05/2018-Popova-WHO-FASD-Prevalance-Report.pdf>
6. Fetal Alcohol Spectrum Disorder Ontario Network of Expertise. 2018. What is FASD? Available at: [www.fasdontario.ca/cms/about-us/what-is-fasd/](http://www.fasdontario.ca/cms/about-us/what-is-fasd/)
7. Canadian FASD Research Network. FASD Fact Sheet. Available at: <https://canfasd.ca/publications/fasd-fact-sheet/>
8. News & Updates for Health professionals. Available at: <https://www.toronto.ca/community-people/health-wellness-care/information-for-healthcare-professionals/archived-newsletters-for-health-professionals/>
9. General Information - Signage Requirement "Sandy's Law". Available at: <https://www.agco.ca/general/general-information-signage-requirement-sandys-law>
10. Stockwell, T., Wettlaufer, A., Vallance, K., Chow, C., Giesbrecht, N., April, N., Asbridge, M., Callaghan, R.C., Cukier, S., Davis-MacNevin, P., Dube, M., Hynes, G., Mann, R., Solomon, R., Thomas, G., Thompson, K. 2019. Strategies to Reduce Alcohol-Related Harms and Costs in Canada: A Review of Provincial and Territorial Policies. Victoria, BC: Canadian Institute for Substance Use Research, University of Victoria. Available at: <https://www.uvic.ca/research/centres/cisur/assets/docs/report-cape-pt-en.pdf>.
11. Ialomiteanu, A. R., Hamilton, H. A., Adlaf, E. M., & Mann, R. E. 2018. CAMH Monitor e-Report: Substance Use, Mental Health and Well-Being Among Ontario Adults, 1977–2017 (CAMH Research Document Series No. 48). Toronto, ON: Centre for Addiction and Mental Health. Available at: <http://www.camh.ca/camh-monitor>.
12. Anderson, Granville. 2015. Fetal Alcohol Spectrum Disorder Provincial Report: A Report form Parliamentary Assistant Granville Anderson to the Minister of Children and Youth Services. Available at: [http://www.children.gov.on.ca/htdocs/English/documents/specialneeds/fasd/FASD\\_Roundtable\\_Report.pdf](http://www.children.gov.on.ca/htdocs/English/documents/specialneeds/fasd/FASD_Roundtable_Report.pdf)
13. FASD ONE. 2013. FASD and Justice: Summary of Activity in Ontario. Available at: <http://www.fasdontario.ca/cms/wp-content/uploads/2014/01/FASD-and-Justice-Survey-Summary-Report-Phase-One.pdf>
14. Canadian Mental Health Association Toronto Branch, Wellesley Institute, and The Access Point. 2018. Seeking Supportive Housing: Characteristics, Needs and Outcomes of Applicants to The Access Point Toronto Mental Health and Addictions

Access Point Waiting List Analysis. Available at:

<https://www.wellesleyinstitute.com/publications/access-point-full/>

15. Office of the Auditor General of Ontario. 2014. Annual Report, 2014. Available at:

<http://www.auditor.on.ca/en/content/annualreports/arreports/en14/310en14.pdf>

16. Supportive Housing Program. Available at: <https://www.toronto.ca/community-people/housing-shelter/seniors-disabled/supportive-housing-program/>