

TORONTO BOARD OF HEALTH

June 10, 2019

TORONTO FASD NETWORK DEPUTATION

Good morning.

I would like to begin my presentation by reading a note recently shared with me by the mother of a 14 year old son diagnosed with FASD.

“Some of you know me some of you think you know me some may not care to know me but regardless, let me tell you who I am.

I am a wife, a very proud mom of two amazing young men who chose me to be their parent a pet owner..... a business owner.

Pretty standard stuff.

I am a fierce advocate a volunteer an educator.... an advisor... .a nurse a doctor.... a referee.

I am the one who stood between conflict in order to have the innocent not hurt.

I am the one who learned the mental health and judicial system quickly and how unfair and underfunded it truly is but what most of you don't know, I am a parent of a young man with FASD.

I may not like him some days but I love him to bits regardless of the troubles and would not have done life differently days are hard and, at times, seem never ending people don't understand and I am looked at as a bad parent, always judged but I know the truth and that's all that matters.

I have lived a lifetime of sadness in the last few years but get great joy out of what most would seem trivial when my son remembers what day of the week it is I am so proud or when the school didn't call it was reason to celebrate.

I have been hit, punched, bit, kicked, battered and bruised and called every name imaginable in both public and private and always having to remember that every day is a new day.

But life is good I have the boys, my husband, my animals, a roof over my head I don't want pity or sad emojis. All I want from you is for you to make just one person aware please do not drink while pregnant or if you are thinking of getting pregnant ... FASD is totally preventable.”

Lori M.

The Toronto FASD Network has submitted written documents telling you who we are, what we do and what we recommend the City can do to better serve the City's children, youth and adults affected by FASD & those who care for them. We urge you to read these documents.

In the few minutes remaining, I would like to leave you with these key messages related to FASD

- FASD, is a brain-based, neuro-developmental disability resulting from pre-natal exposure for a fetus to alcohol and impacts physical, behavioural, emotional, social and cognitive functioning (Health Canada, 2006; PHAC, 2005).
- It is the leading cause of developmental disabilities in North America.
- FASD is now believed to be at least as, if not more, common than autism.

(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 prevalent 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.)

- It is referred to as an invisible disability because while a small percentage of those affected display facial features associated with FASD, most do not, and look no different than those not affected by the disability.
- People affected by FASD can be of average to above average intelligence and so 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.
- FASD is preventable but not curable so those affected will require life- long support.
- Because the disability impacts one's adaptive & executive functioning, those affected will in all likelihood not manage to live independently but can successfully and with support live interdependently.

(Recognizing this reality will require a paradigm shift in how services are planned and delivered for those affected. This will not be easy since many, if not most, human services are founded on a service philosophy with a goal of achieving independence.)

- Dysmaturity is a hallmark of FASD. The rule of thumb is that those affected function at a level about half that of their chronological age. (The service implications of this reality are significant but rarely taken into account.)
- When service systems fail to understand and accommodate the disability, it is harmful to those living with FASD and leads to poor service outcomes.

- Those affected by FASD are beginning to demand to be heard and involved in making decisions about themselves. The campaign “Nothing About Us With Us” reflects this demand.

(The challenge will be to find the appropriate balance between respecting their right to participate in decisions about themselves while at the same time recognizing that the disability can impair their ability to make decisions that are in their own best interest. We can learn much from parents and caregivers who struggle with this challenge every day and have learned how to manage and overcome it.)

- The real FASD experts among us are those living with the disability and those caring for them. For many years, they have had to pretty much go it alone in learning about the disability, experimenting with what works and what doesn't and creating strategies for how the disability can best be managed.

We would be wise to listen to what they've learned so they can teach us how to better serve & support them.

(When it comes to FASD, they are the brave and courageous pioneers, the explorers, the experimenters. They are incredibly generous in sharing what they've learned along the way and in my mind are some of the most valiant and heroic caregivers you'll ever meet. They need to be heard, listened to and actively and meaningfully engaged in the planning, design and delivery of all services related to FASD?)

- The good news is that when children, youth and adults affected by FASD have their disability recognized, can access appropriate assessment & diagnostic services, can access throughout their life time services, resources and supports that understand and accommodate their disability, are appropriately supported to live interdependently rather than independently and have their strengths identified and nurtured, they will experience positive service outcomes and lead full and productive lives.

I will end by saying thank you to Councillor Joe Cressy & bravo to all Toronto Board of Health members for today publically acknowledging FASD and for asking how our City can better support those affected by this disability. I want you all to know what a powerful message you are sending by letting them know that you've heard their desperate pleas for help and as their municipally elected representatives you feel compelled to do what you can to support them.

Thank you

Sharron Richards

Co-Chair, Toronto FASD Network