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Why FASD Diagnostic Assessment is Important

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KEY MESSAGES

Early diagnosis of Fetal Alcohol Spectrum Disorder (FASD) allow for an understanding of an individual's strengths and challenges which facilitates entry into appropriate intervention and support services. In turn, early diagnosis can mitigate the development of difficulties in daily living associated with this neurodevelopmental disability and promote healthier outcomes. Even if individuals do not meet the criteria for a diagnosis of FASD, a comprehensive multidisciplinary assessment process for those who have had prenatal alcohol exposure (PAE) provides important information about learning, behaviour, and physical and mental health that will guide care and appropriate supports. This issue paper outlines the importance of an FASD diagnostic assessment to supporting and improving outcomes for diagnosed individuals and their families.

Issue:

Fetal Alcohol Spectrum Disorder (FASD) is a diagnostic term used to describe the lifelong neurobehavioural and physical impacts on the brain and body of people prenatally exposed to alcohol. Individuals with FASD will experience some degree of challenges in their daily living and need support to navigate these challenges and reach their full potential. Early and effective identification through screening and diagnostic assessment, leading to appropriate interventions, are important to improving outcomes for this complex population.

Background:

FASD is a lifelong disability, affecting 4% of Canadians or over 1.5 million people. [1-5]. Individuals with FASD are often unidentified and when unsupported, may experience complex challenges, including mental health issues (approximately 90% of individuals with FASD) and substance use problems (approximately 48% of individuals with FASD) [6-8]. Symptoms of FASD are often complex, present similarly to other conditions and may not be recognized until later in life, thus individuals with FASD may not come to the attention of service providers until the school years or beyond. “Often children present first to family physicians, paediatricians and psychologists who lack sufficient expertise to confidently diagnose FASD” [9]. PAE is generally underreported because of the stigma and shame attached to both alcohol use during pregnancy and FASD itself. As a result, opportunities for comprehensive assessment are missed. Because of these issues, many individuals with FASD may be misdiagnosed with other disabilities or unrecognized altogether. For these reasons, estimates of prevalence across all studies are believed to be conservative [12].

The effects of PAE are complex and multifaceted. Although PAE can affect individuals of any age, gender, culture, socioeconomic background or geographic region, the likelihood of adverse effects of PAE, including FASD, can increase in groups who have experienced or are experiencing adversity and trauma, mental health challenges, family and peer alcohol consumption, and social and economic isolation [10]. Each individual with FASD is unique and has areas of both strengths and challenges that can be identified as part of multidisciplinary FASD diagnostic assessment [11].

FASD falls well within the definition of a *disability* as provided in the Convention on the Rights of Persons with Disabilities (CRPD) [13]. The second paragraph of Article 1 of the CRPD identifies that “persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others” [13]. However, people with FASD may not secure a diagnosis due to various challenges with the process, which can then create barriers to accessing the necessary supports and services for individual success. Even when an individual is recognized to have FASD, many have average intelligence, thus may not meet the diagnostic criteria for an intellectual disability (i.e., IQ below 70), needed to receive support and services. Furthermore, the inability to secure a diagnosis because of limited diagnostic resources has meant that persons with FASD may not be able to access the necessary supports and services and may continue to experience on-going discrimination and stigma [14].

Ensuring access to comprehensive assessment and diagnostic services are aligned with several articles outlined in the CRPD, including awareness-raising (Article 8) and the right to health and healthcare without discrimination on basis of disability (Article 25) [13]. Despite children and youth with FASD and other complex needs have not been well supported and are largely unidentified in collected data of publicly funded support [16]. Recent research indicates that identified supports and services for persons with FASD are still lacking and FASD remains a low priority in Canada for research and policies informing resources and services [17].

Importance and Implications of an Early FASD Diagnostic Assessment

Although FASD is a permanent, lifelong disability, early and accurate diagnosis provides a mechanism for entry into intervention and support services which can mitigate the development of adverse consequences and associated costs [9,18-20]. The importance of supporting individuals with FASD and their families throughout the lifespan is also critical to achieving and maintaining successful outcomes [22-26].

Diagnosis at any age leads to a better understanding of both the individual's strengths and areas of challenge, although early diagnosis of FASD is associated with fewer adverse outcomes later in life [18]. Diagnosis can help identify the strengths upon which to build and support, as well as guide realistic and personally meaningful goals and expectations in other areas. Families often report a sense of relief when they receive a diagnosis and understand the underlying issues impacting the individual with FASD. Identification of FASD among individuals and their families can also provide a sense of community and a voice for self-advocacy.

Making a diagnosis of FASD may assist those with the disability in obtaining health, education, and vocational services tailored to their unique needs. FASD assessment requires both an etiologic diagnosis (i.e., identifying the cause) and a functional diagnosis (i.e., identifying consequences) as well as an opportunity for prevention. The diagnosis of FASD and improved understanding of an individual that comes with the diagnosis can provide education and encourage meaningful support for women who struggle with problematic alcohol use. Although the diagnosis of FASD is critical in the early years, it is especially important to understand the evolving neurodevelopmental and neuropsychiatric presentations. In particular, this understanding can form the foundation of supports and services that help with difficulties during transition times such as entry into primary school, intermediate and high school and when transitioning into adult life and adult services.

The Role of Screening in FASD Diagnostic Assessment

FASD screening is a process for identifying individuals who have PAE and are displaying behaviours or characteristics that may be associated with FASD. These individuals may benefit from referrals for further assessment, including FASD diagnostic evaluation, and for FASD-informed supports. Sensitive and specific screening is also helpful estimating the prevalence of FASD. At the organizational level, knowing how many people may have FASD can inform program and policy decisions, such as making the case for FASD-focused treatment beds, or advocating for resources to support an FASD-specific worker on staff [27-29].

Screening of children for PAE and early diagnosis can also facilitate the prevention of subsequent PAE-affected births by providing appropriate interventions, treatment, counseling, and support for parents [30]. Appropriate screening strategies may also facilitate early recognition and intervention for other siblings [31].

Screening is *only* effective if individuals are being screened accurately and if the screening tool being applied is validated. Screening may be considered in groups such as:

- Individuals participating in substance use treatment programs who are trying to get pregnant, are sexually active but not using birth control, or during pregnancy
- Children seen in neurodevelopmental and/or genetic clinics
- Children in childcare systems (e.g., orphanages, foster care, child welfare/social services, etc.)

- Prison populations
- Youth in juvenile justice programs
- Clients in the mental health care and addiction systems

Diagnostic Assessment Across the Lifespan

While potentially more challenging, it is possible to accurately diagnose infants and young children with FASD. A recent study reviewed 10 years of evidence for diagnostic assessment of preschoolers with PAE and demonstrated that those who met the criteria for FASD showed significantly greater global developmental impairment compared with those with PAE alone [30]. These preschoolers demonstrated significantly impaired receptive and expressive language abilities, impaired motor skills, and had more difficulties with executive functioning and adaptive functioning skills [30]. Their executive functioning difficulties coupled with significant differences in sensory processing impacted their day-to-day behaviours. It is also important to note that these challenges may get worse over time [28, 32-36].

Researchers have demonstrated that standardized assessment of motor and sensory processing skills along with a comprehensive assessment of language, are significant predictors of FASD diagnosis for preschoolers with PAE [30]. Early assessment and identification will assist parents, caregivers, and professionals in supporting the child to promote optimal development and reduce the effects of FASD by improving developmental patterns as the children age, thereby preventing future potential adverse outcomes commonly associated with FASD [33].

An FASD diagnosis during adulthood can also be beneficial to the individual, their family, and the community. At present, adults in Canada have limited access to diagnostic services compared to children and youth. Adults with FASD frequently require supports to maintain work and housing, financial assistance, specialized treatment for mental health issues, and assistance with a variety of daily living tasks. Access to these types of supports can be dependent on a diagnosis of disability, and in the absence of diagnosis, services for individuals with FASD and their families may be unavailable or withheld [3,27].

Recommendations:

1. Individuals of all ages can benefit from an assessment for a diagnosis of FASD. Referral of individuals at any age for an FASD diagnostic assessment should be made whenever there is evidence of or suspected PAE.
2. Strengthening and increasing access to FASD screening and diagnostic services is crucial in order to enhance opportunities for earlier intervention. Screening could play an important role in populations known to have higher prevalence rates of FASD, including individuals in the child welfare system, corrections, and mental health and substance use treatment programs. Engaging policy makers to establish referral processes and criteria across different systems (health care, education, social services, etc.) to optimize referrals for FASD diagnosis is critical to this effort as is increasing diagnostic capacity across the country. Additionally, policy makers should invest in an FASD-informed and trained workforce as well as screening tools and diagnostic assessment services. Education and training to increase

the capacity for recognition of FASD outside specialist FASD assessment centres is also needed.

3. The diagnostic criteria for FASD are the same for adults as for younger individuals but the diagnostic tools and assessment team may vary as the importance and ability to assess the various brain domains of functioning may differ with age. The length and structure of the assessment must accommodate the individual’s needs and capacity to participate fully in the process. The recommendations following the diagnostic assessment must address basic and immediate needs of the individual and assist them in accessing the supports and services they need. There may be times during an individual’s lifespan when assessments should be updated, particularly the neuropsychological components.
4. Parents, caregivers, and others supporting an individual assessed for FASD should be empowered to participate in the diagnostic process whenever possible, and in care planning activities which result. Supporting family involvement will allow clinicians to obtain more complete information that can facilitate and strengthen the assessment process and will prepare them for their role in assisting their loved ones following a diagnosis. Families and caregivers also play an active and invaluable role in assisting children, youth, and adults with possible FASD to complete the numerous components of the diagnostic process.
5. By ratifying the CRPD in 2010, Canada consented to be bound by this convention and has agreed to develop national policies that provide persons with disabilities with opportunities for protection, provision, and participation. As such, all levels of government are required to ensure that they are implementing policies, legislation, programs, and services to accommodate individual differences while maintaining respect for each person’s inherent dignity. Provinces and territories of Canada need to consider the UNCRPD and the rights of individuals to have access to a diagnosis for FASD.
6. The diagnosis of FASD should include meaningful opportunities to reach out to birth mothers who may be struggling with alcohol and/or other substance use problems and who may be in need of care for themselves in a respectful and sensitive way. Training around best practices for talking to women about alcohol use during pregnancy should also be a mandatory part of healthcare curricula.
7. The diagnostic assessment should provide discussion of an individual’s strengths and challenges, with the goal of facilitating interventions and supports that provide tangible outcomes in partnership with individuals, families, communities and systems.

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