

Fetal Alcohol Spectrum Disorder (FASD)

Term Describing Screening, Assessment, and Diagnosis

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OBJECTIVE

The purpose of this document is to help inform the Coordinating Committee of Senior Officials (CCSO) Criminal Justice Steering Committee on Fetal Alcohol Spectrum Disorder (FASD) and related Federal/Provincial/Territorial Working Groups on commonly used terms describing screening, assessment, and diagnosis of FASD. This document defines these terms and does not attempt to address the myriad of issues within the criminal justice context.

DEFINITIONS

The following terms are commonly used in discussions of FASD.

1. Fetal Alcohol Spectrum Disorder (FASD)

FASD is a non-diagnostic umbrella term used to encapsulate the three medical diagnoses that are caused by pre-natal alcohol exposure (Fetal Alcohol Syndrome, partial Fetal Alcohol Syndrome, and Alcohol Related Neurodevelopmental Disorder)¹. These diagnoses are used to distinguish between different types of adverse consequences to the individual as a result of pre-natal alcohol exposure. One diagnosis is not more severe than another.

Characteristic features of FASD include growth deficiencies, physical malformations (primarily facial features), and central nervous system deficits. Central nervous system deficits vary among individuals with FASD. All areas of the brain can be affected resulting in problems with achievement, adaptation, attention, cognition, executive functioning, memory, motor and sensory responses, and communication (Lang 2006).

¹ Alcohol Related Birth Defects (ARBD) includes congenital anomalies and is excluded here as individuals with ARBD do not have central nervous system damage. In other words, they are considered to have normal brain functioning. According to the Canadian guidelines for diagnosis “the term ARBD should not be used as an umbrella or diagnostic term, for the spectrum of alcohol effects” (Chudley et al. 2005, p. s12).

Experts in FASD emphasize the complexity of the diagnosis:

“The FASD adult needs to be looked upon as a neurologically impaired individual with a brain injury” (Chudley et al. 2007, p. 269).

1.1 Fetal Alcohol Syndrome (FAS)

There are three main criteria for a diagnosis of FAS: pre-natal and/or post-natal growth delays, facial anomalies - thin upper lip, small-set eyes, short palpebral fissures, and a smooth space between the upper lip and nose - and evidence of significant central nervous system deficits in at least three brain domains (e.g., memory, executive functioning, attention, etc.). It is not necessary to have confirmation of pre-natal alcohol exposure for a diagnosis of FAS because characteristic facial anomalies have been found to be exclusively the result of pre-natal alcohol exposure.

1.2 Partial Fetal Alcohol Syndrome (pFAS)

Partial FAS previously was termed Fetal Alcohol Effects (FAE). For a diagnosis of partial FAS, confirmation of pre-natal alcohol exposure is required. Individuals with pFAS have some of the facial anomalies and growth delays, but not to the same degree as with FAS. Individuals with pFAS have evidence of significant central nervous system deficits in at least three brain domains.

1.3 Alcohol Related Neurodevelopmental Disorder (ARND)

For a diagnosis of ARND, confirmation of pre-natal alcohol exposure is required. Physical anomalies are usually nonexistent or minimal for a diagnosis of ARND. Individuals with ARND have evidence of significant central nervous system deficits in at least three brain domains. The prevalence of ARND is higher than for both FAS and pFAS (Chudley et al. 2005).

2. Primary and Secondary Disabilities

Primary disabilities associated with FASD include the central nervous system deficits that result from pre-natal exposure to alcohol. The term “secondary disabilities” describes additional challenges not present at birth that may develop as the individual with FASD progresses through childhood and adulthood. Examples of secondary disabilities include problems with:

- mental health;
- substance abuse;
- employment;
- independent living; and
- justice system involvement (Streissguth et al. 1997).

3. FASD Screening/FASD Referral

FASD screening and/or referral is a process for identifying individuals that may be “at risk” for FASD. In this context, “at risk” refers to individuals who display behaviours or characteristics that have been found to be associated with FASD and suggests they may benefit from undergoing a FASD assessment. If an individual displays behaviours or characteristics associated with FASD, they may sometimes be considered to have “screened” positive on various screening tools (i.e., they are “at risk”). This does not mean they have FASD; it means they should be referred for a FASD assessment to determine through an appropriate evaluation if they do indeed have FASD or another disability. The Canadian guidelines for diagnosis advise that “the purpose of screening should be to facilitate referral to a diagnostic clinic” (Chudley et al. 2005, p. s6). There are no clinically validated screening tools that flag individuals “at risk” for FASD; however, there are several screening tools in existence (Goh et al. 2008).

4. FASD Assessment²

An FASD assessment refers to a multidisciplinary evaluation of an individual’s growth, facial features, central nervous system functioning, and history of pre-natal alcohol exposure. Unlike assessments for a mental disorder which are often completed by one medical professional (family doctor, psychiatrist, or psychologist), an FASD assessment requires expertise and input from both a medical doctor (usually either a paediatrician or geneticist) and a neuropsychologist. Other professionals are also recommended to be part of the assessment team including a speech language pathologist and occupational therapist.

Given the high rate of individuals with FASD who also have mental health problems, some FASD assessment clinics also have a psychiatrist as part of the assessment team. The team of professionals must have knowledge of FASD and the diagnostic criteria associated with this disability.

An FASD assessment also involves synthesizing existing information related to the physical, psychological, behavioural, environmental, historical and genetic history of the individual. Information can come from a variety of sources including birth records, medical records, correctional files, child and family services records, school records and/or interviews with the individual and family members.

An FASD assessment is looking for the etiology (cause) of the behaviours and characteristics of an individual. An FASD assessment is not the same as a diagnosis. A diagnosis (either FAS, pFAS, or ARND) is one of the range of outcomes that can result from an assessment. Multiple other outcomes can result from an FASD assessment other than a diagnosis of FASD.

As examples, outcomes could include:

- no problems or issues identified;
- medical or psychiatric condition not related to FASD;
- neuropsychological deficits of unknown origin (e.g., learning disability, memory problems);
- neuropsychological deficits where there was pre-natal alcohol exposure but the deficits do not meet the criteria for an FASD diagnosis; or
- FASD remains unknown (e.g., pre-natal alcohol exposure remains unknown).

² For more information on the assessment process and diagnostic criteria associated with a FASD diagnosis, please consult the Canadian guidelines for diagnosis (Chudley et al. 2005).

4.1 Differential Diagnosis

There is no blood test available to conduct assessments and make diagnoses under the fetal alcohol spectrum of disabilities. The FASD assessment process involves what is referred to as “differential diagnosis”. This means that the assessment team must first explore other possible explanations such as genetic or medical conditions, developmental level, familial background, environmental factors, etc., for any central nervous system deficits and physical anomalies. Ultimately, determining if it is FASD is largely reliant on evidence of a history of maternal alcohol use during pregnancy (Badry and Bradshaw 2010, p. 43).

4.2 Treatment Planning

As mentioned above, there are three medical diagnoses for FASD: FAS, pFAS, and ARND. A treatment plan is included in all FASD assessments that result in a diagnosis. Treatment plans vary but are based on individual strengths, problems, and needs. The Canadian guidelines for FASD diagnosis state that “treatment planning and implementation, specifically targeted toward the unique needs of the individual and the family form a large part of the diagnosis” (Chudley et al. 2005, p. s14).

In cases where an individual was found to have neurocognitive deficits (but not FASD) (e.g., memory problems, learning disability, executive functioning issues), a treatment plan may also be put in place.

5. Functional Assessment

Functional assessments are a systematic process to examine an individual’s overall functioning to determine their level of social, occupational, and psychological abilities. In other words, functional assessments examine an individual’s ability to perform everyday tasks. A functional assessment is less concerned with the etiology (cause) of the behaviours and characteristics. There are many different types of functional assessments and not all assessments examine if an individual has cognitive deficits. A generic functional assessment is not able to identify if an individual has FASD; that would require an FASD assessment.

ADULT FASD ASSESSMENTS IN CANADA³

FASD assessments for adults occur in Canada following the same guidelines used for children. The Canadian guidelines for diagnosis are used (Chudley et al. 2005). FASD assessment clinics are limited in Canada. FASD assessment clinics generally operate on a fee for service basis and are not covered by provincial/territorial health care plans. As indicated in a recent report for the Public Health Agency of Canada, Badry and Bradshaw stated, “it is a challenge to diagnose adults without an existing infrastructure in policy and practice that supports this community need” (2010, p. 48).

Assessments for adults are more challenging than for children primarily for two reasons:

- ability to confirm pre-natal alcohol exposure; and
- confounding factors – distinguishing FASD from other possible causes (e.g., traumatic brain injury, chronic alcohol abuse, etc.).

³ The same process used to assess adults for FASD is used for children and youth.

Despite these challenges, many FASD assessment clinics have been able to identify individuals with FASD. For example, of 28 referrals for an adult FASD assessment in Whitehorse, 26 of the individuals received a diagnosis under the spectrum of FASD (Badry and Bradshaw 2010). A similar result was found at an adult FASD clinic in Alberta. All 41 referrals received a diagnosis under the spectrum of FASD (Badry and Bradshaw 2010).

Experts in the field continually argue the need and benefits of assessments for FASD. For example, Chudley et al. (2007) states “a diagnosis may mitigate progression or reduce secondary disabilities, provide an answer to the individual for his or her disabilities and failures, and improve their likelihood of being connected to interventions and services for FASD adults” (p. 270).

Furthermore, Badry and Bradshaw (2010) stated that the value of a “diagnosis to these adults is that supports can be delivered through individual planning in order to assist them in negotiating these challenges while living in their community” (p.17). “Where services are limited in the community, an individual should not be denied an assessment for diagnosis and treatment. Often the diagnosis in the individual is the impetus that leads to the development of resources” (Chudley et al. 2005, p. s11).

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