Accessibility of FASD supports and services

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March 24, 2023

FASD prevention

1. Broad awareness building and health promotion strategies (e.g., campaigns for general public)
2. Discussion of pregnancy, alcohol use, and related risks with women of childbearing age and their support networks
3. Specialized, holistic support of pregnant women who use alcohol
4. Support for new mothers to maintain healthy changes made during pregnancy and ongoing support for women who were not able to stop alcohol use

Gaps in current prevention efforts

- Public education campaigns have elevated awareness of FASD, but campaigns alone are not sufficient to change behaviours of women at highest risk of alcohol use in pregnancy (Clarren et al. 2011)
- Use of alcohol by pregnant women occurs within a complex web of other influences, including interpersonal violence, socioeconomic status, mental illness, and isolation (Motz et al. 2006)
- Pregnant women facing multiple and complex issues during pregnancy often "fall through the cracks" of uncoordinated systems of care (Clarren et al. 2011; Marcellus et al. 2015)

Person-centered, trauma-informed framework

Adapted from Poole et al., 2010

Barriers to FASD prevention programs

- Experiences of systemic and institutional racism
- Housing and food insecurity
- Histories of trauma and interpersonal violence
- Mental illness and other substance use
- Childcare and transportation issues
- Fear of stigma, judgment, and child protective services involvement

Implications for tailoring and accessibility

- Need for a more systemic approach to FASD prevention with strong linkages between the multiple levels of prevention efforts, and integrated, multidisciplinary care (Salmon and Clarren 2011)
- Trauma-informed and culturally appropriate: sensitive to histories of violence and systemic/institutional racism
- Holistic: improving health, income, housing, and other social needs (Poole et al., 2008)
- Collaborative, integrated: addressing mental health and other substance use

Practical barriers to care

1. Distance and transportation
2. Lack of accommodations
3. Language barriers

Source: depositphotos.com

Distance and transportation

- Higher rates of alcohol and substance use in rural areas, but lack of multidisciplinary care and treatment (Oni et al., 2020; Russell et al., 2020)
- Women in rural areas:
  - Are 3 times more likely to list accessibility as a barrier to care (Oni et al., 2020)
  - Sometimes travel several hours for services (Ali et al., 2020)
- **Considerations**: Mobile clinics, consultation via videoconference or text message, integration of substance use and primary care services with teleconsultation for primary care providers (Oni et al., 2020; Pijl et al., 2022)

Accommodations

- People with disabilities are at elevated risk of alcohol and substance use but are more likely to experience barriers to preventive and treatment-related services (Krahn et al., 2006)
- Reasons include negative attitudes of health care providers, “double stigma” of disability and substance use, lack of physical and communication-related accessibility, other social determinants
- **Considerations**: Training of program staff, provision of appropriate accommodations, collaboration with disability organizations (Ledingham et al., 2022)

Language

- Although rates of alcohol use in pregnancy are lower in immigrant/ refugee women vs. Canadian-born women, language barriers are a significant issue for those who do need care (Maina et al., 2023)
- Interpretation services are rarely available, prevention and treatment programs rarely consider cultural appropriateness, stigma and shame (Maina et al., 2023)
- **Considerations**: Availability of interpreters, cultural competency of providers, attention to other social determinants of health

Implications

Need for flexible, tailored prevention and treatment supports that attend to multiple facets of accessibility

Source: googledesign.com

A long-term perspective on FASD supports…

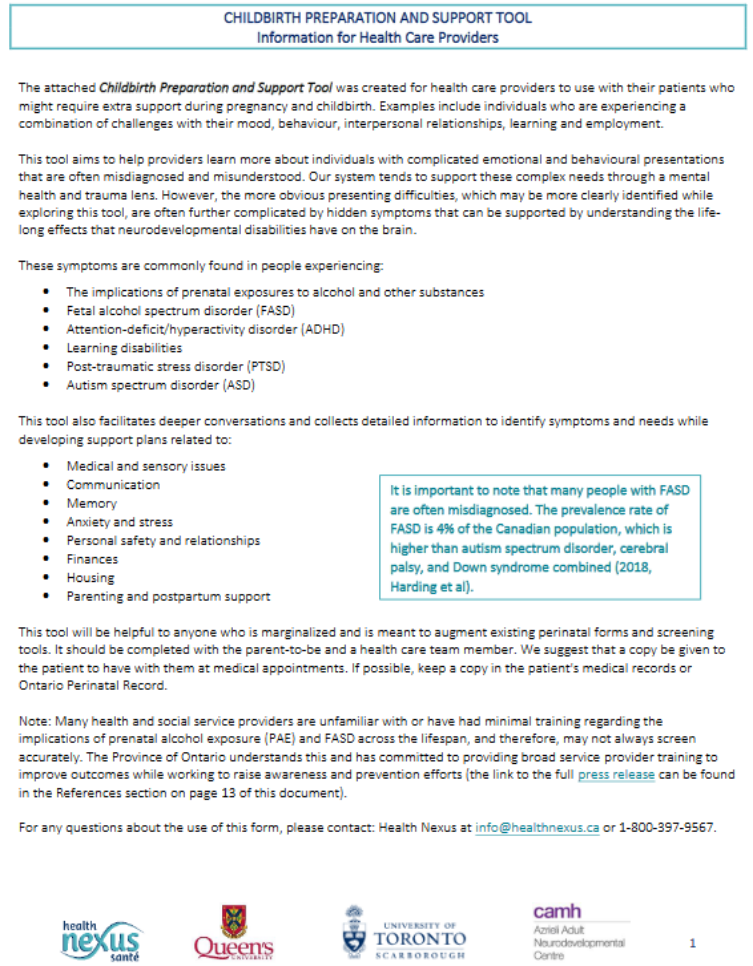
Source: depositphotos.com

FASD in reproductive-aged women

- 4% of Canadians have FASD, with higher rates in certain groups (Flannagan et al., 2018)
- Women with FASD have higher rates of mental illness, substance use, and experiences of interpersonal violence than those without FASD (Popova et al., 2016; McConnell et al., 2020; Weyrauch et al., 2017)
- They also experience barriers to prenatal care (Nishat et al., 2021)
- Women with FASD and other developmental disabilities at elevated risk of pregnancy and postpartum complications (Brown et al., 2018; Brown et al., 2022)

Support for women with FASD in pregnancy

- Support persons
- Medical and mental health needs
- Sensory, communication, and memory needs
- Personal safety and relationships
- Financial, housing
- Postpartum and parenting needs



CHILDBIRTH PREPARATION AND SUPPORT TOOL
Information for Health Care Providers

The attached ***Childbirth Preparation and Support Tool*** was created for health care providers to use with their patients who might require extra support during pregnancy and childbirth. Examples include individuals who are experiencing a combination of challenges with their mood, behaviour, interpersonal relationships, learning and employment.

This tool aims to help providers learn more about individuals with complicated emotional and behavioural presentations that are often misdiagnosed and misunderstood. Our system tends to support these complex needs through a mental health and trauma lens. However, the more obvious presenting difficulties, which may be more clearly identified while exploring this tool, are often further complicated by hidden symptoms that can be supported by understanding the life-long effects that neurodevelopmental disabilities have on the brain.

These symptoms are commonly found in people experiencing:

- The implications of prenatal exposures to alcohol and other substances
- Fetal alcohol spectrum disorder (FASD)
- Attention-deficit/hyperactivity disorder (ADHD)
- Learning disabilities
- Post-traumatic stress disorder (PTSD)
- Autism spectrum disorder (ASD)

This tool also facilitates deeper conversations and collects detailed information to identify symptoms and needs while developing support plans related to:

- Medical and sensory issues
- Communication
- Memory
- Anxiety and stress
- Personal safety and relationships
- Finances
- Housing
- Parenting and postpartum support

It is important to note that many people with FASD are often misdiagnosed. The prevalence rate of FASD is 4% of the Canadian population, which is higher than autism spectrum disorder, cerebral palsy, and Down syndrome combined (2018, Harding et al).

This tool will be helpful to anyone who is marginalized and is meant to augment existing perinatal forms and screening tools. It should be completed with the parent-to-be and a health care team member. We suggest that a copy be given to the patient to have with them at medical appointments. If possible, keep a copy in the patient's medical records or Ontario Perinatal Record.

Note: Many health and social service providers are unfamiliar with or have had minimal training regarding the implications of prenatal alcohol exposure (PAE) and FASD across the lifespan, and therefore, may not always screen accurately. The Province of Ontario understands this and has committed to providing broad service provider training to improve outcomes while working to raise awareness and prevention efforts (the link to the full press release can be found in the References section on page 13 of this document).

For any questions about the use of this form, please contact: Health Nexus at info@healthnexus.ca or 1-800-397-9567.

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1

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Questions?

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