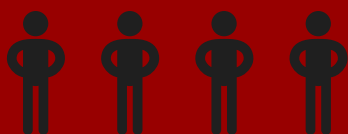


Shining a Light on FASD in Newfoundland & Labrador

fasdNL - December, 2018

Some facts:



- FASD is the leading cause of acquired developmental disability with a prevalence rate of 4% in Canada.

In Canada, FASD is:

- **2.5x more common than Autism (1.53%)**
- **19x more common than Cerebral Palsy (0.21%)**
- **28x more common than Down's Syndrome (0.14%)**
- **40x more common than Tourette's syndrome (0.10%)**

Did you know?



- FASD occurs in every society that consumes alcohol.
- Substance use costs the Canadian economy 38.4 billion dollars per year.
- Early diagnosis & intervention can mitigate adverse outcomes & help develop appropriate supports.
- FASD is permanent, therefore prevention is an important component of FASD work.

Experiences of parents & caregivers in NL

Giving voice to parents & caregivers of individuals with FASD in Newfoundland and Labrador.

Caring for individuals with FASD often requires:

- Significant amounts of time and energy.
- Interruptions in familial tasks and routines.
- Advocating for additional resources or professional help.
- Struggles to teach daily routines.
- Emancipation concerns.

At a glance

- **fasdNL directly supports over 30 parents & caregivers in NL through its own groups, board members, partners, and resources.**
- **We support parents and caregivers in all regions of the province and include biological, foster, and adoptive families.**

What are some of the biggest challenges?



- Dealing with the school system to educate about FASD and seek supports.
- Struggles with teaching and learning of repetitive routines (e.g., hygiene, food choices, planning/organizing, completing school work).
- Encountering resistance when seeking assistance and support for their child.

What
parents &
caregivers
would like
you to **know**.



On FASD & difference.

"FASD isn't always obvious to see and it affects people differently. In my children, they all have different needs."

"Every individual case is different."

On assumptions & stigma.

"Give people with FASD and their parents the benefit of the doubt. It's not easy parenting. I don't always need advice, just an ear."

"Give the child a fighting chance to succeed."

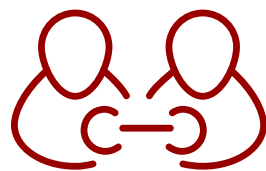


On prevention.

"Alcohol/ FASD does not discriminate. Some harm reduction is better than none. It's important to seek out help if you have concerns about your child, and that you don't have to feel guilt, shame etc if it means getting help you and your child need."



What do
parents &
caregivers
recommend?



- Shorter waitlists to see doctors and professionals.
- Respite care in the home.
- Childcare with staff who know about FASD.
- More support groups for parents.
- Information about growing up with FASD and transition to adulthood.
- Public education and awareness.
- Having a support team.

How do parents & caregivers cope?



Talking with others

"Talking with other parents who have a similar parenting style/approach and have challenges with a child (not necessarily FASD)."

"I try to spread the word on FASD to people all the time when in the right space."

"I talk to others when I know them well or people who are dealing with similar issues."

How has fasdNL helped?



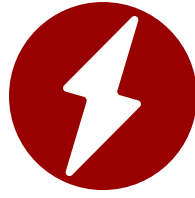
"I received booklets, learned where to get a time-timer and some names of doctors that deal with FASD. It was helpful."

"The get togethers have been an incredible support, wealth of information, place to vent, and place to find hope! How we wished we had this support before in our early months and years of helping our kids navigate FASD. The Virtual Support Group is finally something to meet that need. Now parents across the province can benefit from the vital support, capacity building, and hope that can only come from parents sharing the same worries, fears, and struggles together."

FASD 101: What participants have learned

FASD 101 is an introductory training developed by fasdNL and delivered to over 600 participants across NL and Atlantic Canada.

What are the most important things participants learned from FASD 101?



"Very important to be careful with language and not place any blame on moms for FASD. Instead, offer support."

"Never really thought about the problem with 100% preventable the way it was presented today (despite knowledge of addictions). Thanks!"

"Good reminder of the stigma/myths that occur within the general population."



"That people with FASD can perform incredibly well in school/work and are not what I had in mind (a stereotype)."

"Different approaches that work when working with those that have FASD."

What questions did participants still have?



"What's being done to increase supports in NL? i.e., diagnostic team being developed? where are they? why aren't they here?"



"What supports are available for parents, caregivers, front line workers?"