

TORONTO FETAL ALCOHOL SPECTRUM DISORDER (FASD) COORDINATING NETWORK

*“No safe time, No safe kind, No safe amount.
Drinking alcohol during pregnancy can lead to
permanent brain damage in children”*

The Toronto FASD Coordinating Network was established in 2005 to enhance the capacity throughout Toronto to prevent and address FASD through the coordination and development of resources and initiatives serving children, youth, and adults living with FASD, their parents and care providers, pregnant women, and community stakeholders.

THE DISABILITY

**“The Charter of Rights and Freedoms says that all Canadians receive justice. But some children are born who do not receive justice. Nor will they ever be equal. It’s because they have damaged brains at birth, through no fault of their own”
Dr. Clifford Jones**

People affected by FASD are some of the most vulnerable, misdiagnosed, misunderstood and at-risk members of our community.

Fetal Alcohol Spectrum Disorder (FASD) is a brain-based, neuro-developmental disability with behavioural symptoms resulting from pre-natal exposure for the fetus to alcohol. The neuro-developmental impacts of FASD are on physical, behavioural, emotional, social and cognitive functioning (Health Canada, 2006; PHAC, 2005). FASD is the leading cause of developmental disabilities in North America and a recent study conducted with elementary school children in the Greater Toronto Area in Ontario revealed that 2-3% of the students studied were affected by FASD (Dr. Lana Popova, CAMH, 2018). In a recent United States prevalence study, the rate was estimated to be 3-5%, making FASD at least as, if not more, common than autism. All figures are considered to be conservative since the shame and blame often experienced by women who drank alcohol while pregnant results in it being under-reported.

FASD is referred to as an invisible disability because while a small percentage of those affected display facial features associated with FASD, the majority do not. The majority are of average or above average intelligence and look no different than those not affected by FASD. They are assumed to be able to behave, perform and achieve like everyone else, whereas in reality they simply cannot because of their disability. Every day they experience failure when they are expected to live up to expectations that are unrealistic and do not take into account their damaged brains.

Children, youth, and adults affected by FASD experience the following primary characteristics as a result of their disability:

- Are unable to adapt their behaviour to meet their own basic needs (Nathan Ory, Nov, 2004);
- Difficulty storing and retrieving information;
- Poor decision making;
- Inability to plan, remember and execute their plans
- Inability to remember dates, times, appointments, expectations, schedules, remember tomorrow what learned today;
- Sensory integration challenges affecting their sleep, their sense of hot & cold, sensitivity to touch, (labels on clothing/rough textures), eating difficulties (textures & spicing), noise, light, stimulating environments;
- Inability to learn from their experiences and self regulate their own actions;
- Dependence on others to assist them to be relatively organized. (Nathan Ory, Nov, 2004);
- Tendency to perseverate and repeat the same behaviour over and over because it becomes familiar and is easy to remember;
- Will get stuck in an arguments and can't let go;
- Tendency to get stuck in the here and now, can't move on with "regular" explanations, and need immediate gratification;
- Unable to follow more than one or two instructions at a time;
- Experience dysmaturity - the gap between their chronological age and the age at which they function. For example, a 30 year old adult may function at the level of a 12 year old;
- Difficulty understanding social cues;
- Poor money management;
- May appear articulate and able to communicate well, but have little to no comprehension of what they are communicating.
- Vulnerable to being easily influenced to please others;
- Concrete thinkers and react literally to what's being said;
- Likely to tell people what they think they want to hear, so will confess to crimes they haven't committed.

When FASD is not diagnosed early and followed by effective interventions, adverse outcomes can be expected. We know from the seminal research Streissguth et al, as well as other research studies, the following secondary disabilities and adverse outcomes may be experienced:

- 95% have mental health issues;
- 82% were unable to live independently (ages 12-51);
- 80% were raised by someone other than a biological parent;
- 70% had problems with unemployment (ages 12-51);
- 68% had disrupted school experience;
- 68% experienced trouble with the law;
- 52% exhibited inappropriate sexual behaviour;
- 30% had substance abuse problems;
- Youth with FASD are 19 times more likely to be incarcerated than their non-affected peers (Popova 2011);
- 43% will confess to crimes they did not commit (McLaughlin 2012);

- FASD is believed to affect at least 23% of those in youth corrections facilities (Conry, 2000) and a minimum of 30% of the adult inmate population, though escalation in the severity of crime is rare (MacPherson).

A recent study of Ontario youth living with FASD found that 86% had never been referred to or received any FASD-informed interventions or services, despite high levels of functional impairment across all domains. For those who did receive specialized intervention, the majority did so when participating in research studies (Todorow M, Moore TE, Fantus E, Sorbara D, Nulman I, 2011, a,b).

It has also been determined that the following factors protect individuals with FASD from developing secondary disabilities or adverse outcomes:

- Living in a stable and nurturing home;
- Being diagnosed before the age of 6;
- Never having to experience violence against oneself.

The costs of supporting those affected by FASD in Canada is estimated at \$6.2 billion annually (Thanh NX, Johnsson E, Dennet L, & Jacobs P,2011). The estimated return on investment in prevention of FASD is significant: “For every \$150,000 spent on prevention we will see \$1.5 million dollars in return” (Thanh,NX, & Jonsson E., 2009)

THE NETWORK

The role of the Network is to:

1. Act as a city wide planning and coordinating body to support those affected by FASD and their families.
2. Promote the prevention of FASD among women and men of child bearing age.
3. Increase awareness of the impact of FASD as a brain based disability on care and service provision in order to make services, supports and resources accessible to those living with the disability.
4. Pursue short term goals within broader strategic directions on how to best serve children, youth, adults, pregnant women, parents and care providers affected by FASD.
5. Identify, facilitate, exchange information and foster linkages between current and emerging programs, services, and initiatives.
6. Identify and address service gaps in order to promote the provision of a continuum of FASD specific supports, resources and services for children, youth, adults, pregnant women, parents and care providers.
7. Promote, coordinate and provide FASD related awareness, education/training and skill development opportunities for parents/care providers, service providers and the community at large
8. Promote the need to transform service systems to learn to accommodate the disability in sectors including, but not limited to: education; health; child welfare; early childhood and learning - including child care; developmental services; child, youth and adult mental health; justice and corrections; supportive housing and employment; recreation; policy makers; and funders.

9. Encourage the expansion of the current capacity to address FASD in the City of Toronto by identifying key resources and building on existing expertise.
10. Promote the incorporation of FASD into the education curriculum of relevant disciplines.
11. Advocate for and support policy development, research, and funding opportunities.
12. Act collaboratively in accessing relevant FASD funding opportunities.

The Network membership is comprised of over 40 members representing parents and caregivers, service providers, community volunteers and government representatives (Appendix A).

2015-18 strategic priorities identified in a 2014 community consultation hosted by the Network were:

1. Prevention & Early Intervention;
2. Case Management;
3. Supportive Housing

2019-22 Action Plan priorities were recently been identified as:

1. Prevention & Awareness
2. Intervention & Supports
3. Advocacy
4. Supportive Housing

ACCOMPLISHMENTS (2005-2019)

The Network is proud of its many accomplishment, having played a significant role in increasing awareness of FASD within the City Toronto as well as the encouraging the development of programs and services to address it.

Some of these accomplishments include:

PAST

- The production of a FASD Information Booklet widely distributed in and accessed by groups in Toronto, Ontario, Canada, the U.S.A. and internationally.
- Involvement in the development of the Toronto FASD Leadership Team (over 2000 professionals and caregivers trained; over 80 consultations provided).
- Involvement in the planning and organizing of Toronto's annual FASD Awareness Day held on September 9th each year, as well as throughout September which has been designated by the province as FASD Month.
- Consultation with other communities interested in developing FASD specific networks and/or training and leadership teams.
- Involvement in the development of the Toronto Child Welfare Respite Program
- Child Welfare Parent Support Group provided for adoptive and foster parents involved with CAS Toronto & CCAS. .
- Promotion of the establishment of a Toronto District School Board FASD designated classroom.
- Toronto has experienced a 50-60% reduction in diagnostic services. The Network has unsuccessfully advocated for those diagnostic services to be restored and sustained and

will continue to do so until every person affected by FASD living in Toronto has access to assessment and diagnostic services.

- Sponsor of workshops for parents/caregivers of children, youth and adults affected by FASD.

CURRENT

- Network received funding from the Circle for Children Foundation to offer a series of workshops for parent/caregivers in 2017-19 and again in 2019-20. To date the workshops have been attended by an estimated 450 parents/caregivers from Toronto as well as across central, east and south central Ontario region.
- Accessed funding to offering a “Changing the Script: Relationship Is the Key” group for foster, adoptive parents & caregiver of children, youth and adults affected by FASD. In 2018, two Network members (Jean Tweed Centre for Women & Bridgeway Family Homes) collaborated to offer the first group attended by 12 parent/caregivers. The group was located in Toronto’s west end and funding has been accessed to offer 2019 groups, one in the west end and one to be available in Scarborough for parent/caregivers living in the east area of the City.
- Advocating with the provincial government to ensure compliance by all alcohol selling outlets in the City of Toronto with the provincially legislated Sandy’s Law. Sandy’s Law requires all Ontario alcohol retailers to post visible signage informing customers about the risks of drinking alcohol while pregnant. Network members monitored a number of LCBO and other alcohol selling outlets to determine compliance and observed that few, if any, City of Toronto LCBO’s are in compliance. Where there is compliance, the poster may not be readily visible or the information is provided in a brochure form that is not easily seen or accessed. The Network’s observations and concerns have been to the attention of the Ontario Alcohol & Gaming Commission, the provincial body responsible for enforcing compliance with Sandy’s Law. It should be noted that in many Loblaw’s stores selling beer in Toronto, there is excellent signage warning of the risks associated with alcohol consumption during pregnancy.
- Developed a “Case Management Model”, for which funding is being sought to implement as a pilot.
- Developed a “FASD Supportive Housing Model” that will be shared with all supportive housing providers in Toronto, as well as with relevant government stakeholders.
- On July 17, 2018 a motion brought forward to the Toronto Board of Health by Toronto Councillor Joe Cressy, acting on behalf of the Network was approved. The motion reads as follows: “ *The Board of Health request the medical Officer of Health to consult with the Toronto FASD Coordinating Network 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, in consultation with the Affordable Housing Office, Social Development, Finance and Administration and Shelter, Support and Housing Administration as part of this report and report back in Q1 of 2019. (July 17 , 2018)* ”
- Will offer a Men’s Group, starting in the fall of 2019.

ADDENDUM A

TORONTO FASD COORDINATING NETWORK MEMBERSHIP: 2018

1. Amanda Rawn-Alton
Bridgeway Family Homes
2. Stephanie Ambert
Child Development Institute
3. Patricia Atchison
Bridgeway Family Homes
4. Christine Berube
Ministry of Children, Community and Social Services
5. Linda Boyd
Toronto Association for Community Living & grandparent
6. Tochil Carranza
Turning Point Youth Services
7. Trudy Clifford
Parent
8. Steve Catney
Alliance Youth Services
9. Amanda De Simone
Youthdale Treatment Centres
10. Rob Davidson
Children's Aid Society of Toronto
11. Paul Demaniw
LOFT Community Services
12. Mabinti Dennis
Native Child & Family Services
13. Diane Doucette
Bayfield treatment Centre
14. Medina Esmail
Covenant House
15. Tessa Feudale
Toronto Catholic District Board
16. Maureen Flynn
Parent
17. Tahmo Gharabaghi
George Hull Centre
18. Mary Hutchings
Toronto FASD Leadership Team/Community Volunteer
19. Victoria Jakawenko
Toronto District School Board
20. Ashleigh Judge
College Montrose Children's Place
21. Amber Kellen
John Howard Society of Toronto
22. Johanna Lake
CAMH
23. Ann Lindsay
Surrey Place Centre
24. Eric Marier-Toronto FASD Coordinator, Surrey Place Center
25. Lori Mastrogiuseppe
Parent
26. Jason McCormack (Co-Chair)
Turning Point Youth Services
27. John McKenzie
Parent
28. Rose Medeiros
Aisling-Discoveries Child & Family Centre
29. Cheryl Perera
Skylark Youth
30. Brian Philcox
Parent, FASWorld Toronto/Canada
31. Brianne Redquest
Centre for Addiction & Mental Health (CAMH)
32. Sharron Richards (Co-Chair)
Community Volunteer
33. Irene Rodero
Parent
34. Sonali Sagare
Jean Tweed Centre for Women & Their Families
35. Erin Sclisizzi
Catholic Children's Aid Society
36. Shirley Shedlesky
CARS/Skylark
37. Noel Simpson
Community Volunteer
38. Michelle Siple
Toronto Public Health

39. Antonella Tersigni
40. Paul Van de Laar
41. Marjorie Wingrove

Maple Star Specialized Foster Care
COTA
Parent

ADDENDUM B

REFERENCES

Health Canada (2006). *It's Your Health: Fetal Alcohol Spectrum Disorder*. Health Canada, Ottawa, Canada. ISBN#0-662-44064-1.

Public Health Agency of Canada (2005). *Fetal Alcohol Spectrum Disorder (FASD): A Framework for Action*. Public Health Agency of Canada, FASD Team, Ottawa, Canada.
<http://www.phac-aspc.gc.ca/publicat/fasd-fw-etcaf-ca/index-eng.php>

Streissguth, A.P., Barr, H.M., Kogan, J., & Bookstein, F.L. (1996). *Understanding the occurrence of secondary disabilities in clients with fetal alcohol syndrome: Final report to the Centers for Disease Control and Prevention on Grant No. R04/CCR008515* (Tech. Report No. 96-06). Seattle: University of Washington, Fetal Alcohol and Drug Unit.

Streissguth, A. P., Bookstein, F. L., Barr, H. M., Sampson, P. D., O'Malley, K., & Young, J. K. (2004). Risk factors for adverse life outcomes in fetal alcohol syndrome and fetal alcohol effects. *Journal of Developmental Behavioural Pediatrics*, 25(4), 228–238. doi:0196- 206X/00/2504-0228

Thanh NX., & Jonsson E. (Winter 2009). Costs of fetal alcohol spectrum disorder in Alberta, Canada. *Canadian Journal Clinical Pharmacology*. 16(1): e80-90. Epub 2009 Jan 16.

Thanh, N.X., Jonsson, E., Dennett, L., & Jacobs, P. (2011). *Fetal Alcohol Spectrum Disorder: Management and Policy Perspectives of FASD*, edited by Edward P. Riley, Sterling Clarren, Joanne Weinberg, Egon Jonsson pg 45-125. Wiley, John & Sons, Incorporated.

Todorow, M., Moore, T. E., Fantus, E., Sorbara, D., & Nulman, I. (2011a). Following adolescents with fetal alcohol spectrum disorder: A need for further services (preliminary results). *Alcoholism Clinical & Experimental Research*, Supplement 35(6), 113A.

Todorow, M., Moore, T. E., Fantus, E., Sorbara, D., & Nulman, I. (2011b). Available interventions and services used by Canadian adolescents with FASD and their families. *Journal of Population Therapeutics and Clinical Pharmacology*, Supplement 18(3), e421–e422.

September, 2018

THE TORONTO FETAL ALCOHOL SPECTRUM DISORDER
(FASD) NETWORK

REPORT TO THE
TORONTO BOARD OF
HEALTH

“No safe time, so safe kind, no safe amount.
Drinking alcohol while pregnant can lead to life-
long brain damage in children

Sharron Richards, Network Co-Chair

2019

***“No safe time, no safe kind, no safe amount.
Drinking alcohol while pregnant can lead to life-long brain damage in children.”***

On July 10, 2018, at the request of Councillor Joe Cressy, the Toronto Board of Health approved the following motion:

“The Board of Health request the Medical Officer of Health to consult with the Toronto FASD Coordinating Network 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, in consultation with the Affordable Housing Office, Social Development Finance and Administration, and Shelter, Support and Housing Administration as part of this report, and report back in Q1 of 2019. (July 10, 2018)”

The following is The Toronto FASD Network’s recommendations *“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 “.*

THE DISABILITY

Fetal Alcohol Spectrum Disorder (FASD) is a brain-based, neuro-developmental disability with behavioural symptoms resulting from a fetus’ pre-natal exposure to alcohol. The neuro-developmental impacts of FASD are on physical, behavioural, emotional, social and cognitive functioning (Health Canada, 2006; Public Health Agency of Canada, 2005). FASD is the leading cause of developmental disabilities in North America and a recent study conducted with elementary school children in the Greater Toronto Area revealed that 2-3% of the students studied were affected by FASD (Dr. Lana Popova, CAMH, 2018). In a United States prevalence study, the rate is estimated to be 3-5%. (May et al, 2009). Based on current research, it is now recognized that prevalence rates for FASD are higher than those for autism.

2016 census data established the population of the city of Toronto at 2.732 million people. Using current estimated FASD prevalence rates of 2-3% for Toronto, it can be conservatively estimated that the number of Toronto residents affected by FASD ranges from 54,640 to 81,960. This number does not account for an increased population since 2016. It is also important to note that FASD tends to be under reported due to 3 primary factors: 1) the reluctance of birth mothers to acknowledge drinking alcohol while pregnant due to the “blame and shame” they experience; 2) the requirement for women to confirm having consumed alcohol during pregnancy in order to access a diagnosis; and 3) the lack of FASD diagnostic services in Toronto and across Ontario. The City of Toronto has seen a significant loss of FASD diagnostic services over the past 5 years

as a result of the closure of Hospital for Sick Children's Mother Risk and the St. Michael's Hospital FASD diagnostic clinic. Therefore, the prevalence numbers quoted are probably both conservative and lower than in reality for 2019.

FASD is referred to as an invisible disability because, while a small percentage of those affected display facial features associated with FASD, the majority do not. The majority are of average or above average intelligence and look like those not affected by FASD. They are assumed to be able to behave, perform and achieve like everyone else whereas, in reality, they simply cannot. Every day they experience failure when they are expected to live up to expectations that are unrealistic and do not take into account their damaged brains.

Children, youth, and adults 16+ affected by FASD experience the following primary characteristics as a result of their disability:

- Are unable to adapt their behaviour to meet their own basic needs (Nathan Ory, Nov, 2004);
- Difficulty storing and retrieving information;
- Poor decision making;
- Inability to plan, remember and execute their plans
- Inability to remember dates, times, appointments, expectations, schedules;
- Remember tomorrow what learned today;
- Sensory integration challenges affecting their sleep, their sense of hot & cold, sensitivity to touch, (labels on clothing/rough textures), eating difficulties (textures & spicing), noise, light, stimulating environments;
- Inability to learn from their experiences and self regulate their own actions;
- Dependence on others to assist them to be relatively organized. (Nathan Ory, Nov, 2004);
- Tendency to perseverate and repeat the same behaviour over and over because it becomes familiar and is easy to remember;
- Will get stuck in an arguments and can't let go;
- Display a tendency to get stuck in the here and now, can't move on with "regular" explanations, and need immediate gratification;
- Unable to follow more than one or two instructions at a time;
- Experience dysmaturity: the gap between their chronological age and the age at which they function. For example, a 30 year old adult may function at the level of a 12 year old. In other words, they function at about half the age of their chronological age;
- Difficulty understanding social cues;
- Poor money management;
- May appear articulate and able to communicate well, but have little to no comprehension of what they are communicating.
- Vulnerable to being easily influenced to please others;
- Concrete thinkers and react literally to what's being said;
- Likely to tell people what they think they want to hear, so will confess to crimes they haven't committed.

When FASD is not diagnosed early and followed by effective interventions, adverse outcomes can be expected. We know from the Streissguth study, as well as other research studies, the following secondary disabilities and adverse outcomes may be experienced:

- 95% have mental health issues;
- 82% were unable to live independently (ages 12-51);
- 80% were raised by someone other than a biological parent;
- 70% had problems with unemployment (ages 12-51);
- 68% had disrupted school experience;
- 68% experienced trouble with the law;
- 52% exhibited inappropriate sexual behaviour;
- 30% had substance abuse problems;
- Youth with FASD are 19 times more likely to be incarcerated than their non-affected peers (Popova 2011);
- 43% will confess to crimes they did not commit (McLaughlin 2012);
- FASD is believed to affect at least 23% of those in youth corrections facilities (Conry, 2000) and a minimum of 30% of the adult inmate population, though escalation in the severity of crime is rare (MacPherson).
- The odds of escaping these adverse life outcomes are increased 2 to 4-fold by receiving the diagnosis of FASD or FAE at an earlier age and by being reared in good stable environments..

The costs of supporting those affected by FASD in Canada is estimated at \$6.2 billion annually (Thanh NX, Johnsson E, Dennet L, & Jacobs P, 2011). The estimated return on investment in prevention of FASD is significant: “For every \$150,000 spent on prevention we will see \$1.5 million dollars in return” (Thanh, NX, & Jonsson E., 2009)

PREVENTION

FASD is preventable when the risks associated with drinking while planning and during pregnancy are well known. Unfortunately, public awareness about FASD is lacking. Yet public awareness and education are key to ensuring that all of society, but especially women & men of child bearing age, pregnant women and those who serve them, are aware of the risks associated with drinking alcohol during pregnancy.

It is imperative that medical practitioners understand and acknowledge the risks associated with alcohol use during pregnancy. They need to communicate this information to their patients wanting to become pregnant, already pregnant or at high risk of becoming pregnant resulting from their use or misuse of alcohol.

Provincial alcohol retailers must also be involved in public education and awareness by complying with the Liquor License Act. According to a letter received by the Network from the Alcohol and Gaming Commission of Ontario (AGCO) :

“.....as of July 1, 2016, regulatory amendments have been implemented requiring all retailers of alcohol in Ontario to post Sandy’s Law signage warning about the dangers of consuming alcohol while pregnant.

The affected retailers include restaurants and bars licensed to sell beverage alcohol, The Beer Store, LCBO stores, manufacturer’s retail stores (“on-site retail stores”), wineries selling at farmers’ markets, and grocery stores authorized to sell wine, beer and cider.

The warning signs must be at least 8 by 10 inches in size, and printed in landscape format (horizontally). It must be prominently displayed in all locations where beverage alcohol is sold or where customers brew their own wine or beer for take home consumption.

Failure to comply with the signage requirements may result in administrative actions by the AGCO, as it is an offence under the Liquor Licence Act, with a maximum penalty of a \$250,000 fine for a corporation, or a \$100,000 fine and /or imprisonment for up to one year for an individual.”

There is minimal compliance with Sandy’s Law as stated above. Two of Ontario’s largest alcohol retailers – the LCBO and the Beer Store are some of the worst culprits of non-compliance with Sandy’s law. If any information about the risks associated with drinking alcohol when planning and during pregnancy is made available at the LCBO, it is rarely, if ever, as prescribed under the Liquor Licence Act prominently displayed in an 8 x 10, horizontal format. More usually, and if available at all, it will be found in brochures placed in a small brochure stand somewhere near the store exit. Customers may be unlikely to notice the brochures let alone pick one up when they are carrying the product they’ve just purchased.

RECOMMENDATIONS:

1. The City of Toronto engage in an active, year round public awareness and education campaign calling attention to the known risks associated with drinking alcohol during pregnancy. Special attention should be paid to relaying this message to women and men of child bearing age, university and community college students and pregnant women.
2. The City of Toronto to continue to actively engage in and support FASD Awareness Day activities occurring annually throughout the month of September, and particularly on September 9. The Mayor of Toronto officially proclaim September 9 as FASD Awareness Day, just as mayors since 1999 have done. The media should be informed about the proclamation by the City.
3. The Mayor or the Mayor’s delegate attend the September 9 FASD Awareness Day activities to speak on behalf of the City’s families.
4. The Medical Officer of Health strongly urge all medical practitioners in Toronto to adopt a zero tolerance to drinking for pregnant women and women planning to become pregnant by:
 - Establishing alcohol use protocols for dissemination of information to all female women and men of child bearing age;

- Discussing alcohol use with all patients of child bearing age;
 - Providing patients with appropriate FASD specific information, both pre & post conception.
5. The Toronto Medical Officer of Health urge local school boards to add information about FASD to their Family Studies/Life Skills curriculum for both primary and secondary grades.
 6. The Medical Officer of Health join with the Toronto FASD Network in requesting the provincial government's Alcohol and Gaming Commission of Ontario (AGCO) to enforce compliance with the Liquor Licence Act by all alcohol retail outlets in the City of Toronto, and especially the LCBO which is owned and operated by the provincial government.
 7. The Toronto Medical Officer of Health collaborate with Health Canada to establish appropriate packaging for all beverage alcohol products to advise consumers of the risks associated with drinking alcohol when planning and during pregnancy.

ACCESS TO SERVICES

FASD cannot be cured nor reversed. Individuals affected by FASD will require support throughout their lifetime. Interdependence and not independence is a more realistic goal for those living with FASD as they will require support across their lifespan.

Despite being significant users of most of our service systems, individuals affected by FASD have not been well served. Service systems have historically not understood FASD as a brain based disability and as a result have not learned to design and deliver services to accommodate the disability. The result is not benign. When service systems expect those affected by FASD to adjust to and accommodate how their services are delivered, service goals and expectations most often cannot be achieved. Failing to behave and perform as expected because their damaged brain impairs their ability to do so produces individuals who grow to think of themselves as “stupid”, disappointments and failures. They will go from requiring least intrusive interventions to most intrusive and are often described as those for whom no intervention effectively worked to help them successfully manage their lives.

Research and experience tells us that early diagnosis accompanied by an appropriate and doable intervention plan is key to improving life trajectories for those affected by FASD and for preventing the onset of secondary disabilities listed above. With the closure of both the Hospital For Children's Mother Risk Program and St. Michael's Hospital FASD diagnostic clinics in Toronto, we are currently reduced to one diagnostic service for Toronto's Indigenous community (Anishnawbe Health Toronto) and one for Toronto's non-Indigenous community (Surrey Place). Confirmation of alcohol use during pregnancy is required to obtain a diagnosis. It would be an understatement to say that Toronto is underserved when it comes to FASD assessment & diagnostic services.

When able to access services, supports and resources that accommodate their disability, those affected by FASD can do well. Unfortunately, in the current service delivery system, it is too often assumed that because they are doing well, they are no longer in need of those services and

supports, so they are withdrawn. When that happens, often repeatedly throughout their lives, all the progress they've made is lost. Service delivery must accommodate their disability on a consistent and continuous basis across the life span in order to produce positive, cost effective and sustainable results.

Because of impairments to their executive and adaptive functioning, a significant challenge for adults, 16+ affected by FASD is navigating service systems to access the resources and supports they require. Those affected by FASD don't remember appointments, misplace required documentation, are baffled by the language, length and complexity of the forms they are required to complete and can't recall information they are expected to provide such as relevant dates, events, relationships and personal history.

Yet it is critical they access the resources, services and supports they will always require. In response to this reality, the Network has developed a *Case Coordination Model For Adults 16+ Affected by FASD*. The goal of the Model is to assist and support affected adults access the services, resources and supports they will require to manage their disability over the course of their life span. A comprehensive funding proposal has been completed, in the hope that if/when funded, the FASD specific Case Coordination Model can be implemented as a pilot project for the City of Toronto

In addition to the challenges FASD creates for those affected by this disability, service eligibility criteria and service agency expectations too often reflect a lack of awareness and understanding of, as well as, accommodation for the disability. All those providing publically funded services to residents of the City of Toronto must become knowledgeable about this disability. They must then apply this knowledge to design and deliver their service to accommodate people living with FASD rather than the reverse.

RECOMMENATIONS:

1. FASD specific awareness, education and professional skill development should be made mandatory for all relevant City service providers and all front line agencies funded by the City.
2. The City of Toronto urge the government of Ontario to allocate the funding required to develop diagnostic services to adequately meet the need of City residents assessed or believed to be affected by FASD.
3. The City of Toronto, through advocacy and the allocation of resources, promote and support the implementation of FASD specific, case coordination services for FASD-affected adults 16+, including the City operated shelter system, supportive housing facilities and all frontline agencies funded by the City.

SUPPORTIVE HOUSING

Most adults, 16+, affected by FASD cannot manage living independently without life-long supports. In a seminal study conducted by Streissguth et al, 1996 & 2004, it was determined that:

- 82% of individuals, ages 12-51, affected by FASD, were unable to live independently.
- 68% experienced trouble with the law;
- Youth with FASD are 19 times more likely to be incarcerated than their non-affected peers (Popova 2011);
- 43% will confess to crimes they did not commit (McLaughlin 2012);
- FASD is believed to affect at least 23% of those in youth corrections facilities (Conry, 2000) and a minimum of 30% of the adult inmate population, though escalation in the severity of crime is rare (MacPherson).

People affected by FASD are some of the most vulnerable, misdiagnosed, undiagnosed, misunderstood, at-risk and underserved members of our community. It can be estimated that a significant number of adults 16+ affected by FASD experience homelessness and disproportionately access Toronto's shelter and correctional system..

Considering the above, it is not surprising that adults 16+ affected by FASD will experience significant challenges living independently and accessing permanent housing. Unless they have family to support them, most will experience homelessness. For those fortunate to have family with whom to live, aging parents and caregivers are gravely concerned about and fear for what will happen when they are unable to care for their affected family member(s). Others, with no family will end up "couch surfing", using the shelter system or living on the street. Too many are being housed in our mental health and addictions programs or correctional facilities. Housing providers are learning that living with FASD makes it very difficult for them to cope with group living, to meet service provider expectations and to feel secure in knowing that their living arrangement is permanent and stable.

While preventable, FASD is incurable and those affected will require support across the life span. It is unrealistic and ineffective to expect adults affected by FASD to successfully live independently. Our service systems and housing providers will be required to rethink the current service philosophy founded on a service goal of achieving independence. That philosophy and service goal must shift to one of interdependence, which those affected by FASD can achieve when appropriately supported. Without a shift to expecting successful interdependence with life-long support rather than independence, we will continue to fail those living with FASD.

While this may sound like an easy adjustment for service providers and supportive housing providers to make, in reality, it will require a substantial paradigm shift in thinking on the part of everyone involved in the provision of supportive housing (legislators, policy makers, funders, and service providers). To continue the current practice with people affected by FASD is unrealistic, harmful, expensive, and will continue to produce poor service outcomes.

Making this paradigm shift from expectations of independence to life- long interdependence will require unlearning things we have taken for granted for centuries in western culture. FASD specific training for all housing providers, especially all supportive housing providers, will be essential to successfully making this required paradigm shift. Government funding will be required to support this training.

When those affected by FASD can experience housing stability, many of their other problems will disappear or become manageable.

While the cost of providing supportive housing for adults affected by FASD may/will be high, the cost savings of providing permanent, FASD specific, supportive housing, will over time, offset those costs. Costs savings will be realized in reduced use of health, mental health, addictions, child welfare, justice and corrections services. For example, we know that significant numbers of correctional system inmates are affected by FASD. In most instances it will be undiagnosed and /or misdiagnosed. If, as estimated, it costs \$200,000 per year to incarcerate one female inmate and \$114,000 for one male inmate, any reduction to the number of people affected by FASD being incarcerated will produce cost savings. Having a permanent place to live will go a long way to allowing those living with the disability to experience the stability required to lead productive lives while keeping them off the streets and out of trouble with the law.

Adults incarcerated in the provincial correctional system are an especially high risk of homelessness population. A 2010 research study conducted by the John Howard Society of Toronto showed that:

- 44.6% of provincial inmates are homeless or at risk of homelessness upon release from correctional custody
- 43.3% of these individuals had severe health impairments.
- There are close to 2000 individuals currently on the wait list for the only type of housing that specifically targets individuals who are justice involved in Toronto, with an average wait time of 4.2 years. (Frank Sirotish et al, Wellesley, The Access- Point-Waiting-List-Analysis, March 2018, Wellesley Institute)
- 72% were homeless when they applied for supportive housing compared to 45% in the overall cohort of applicants (Ibid)

Supported housing gives adults the core of the structure they require to cope effectively as adults in the community. Supported housing - which includes a wide range of options, from semi-independent living to fully staffed facilities - provides structured environments, on-going social support, and in some cases, close supervision, all of which have been identified as effective interventions for adults with FASD”. (A Bridge to Adulthood: Maximizing the Independence of Youth In Care With Fetal Alcohol Spectrum Disorder, Child & Youth Office, British Columbia, 2006.)

While some FASD specific housing has been developed in the children’s and youth residential care system, little to none exists in the adult 16+ and youth transitioning to

adulthood supportive housing sector. The Network members believe that the recently announced national housing strategy, the Ontario FASD strategy and at the municipal level, the City of Toronto housing strategy has created an ideal environment to address the lack of supportive housing for adults affected by FASD.

The areas of greatest need as highlighted in the Streissguth et al. “Longitudinal Study of Adults 21+ Affected by FASD”, shows a strong correlation with the needs of Adults with Complex Mental Illness and Addictions as evidenced on the Supportive Housing Application Form. The individuals with such needs are streamed to 24/7 High Support Housing.

The program model for individuals exhibiting symptoms of FASD needs to have the same 24/7 High Support Supportive Housing. It is also important to note that the levels of support received by the individual prior to their 18th birthday should be continued in their adult life with an eye to providing age appropriate supports as they mature, all the while recognizing that the high support program may be essential for protracted periods of time.

The Toronto FASD Network has developed a model titled “*Housing to Effectively Support Adults 16+ Affected By FASD*”. The foundational values are: client centered; strength based; comprehensive; family engaged; access to required resources across an individuals’ life span; collaborative; culturally appropriate; and evidence based.

The intent is to share the “model” with Toronto’s supportive housing providers for feedback as well as to gain their buy-in. It will also be shared with relevant provincial government ministries in the hopes that they will support the model and fund its implementation as part of their recently announced provincial FASD strategy.

An initial approach might be to consider funding a pilot project here in Toronto that would be based on the Network model, be a collaboration of Network members, existing supportive housing providers and the City of Toronto. It would include training and skills development as well as evaluation and research.

The Toronto FASD Network would welcome an opportunity to collaborate in such a FASD supportive housing pilot project.

RECOMMENDATIONS:

1. FASD specific training be mandated for all shelter and supportive housing staff as well as all front line service agencies funded by the City. The Toronto FASD Leadership Team, an inter-agency training and consultation team established by the Network, is available to provide this training.
2. City funded supportive/alternative housing promote life-long interdependent living for those affected by FASD, be considered permanent housing and include a range of supports such as: life skills; money management; service coordination; employment support; etc.

3. City sponsored supportive housing should include individualized service plans based on the unique needs of individuals affected by FASD.
4. A portion of new supportive housing units created by the City be designated for adults living with FASD. The number could potentially be based on the estimated prevalence rate. Case coordination services are essential to creating stable housing.
5. The Network's *FASD Supportive Housing Model For Adults 16+* be shared with all City of Toronto shelter and supportive housing staff and all City funded front line agencies, for the purpose of education and possible implementation purposes.
6. The City and the Toronto FASD Network, develop an inventory of successful national and international FASD specific supportive housing services.
7. Given the documented high risk of homelessness for female and male inmates upon release from provincial correctional facilities, the City collaborate with the Elizabeth Fry Society of Toronto and the John Howard Society of Toronto to address the supportive housing needs of this exceptionally vulnerable population of the City.

The Toronto FASD Network welcomes this opportunity to work with Toronto's Medical Officer of Health and City of Toronto staff to improve the quality of life for the City's children, youth and adults affected by FASD and their families.

RECOMMENDATIONS SUMMARY

PREVENTION

1. The City of Toronto engage in an active, year round public awareness and education campaign calling attention to the known risks associated with drinking alcohol during pregnancy. Special attention should be paid to relaying this message to women and men of child bearing age, university and community college students and pregnant women.
2. The City of Toronto continue to actively engage in and support FASD Awareness Day activities occurring annually throughout the month of September, and particularly on September 9. The Mayor of Toronto officially proclaim September 9 as FASD Awareness Day, just as mayors since 1999 have done, and the media be informed about the proclamation by the City.
3. The Mayor or the Mayor's delegate attend the September 9 FASD Awareness Day activities to speak on behalf of the City's families.
4. The Medical Officer of Health strongly urge all medical practitioners in Toronto to adopt a zero tolerance to drinking for pregnant women and women considering becoming pregnant by:
 - Establishing alcohol use protocols for dissemination to all female women and men of child bearing age;
 - Discuss alcohol use with all patients of child bearing age;
 - Provide patients with appropriate FASD specific information, both pre & post conception.
5. The Toronto Medical Officer of Health urge local school boards to add information about FASD to their Family Studies/Life Skills curriculum for both primary and secondary grades.
6. The Medical Officer of Health join with the Toronto FASD Network in requesting the provincial government's Alcohol and Gaming Commission of Ontario (AGCO) to enforce Sandy's Law in all alcohol retail outlets in the City of Toronto, and especially in those owned by the provincial government - The Beer Store & LCBO.
7. The Toronto Medical Officer of Health collaborate with Health Canada to establish appropriate packaging for all beverage alcohol products to advise consumers of the risks associated with drinking alcohol while pregnant.

ACCESS TO SERVICES

8. FASD specific awareness, education and professional skill development should be made mandatory for all relevant City service providers and all front line agencies funded by the City.
9. The City of Toronto urge the government of Ontario to allocate the funding required to develop diagnostic services to adequately meet the need of City residents assessed or believed to be affected by FASD.
10. The City of Toronto, through advocacy and the allocation of resources, promote and support the implementation of FASD specific, case coordination services for FASD-affected adults 16+, including the City operated shelter system and all frontline agencies funded by the City

SUPPORTIVE HOUSING

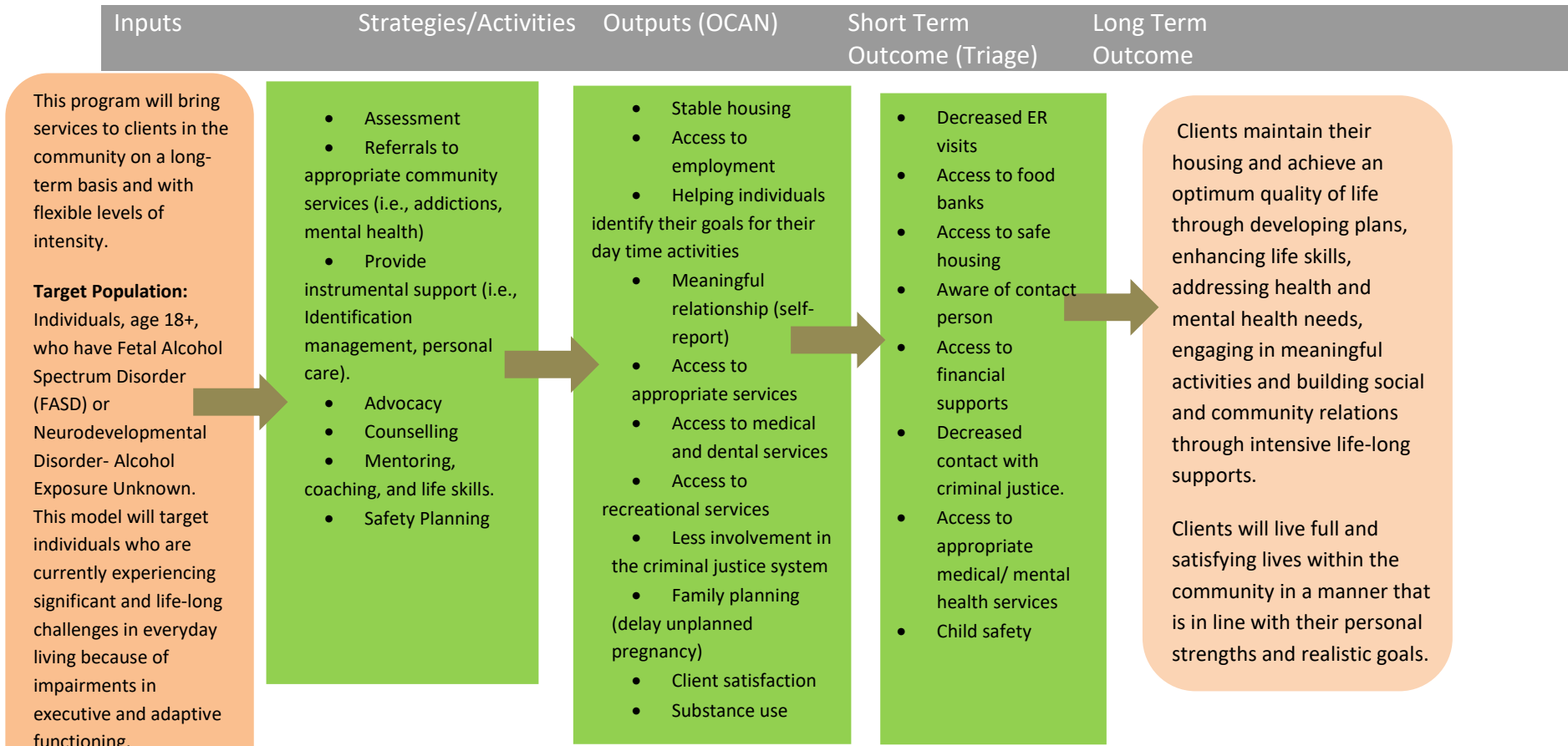
- 12 FASD specific training be mandated for all shelter staff and all front line service agencies funded by the City. The Toronto FASD Leadership Team, an inter-agency training and consultation team established by the Network, is available to provide this training.
- 13 City funded supportive/alternative housing promote life-long interdependent living for those affected by FASD, be considered permanent housing and include a range of supports such as: life skills; money management; case coordination; employment support; etc.
- 14 Supportive housing should include individualized service plans based on the unique needs of individuals affected by FASD.
- 15 New supportive housing units be created by the City to be designated for adults living with FASD. The number could be based on the estimated prevalence rate. Case coordination services are essential to creating stable housing.
- 16 The Network's *FASD Supportive Housing Model For Adults 16+* be shared with all City of Toronto shelter staff and all City funded front line agencies, for the purpose of education and possible implementation purposes.
- 17 The City and the Toronto FASD Coordinating Network, develop an inventory of successful national and international FASD specific supportive housing services.
- 18 Given the estimated, significant numbers of female and male correctional system inmates believed to be affected by FASD, along with the documented high risk for homelessness they experience upon release from correctional facilities, the City collaborate with the Elizabeth Fry Society of Toronto and the John Howard Society of Toronto to address the supportive housing needs of this exceptionally vulnerable population of the City

REFERENCES

1. Child and Youth Officer for British Columbia. (2006). Special Report: A Bridge to Adulthood: Maximizing the Independence of Youth in Care with Fetal Alcohol Spectrum Disorder. 46pp. <http://www.llbc.leg.bc.ca/public/pubdocs/bcdocs/406749/bridgeadulthood.pdf>
- 2.
3. Health Canada & the Public Health Agency of Canada
4. Implications of Higher Than Expected Prevalence of Fetal Alcohol Spectrum Disorders. Lange S, Rehm J, Popova S.JAMA. 2018 Feb 6;319(5):448-449. doi: 10.1001/jama.2017.21895.
5. May, PA, Gossage, JP et al. (2009). Prevalence and Epidemiological Characteristics of FASD from various research methods with an emphasis on recent in-school studies. *Dev Disabil Res Rev* 15: 176-192. <http://www.ncbi.nlm.nih.gov/pubmed/19731384>
□
6. Fetal alcohol spectrum disorder prevalence estimates in correctional systems: a systematic literature review. Popova S, Lange S, Bekmuradov D, Mihic A, Rehm J.Can J Public Health. 2011 Sep-Oct;102(5):336-40. Review.PMID:22032097
7. 4. Frank Sirotnish et al, Wellesley, The –Access- Point-Waiting-List-Analysis, March 2018, Wellesley Institute
8. Streissguth AP¹, Bookstein FL, Barr HM, Sampson PD, O'Malley K, Young JK. Risk factors for adverse life outcomes in fetal alcohol syndrome and fetal alcohol effects. Dev Behav Pediatr. 2004 Aug;25(4):228-38.

FASD: Case Management Model

Falling Between the Cracks: An FASD Case Management Model (Paradigm Shift in Service Delivery)



Parent Support Services: this model involves ongoing: training, consultation, coaching, support groups, grief and loss work to the client's informal support network (i.e., parents, siblings, partners, employers).

KEY ASSUMPTIONS:

- Case management workers will have comprehensive training and experience of FASD and appropriate intervention strategies. Ongoing training will be provided.
- Case management workers will employ a client centered strengths based approach.

KEY CHALLENGES/ RISKS:

- Lack of appropriate resources.
- Client adherence to/participation in developed plans/program. Therefore, it will be necessary to build in the provision of incentives (clothes, transit passes, calling cards, gifts cards) for attendance and participation.
- Burn out of caregivers and staff members.