Chapter 11

Fetal Alcohol Spectrum Disorder: Evidence, Theory and Current Insights

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Abstract

Fetal Alcohol Spectrum Disorder (FASD) results from brain injury associated with prenatal alcohol exposure (PAE) and comprises pervasive, permanent neurodevelopmental differences which impact health, educational and vocational outcomes. Social workers have important roles in preventing PAE and supporting individuals with FASD at all life stages. An interdisciplinary approach to diagnosis, prevention, earlier intervention, and systems navigation that includes social workers helps optimize opportunities and mitigate secondary adverse outcomes for individuals affected by FASD. Interprofessional practice will enable social workers to apply their knowledge and skills to recognize functional challenges, develop relationships and empower individuals, families, and communities impacted by FASD.

Keywords: Fetal Alcohol Spectrum Disorder/Disorders, alcohol, pregnancy

Background

Fetal alcohol spectrum disorder (FASD) represents a continuum of effects encompassing physical, developmental, emotional, and behavioral consequences of injury resulting from prenatal alcohol exposure (PAE). PAE is common (Popova et al, Chapter 3, in press), but the factors leading to alcohol use during pregnancy are complex and variable. The risk of developing FASD depends on unpredictable interactions between PAE and other factors, including genetics, epigenetics, and environment but FASD is preventable if PAE can be avoided. FASD occurs all over the world, in every ethnic group, and in every stratum of society, although higher risk groups are identifiable. The functional consequences of FASD are heterogeneous but, regardless of the individual's needs, FASD has impacts across the lifespan. Through earlier diagnosis and intervention, adopting a strengths-based approach and cognizant of the social determinants of health (SDoH), collaborative approaches can mitigate primary effects of FASD and secondary adverse outcomes. Lifelong support is required to assist with navigating health, mental health, disability, employment, legal, and family services and accommodating for challenges in adaptive skills, including activities of daily living (ADL), self-care, employment, and housing.

In this chapter we highlight the role of social workers in prevention and earlier identification of FASD and support of individuals to navigate systems. This will enable these individuals to maximize their potential, mitigate secondary adverse outcomes, and support families and communities in the process. We will briefly review the history and prevalence of PAE and FASD; provide recommendations for reframing our 'professional jargon' through use of respectful language; and consider trauma, disability and culturally informed practices. We will describe the common ['universal'] elements of the medical diagnosis of FASD, the functional impacts and secondary adverse outcomes in FASD; and provide recommendations for a collaborative approach to shared care and decision making to improve outcomes.

Chapter Highlights

- **PAE** is common and can be harmful to mother and child. “No amount of alcohol consumption can be considered safe during pregnancy”. (US Surgeon General, CDC, 2005)
- Not all PAE results in measurable effects or a diagnosis of FASD. Outcomes of PAE are unpredictable due to complex interactions between dose and timing of alcohol exposure, maternal/fetal genetics, metabolism, placental function , and pre- and post-natal environment.(Thomas, 2010)
- Risk for FASD is increased when women drink in high quantity and/or frequency (eg binge pattern), when absorption is increased (fasting, poor nutrition, lower body weight), and when there is concurrent exposure to smoking or substances. (May, 2011)
- All women who drink alcohol should be informed of the potential risk of harms associated with PAE. FASD has a higher prevalence in any population where women in their childbearing years consume alcohol. (Popova et al., Chapter 3 in press)
- FASD is primarily a Neurodevelopmental Disorder (ND) and diagnosis requires assessment by a multidisciplinary team. (Stratton, 1996; Chudley, 2005)
- Timing of PAE and maternal nutrition and other exposures may contribute to the appearance of physical signs (e.g. smoking, maternal nutrition and general health status, etc). (Thomas, 2011)

- Individuals with FASD have a pattern of brain function which may affect all aspects of development: physical, intellectual,~~lmental,~~ emotional, and social and result in early developmental delays, challenging behaviours and difficulties in learning and adaptive skills (Mattson, 2001, O'Connor, 2014))
- FASD is frequently described as a prenatally 'acquired brain injury' and an 'invisible disability', as many individuals may not show other physical signs. Persons with FASD are often perceived as *being the problem*, as opposed to being recognized as *having a disability*.
- While recognized as one of the most common causes of developmental disability worldwide, the majority of individuals diagnosed with FASD do not have intellectual impairment (IQ score below 70) and may be excluded from education and disability support services if defined solely by their IQ score (Streissguth, 1996).
- It is never too late to make a FASD diagnosis because the brain is 'plastic' and new skills can be learned, however interventions in early life may mitigate secondary adverse outcomes and increase developmental potential. (Thomas, 2011)
- All systems working with individuals in child welfare, juvenile and adult justice systems should enhance awareness, collaborate with medical, mental health, and disability, and adopt policies and that acknowledge and treat the effects of PAE and better assist individuals with FASD. (ABA, 2014; TRC, 2015)
- The social worker can play a key role across the lifespan in helping individuals with FASD and their families navigate support services.

Prenatal Alcohol Exposure (PAE)

Most international guidelines recommend abstinence from alcohol for women who are planning pregnancy, are pregnant, or breastfeeding (CDC, 2005, Chudley, 2005, NHMRC, 2009; Carson et al., 2010; Cook, 2015). Despite this advice and the known harms of PAE, alcohol use during pregnancy remains common. Detailed prevalence data from the World Health Organization (WHO), included in Chapter 3 (Popova et al., Chapter 3 in press), show that approximately 10% of pregnancies worldwide are associated with PAE and 25% of pregnant women who drink any alcohol consume four or more drinks on an occasion. However, rates vary significantly by geographic region and socio-economic status, with the highest rates among women from high-income countries and lowest rates among women from low-income countries (Popova et al., *in press*). For example, alcohol use during pregnancy is most prevalent in the WHO European region and lowest in the South-East Asia and Eastern-Mediterranean regions. This pattern is changing, with significant increases in alcohol use during pregnancy in South America, Africa and Asia.

Individual country data indicate that rates of any alcohol use during pregnancy are much higher than 10% in certain sub-populations. For example, about 60% of pregnant women in Quebec Canada (Popova et al., Chapter 3 *in press*), Melbourne (Muggli et al., 2016) and Sydney, Australia (McCormack et al., 2017) consumed alcohol. Furthermore, high rates of risky alcohol use in pregnancy have been recorded in disadvantaged communities, including Indigenous communities in Australia (Fitzpatrick et al., 2015) and South Africa (May et al, 2013).

Pregnancy is a powerful motivator for women to stop using alcohol: women rarely drink to harm their offspring and many women abstain or cut down alcohol use once they know they are pregnant. However, approximately half of all pregnancies in middle- to high-income countries are unplanned, frequently resulting in unintended PAE during the first trimester - after conception but before pregnancy recognition. PAE continues throughout some pregnancies, potentially harming the woman, their pregnancy and infant outcomes. PAE can have lifelong consequences for offspring, including FASD (Popova et al, Chapter 3).

Why Women Drink During Pregnancy

Reasons for alcohol use during pregnancy are many and include intrinsic and extrinsic factors. Intrinsic factors, such as family history (Astley, et al,2000) and possible genetic predisposition to alcohol use disorder, are detailed elsewhere in this book (Chapters 4 through 6). Extrinsic factors include social determinants of health (overcrowded housing, unemployment, poor access to education and health care), a history of adverse childhood experiences or ACEs, (Felitti et al., 1998), smoking and other drug use, mental health challenges, alcohol use by partners and family, and exposure to domestic or sexual violence (Chapters 7, 34, and 35). The impact of early-life trauma including child abuse and neglect and historic trauma (such as forced removal from family, displacement from traditional lands, war and famine) may be transmitted over generations via epigenetic mechanisms.

As a result, some clinicians perceive FASD to be primarily a problem for children of women with alcohol use disorders or belonging to marginalized or oppressed groups. However, higher socio-economic status is a strong predictor of PAE and it is likely that FASD is underdiagnosed in educated, financially secure groups (McCormack et al, 2017; Popova et al. Chapter 3).

Reframing the Language of PAE and FASD

Many health professionals are reluctant to ask about PAE for fear of stigmatizing women or damaging their relationship with the patient; others don't know how to ask, what to advise or where to refer, indicating the need for building skills and knowledge. The consensus of health professionals is that use of the term "prenatal alcohol exposure" (PAE) is preferable to "maternal alcohol use during pregnancy" when possible, because it acknowledges that alcohol – a known teratogen and neurotoxin – is the cause of harm to the unborn child. It reminds us that women drink alcohol for many reasons and that it is important to resist placing stigma, shame or blame.

In an effort to decrease stigmatization regarding PAE and promote dignity in those with FASD and their families, international and bi-annual satellite meetings held in Vancouver Canada have been designed to challenge assumptions and change the conversations about FASD and include the voices and 'lived experience' of parents and adults with FASD. Recommendations from the "Map the Gaps Report from Manitoba Canada" include reframing and refocusing our dialogue on FASD to avoid ascribing blame, shame, hopelessness, and fatalism. These include shifting from a focus on the individual to a focus on the context, including community factors and values that led to PAE. Core values that are promoted as solutions include community interdependence, resourcefulness to create change, pragmatic harm reduction approaches, and healthy public policy to address the root causes associated with multiple social determinants of health. (FrameWorks Institute, 2017)

"Fetal alcohol spectrum disorder (FASD) can result from exposure to alcohol during pregnancy. Whether or not alcohol exposure leads to FASD depends on a complex set of biological and

social factors that interact in different ways for each person. Biological factors can include a woman's sensitivity to alcohol, metabolism, and size. Social factors like chronic stress, violence, trauma, or poverty can increase the chances that a baby might be born with FASD.
*(*FrameWorks Institute, 2017, p41)

Clinicians and researches working in the field of FASD prevention, diagnosis and support agree that working to develop evidence-based policies and programs can lead to better outcomes. Changing the conversation about persons with FASD is also important:
People with FASD may have an "invisible disability" that can include difficulties with memory and cognition, organization, and sensory overload. But the brain is always growing and changing, and innovative programs can help people with FASD… (FrameWorks, 2017)

Guidelines to help change public and professional language are now under development in several jurisdictions. See the references for the "Language Guide for Promoting Dignity for those impacted by FASD" developed with the Canada Northwest FASD Partnership, 2017 http://www.fasdcoalition.ca/wp-content/uploads/2016/10/LAEO-Language-Guide.pdf.(Canada Northwest FASD Partnership, 2017)

SDOH, ACES and FASD

Relevant to social workers, many individuals with FASD have experienced adverse childhood experiences (ACEs) including early life trauma, separation, family dysfunction and substance use in the home. Additional adverse social determinants of health (SDoH) including overcrowding, financial and social poverty, and lack of access to quality health care and education may co-exist. Some clinicians discuss FASD in the context of "Family Adversity and

Stress Disorders (FASDs) because PAE may be a marker of maternal social adversity and physiological stress - whether due to historic or current trauma or disadvantage. There is emerging evidence pertaining to the developmental origins of adult health and disease suggesting that the fetus may be hyper stressed *in utero* as a result of both PAE and maternal stress hormones (Kobor, 2011). A survey of over 200 participants from the 2019 International FASD Conference in Vancouver revealed universal agreement that FASD is associated with historical or continued adverse SDoH. (Loock, Elliott, 2019).

An Historical Perspective on Fetal Alcohol Syndrome (FAS)*

For centuries and in many cultures, PAE has been described as harmful, (Judges 13.7, Sullivan, 1899) as summarized by O'Neil (O'Neil, 2011)

. However, PAE also has been considered safe at various times in history in the belief that the placenta could filter and protect the fetus from harm, with the conclusion that:

> *"The offspring of alcoholics have been found defective not because of alcoholism of the parents but because the parents themselves came from a defective stock"* (JAMA, 1946).

The harms of PAE were 'rediscovered' in the 1960s in France among 127 infants born to "des parents alcoholiques" (Lemoine et al, 1968). However, Jones and Smith in Seattle were the first to apply the name Fetal Alcohol Syndrome (FAS) to the constellation of characteristic facial features, developmental problems, and growth failure observed among children with high levels of PAE (Jones and Smith, Lancet 1973 a,b). Alcohol is now well recognised as a teratogen (a substance that may disrupt normal development of the embryo and fetus resulting in physical or birth defects) and neurotoxin (a substance that may interfere with or injure the developing brain and nervous system and cause intellectual and other functional impairment).

What Is FASD?

During the three decades after the term FAS was coined - it became evident that a spectrum of problems may result from PAE. By 2000, the term FASD emerged as an umbrella term to encompass a range of diagnoses and disabilities associated with PAE (Streissguth, O'Malley,2000) and in 2005 was incorporated into clinical guidelines (Chudley et al., 2005). The key feature of FASD is injury to the brain resulting in neurodevelopmental impairment, which manifests as behavioral, learning, developmental and emotional problems. A diagnosis of FASD requires documentation of multiple, pervasive, marked functional impairments, involving several domains of brain function, which requires measurement and validation through a multi-disciplinary assessment. Facial or other physical anomalies and growth deficiencies are variable. (See below).

How much is TOO much?

Since the precise lower threshold for effects from PAE including FASD is unknown, pregnant women should be advised to abstain from all alcohol use if possible. (Loock, 2005)

> *"There is evidence that alcohol consumption in pregnancy can cause fetal harm. There is insufficient evidence regarding fetal safety or harm at low levels of alcohol consumption in pregnancy. There is insufficient evidence to define any threshold for low-level drinking in pregnancy. Abstinence is the prudent choice for a woman who is or might become pregnant. Intensive culture-, gender-, and family-appropriate interventions*

> *need to be available and accessible for women with problematic drinking and/or alcohol dependence."* (Carson, et al, 2010).

The alcohol guideline used in Canada is shown in Box 1 and the advice to women who are pregnant or planning pregnancy (Guideline 4) is similar to that provided in other countries including the UK, USA and Australia.

Box 1: Canada's Low Risk Drinking Guidelines (2011):

Guideline 1 recommends no exposure in certain situations including … "working; making important decisions; if pregnant or planning to be; before breastfeeding; while responsible for the care or supervision of others …

Guideline 4: When pregnant or planning to be pregnant: The safest option during pregnancy or when planning to become pregnant is to not drink alcohol at all. Alcohol in the mother's blood stream can harm the developing fetus. While the risk from light consumption during pregnancy appears very low, there is no threshold of alcohol use in pregnancy that has been definitively proven to be safe.

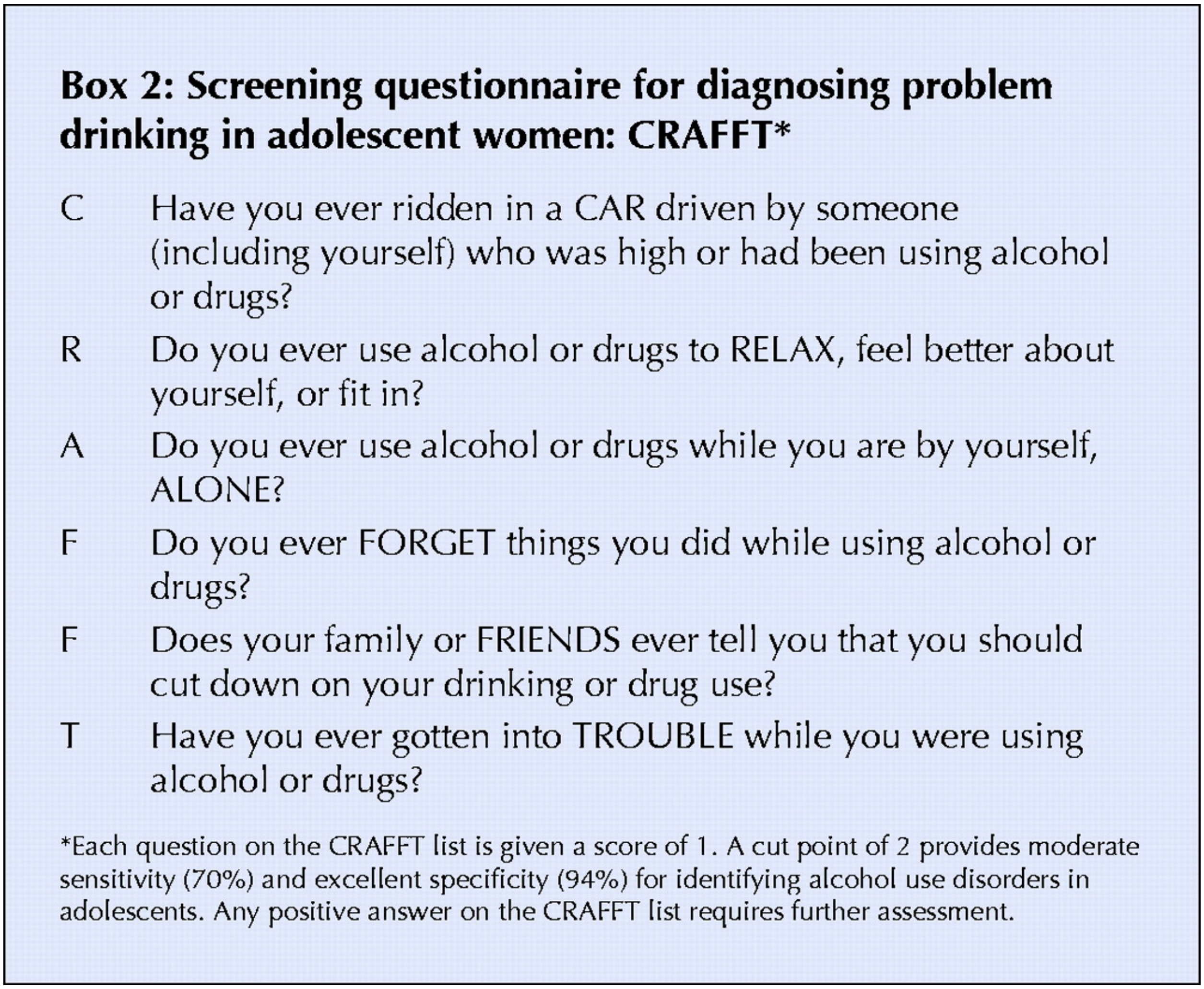
Screening and Referral for PAE: Always ask all women

Consistently asking all women screening questions related to their current and past alcohol consumption in a sensitive and culturally appropriate manner is essential. Tools for asking in a standardized and valid way and referral resources for women at risk are discussed in other chapters. (Chapter xxx in press)

When a woman shares concerns regarding preconception or prenatal alcohol exposure or FASD, the social worker may be the first contact able to provide support, make referrals when indicated, and if trained, provide counselling using early brief intervention techniques.

> *"The public should be informed that alcohol screening and support for women at risk is part of routine women's health care."* (Carson, et al 2010)

Updated consensus guidelines reaffirm the need for universal screening for PAE in all pregnant women and women of child-bearing age, using trauma- informed practices (TIP). (Carson, G et al, 2017, Cook, Jocelynn pc, 2019) Several screening tools for alcohol use and PAE have been found to be sensitive and specific. These include CRAFFT (Knight,) for adolescent women (Box 2); the modified CAGE (Cut-Down, Annoyed, Guilty, Eye-Opener) questions developed by Sokol and colleagues (Sokol et al 1989) which includes T [TOLERANCE]-ACE and TWEAK which ask additional questions about alcohol tolerance for pregnant and nonpregnant women; and the AUDIT-C~~. SEE CHAPTERS XXX FOR FURTHER DISCUSSION OF SCREENING.~~



Box 2: Screening questionnaire for diagnosing problem drinking in adolescent women: CRAFFT*

C	Have you ever ridden in a CAR driven by someone (including yourself) who was high or had been using alcohol or drugs?
R	Do you ever use alcohol or drugs to RELAX, feel better about yourself, or fit in?
A	Do you ever use alcohol or drugs while you are by yourself, ALONE?
F	Do you ever FORGET things you did while using alcohol or drugs?
F	Does your family or FRIENDS ever tell you that you should cut down on your drinking or drug use?
T	Have you ever gotten into TROUBLE while you were using alcohol or drugs?

*Each question on the CRAFFT list is given a score of 1. A cut point of 2 provides moderate sensitivity (70%) and excellent specificity (94%) for identifying alcohol use disorders in adolescents. Any positive answer on the CRAFFT list requires further assessment.

FASD is clinically heterogenous

FASD does not occur following every pregnancy associated with PAE because the FASD phenotype depends on a complex interplay between factors – exposure, timing, dose and frequency of PAE, maternal and fetal genetics, epigenetics (Kobor, 2011) and maternal stress (Ref). Clinical outcomes are modified by post-natal exposures including early childhood trauma and ACEs.

Even with similar levels of PAE, clinical outcomes among offspring may differ: for example, there is greater concordance between monozygotic than dizygotic twins. (Streissguth and Dehaene, 1993, Astley-Hemingway, 2019). The timing of PAE is an important determinant for a range of alcohol related birth defects that occur following first trimester exposure. The characteristic [sentinel] facial features associated with FASD begin to develop within the first three weeks post conception (Sulik, 1981, Astley and Clarren, 1999).

Certain groups are at higher risk of FASD including individuals: who have siblings with FASD; have mothers with alcohol misuse disorders; are in foster, adoptive or out-of-home care including orphanages; live in disadvantaged communities; are in contact with the justice system or in juvenile detention (Fast, 1999) ; or have developmental problems of unexplained etiology. (Popova et al., 2019). Although universal screening is not indicated, targeted screening for PAE, developmental delay and characteristic [sentinel] facial features may be indicated in high risk groups. (Astley, 2002; Fast ,1999).

Preventing “secondary” adverse outcomes through earlier diagnosis

The Streissguth “Secondary Disability” study described multiple adverse challenges and outcomes among adolescents and adults with FASD including problems with mental health, independent living and contact with the justice system (Streissguth et al.,1996). She proposed that many of these “secondary” effects might be modified by earlier intervention and hence were not “primary” impacts or disabilities related to PAE. (Streissguth et al., 2004). Newer research suggests that some of these secondary effects may actually be “primary”, such as mental health and social communication. (O’Connor, 2009; O’Connor 2014)

Table X: **Secondary Conditions or Outcomes identified in a longitudinal study of FASD (1996 University of Washington ‘Secondary Disabilities” study)**

Secondary outcomes

- Disrupted schooling experienced by 60% (age 12 and older)
- Trouble with the law experienced by 60% (age 12 and older)
- Confinement: For inpatient psychiatric care, inpatient chemical dependency care, or incarcerated for a crime, experienced by about 50% of the subjects (age 12 and older)
- Inappropriate sexual behavior: Sexual advances, sexual touching, or promiscuity, experienced by about 50% of the subjects (age 12 and older)
- Alcohol and drug problems for 35% of the subjects (age 12 and older)

1. Dependent living experienced by 80% of the subjects (age 21 and older)
2. Problems with employment experienced by 80% of the subjects (age 21 and older)
3. Mental health problems [which may be primary or secondary] were reported in over 90% of the subjects.

Protective factors and strengths

- Living in a stable and nurturing home for over 73% of life
- Being diagnosed with FAS before age six years
- Never having experienced violence
- Remaining in each living situation for at least 2.8 years
- Experiencing a "good quality home" from age 8 to 12 years old
- Having been found eligible for developmental disability (DD) services
- Having basic needs met for at least 13% of life
- Having a diagnosis of FAS (rather than another FASD condition)

Every individual with FASD is unique and a full multi-disciplinary assessment allows clinicians to identify each individual’s strengths and needs so that the relevant systems can develop individualized support plans. Outcomes are influenced and can be significantly improved by social and environmental factors – a stable and nurturing environment, early diagnosis, and earlier disability interventions and supports. As one young adult with FASD pointed out, clinicians should not take the attitude that the destiny is set for a person with FASD at birth:

”FASD is an origin story; it is not a destination.” – CJL (p.c. Loock, 2019)

Making a Diagnosis of FASD

A multi-disciplinary assessment is required to make a diagnosis of FASD and this can be performed by a team including a paediatrician, adult physician or psychiatrist, allied health clinicians (occupational, speech and physiotherapists and social workers) and a clinical, neuro- or educational psychologist. Concurrent multi-disciplinary assessment may be possible in a child development or FASD assessment service, but the reality is that many clinicians must refer out for and then collate assessments and make the diagnosis.

The Role of Social Work for Screening, Earlier Identification and Referral

Although a social worker would not be expected to make a diagnosis of FASD, it is important for them to recognize and understand the predisposing ACE and SDoH history and functional neurodevelopmental features requiring further assessment or support. For many individuals with FASD and their families, the social worker plays a key role in translating the components of a FASD diagnosis into a support strategy that avoids stigma and enables the person with FASD to navigate services throughout life. In their various roles (e.g. support for disability and chronic health needs, child welfare, youth outreach, mental health and addiction, adult and family services for housing and food insecurity), social workers may also be the first to identify signs associated with unrecognized PAE or missed FASD, and to make a referral for diagnosis.

Screening and Referral for FASD:

A non-judgemental TIP approach avoiding stigma and shame is required for discussing a referral for FASD assessment, at all ages and in all settings, for birth, foster and adopted clients. In addition to PAE, information regarding adverse SDoH and ACE, family health and risk factors for PAE are essential aspects of TIP. It is also important that a referral include as much information as possible regarding other potential teratogen exposures (eg environmental lead, certain medications and viral infections) and possible genetic factors to assist with diagnostic accuracy and to consider and exclude other confounding or concurrent conditions.

Social work clients should be referred for screening or multidisciplinary assessment for FASD in the following situations:

1. Known PAE in the presence of a history of developmental, cognitive, neurobehavioral, or other functional differences. History of growth delay, failure to thrive, or other physical characteristic should be included in the referral if available.
2. Siblings or other first-degree relatives with PAE or FASD
3. In the absence of known PAE (e.g. in individuals who have experienced family separation or been placed in foster or adoptive care), facial features would justify referral for assessment. The presence of three sentinel facial features is both sensitive and specific for FASD., (Astley, 2003)

See tables below.

The Importance of Making a FASD Diagnosis

Individuals and families affected by FASD consistently say that the diagnosis and the multi-disciplinary process to confirm a diagnosis can be meaningful and useful, and provides:

- understanding of the strengths and needs of the individual to guide appropriate supports and eligibility for services across the lifespan.

- opportunity for families and educators to reframe behavior and adjust and have realistic expectations of an individual.
- potential access to funding for educational support, health services, disability and other government programs, depending on the country and jurisdiction.
- recognition of possible PAE and FASD for other family members, who may be in need of support
- with support and “appropriate treatments”, improvement or prevention of FASD related “secondary” conditions [disabilities] CDC, 2017
- diagnosis of concurrent genetic or other environmental conditions, early life trauma or ACEs that contribute to neurodevelopmental impairments and health co-morbidities
- support for all parents -birth, adoptive and foster- who have frequently been uninformed and unsupported, and for whom systems may have misattributed child behaviors to ‘poor parenting’.
- help for risk drinking behaviors and potentially preventing the recurrence of FASD
- support for the partner and family, including management of health and mental health
- referral to peer-support organizations that exist globally e.g. on-line parent support and advocacy groups (e.g in US: NOFAS (nofas.org) and Australia: NOFASD (nofasd.org.au)

Challenges in Making a FASD Diagnosis

FASD is often misdiagnosed or unrecognized (Chasnoff et al., 2015). There are a number of challenges in making the diagnosis:

- There is no single “gold standard diagnostic [blood, imaging, or cognitive] test”.
- Multi-disciplinary diagnostic capacity and access to services is limited globally and often costly.
- Although FASD is due to PAE, many health professionals don’t ask about PAE
- Evidence of PAE is often difficult to obtain, especially for adolescents, adults, children in out-of-home or foster care, and individuals who are in detention or incarcerated.
- Genetic and other conditions (severe iron deficiency, lead poisoning, underactive thyroid) may result in neurodevelopmental impairment and must be excluded.
- Co-existing medical diagnoses are common and must be documented. Some congenital conditions, e.g. common birth defects and cerebral palsy may be confounded by PAE plus other factors e.g. birth asphyxia, infection, other teratogens, and jaundice, making it difficult to attribute the condition solely to PAE.
- A range of environmental exposures known to contribute to neurodevelopmental impairment may co-occur with PAE, including early life trauma or stress. In these circumstances, all relevant exposures should be documented.

FASD Diagnostic Systems

A number of guidelines including the diagnostic criteria for FASD have been published internationally to assist clinicians. All international guidelines recommend diagnosis by a multi-disciplinary team when possible and the development of an interconnected process for screening and referral in all systems that includes primary health, counselors, psychologists, social workers, allied health, psychology, psychiatry, education, and vocational training. From a frontline and social worker perspective, the diagnostic systems are more alike than different.

In the 1990s two major diagnostic systems emerged: the Institute of Medicine guidelines (Stratton et al., 1996) which were subsequently updated (Hoyme, 2005) and the University of Washington 4-digit Diagnostic System (Astley, 2000). In 2005 the two were harmonized in the Canadian Guidelines (Chudley et al., 2005), which provided the first consensus criteria for diagnosing the full spectrum of neurodevelopmental effects. The 2005 Canadian Guidelines have been updated (Cook J et al., 2015) and have been adapted for use elsewhere including. the Commonwealth countries of New Zealand, Australia and Scotland (Rowan, 2010, Bower & Elliott, 2016; Scottish Intercollegial Guidelines Network 2019). Because there are multiple guidelines, various different terms have been used historically to describe the effects of PAE (Table 1). Although some differences exist in the requirements for diagnosis (including the definition of PAE and the criteria for neurodevelopmental impairment) and the terminology, there exist many more similarities.

Table 1. Terms used internationally to describe FASD and its diagnostic categories

FAS	Fetal Alcohol Syndrome (Jones and Smith,1973)
FAE	Possible Fetal Alcohol Effects (1980s- lacked operational criteria, Sokol and Clarren, 1989
FASD	Fetal Alcohol Spectrum Disorder(s) note: pluralized in US to Disorders (2005-present)
pFAS	Partial Fetal Alcohol Syndrome (partial or atypical, requires some but not all predictive physical findings including facial features) (IOM, 1996)
ARBD	Alcohol-Related Birth Defects (major congenital anomalies vary, and not always present) (Sokol and Clarren, 1989)
ARND	Alcohol-Related Neurodevelopmental Disorder (no physical biomarkers) (IOM, 1996; Hoyme, 2016)
ND-PAE	Neurodevelopmental Disorder associated with PAE (DPN, 2004, DSM-5, 2013)

Currently, in the USA, South Africa, and parts of Europe, the term FASD is used as an umbrella term (Hoyme et al., 2005) which includes the diagnostic groups of Fetal Alcohol Syndrome (FAS), Partial FAS, alcohol-related neurodevelopmental disorder (ARND), and alcohol-related birth defects (ARBD). ARBD are birth defects that have been associated with PAE in human and animal models and include congenital heart, cranial-facial, renal, neural tube/spinal, and skeletal defects.

In contrast, the Canadian, Australian, New Zealand and Scottish guidelines discussed above use FASD as a diagnostic term, with two diagnostic sub-groups: 1) FASD with the three sentinel facial features that are highly predictive of the diagnosis (this equates to FAS) and 2) FASD with fewer than three of these facial features (this includes pFAS and ARND). These guidelines recommend recording alcohol-related birth defects and growth impairment, but do not require these for a diagnosis.

The updated Canadian FASD Guidelines (Cook et al., 2015) address diagnosis across the lifespan and have led the way for adults with FASD to become more active in leadership and advocacy for FASD-informed adolescent and adult diagnosis and services(Chapter 12, in press).

It is beyond the scope of this chapter to review and compare the current international FASD diagnostic systems. For a detailed comparison of current diagnostic systems, refer to the 2015 Canadian Guidelines Supplement (Cook et al 2015) Appendix A: Examples of the interface with other diagnostic systems.

Global efforts are underway, led by researchers, clinicians and other stakeholders to adopt a global approach and develop ‘universal’ FASD diagnostic guidelines that are valid, reliable, flexible and relevant for all jurisdictions (pc Hiemstra, Loock and Elliott, UBC-IPCE Pre-conference Proceedings, 2019). In the absence of current consensus, we recommend that readers access and use diagnostic guidelines relevant to their own country.

Diagnostic Criteria for FASD

The common features of the diagnosis of FASD, relevant for all diagnostic systems, are shown in Table 3 and include: prenatal alcohol exposure, neurodevelopmental impairment and abnormal [sentinel] facial features (small palpebral fissure - narrow eye opening; thin upper lip; and indistinct or smooth philtrum – the area between the base of the nose and the upper lip). Other criteria required for the diagnosis in some systems include growth impairment.

Table 3. Common elements of the diagnostic criteria for FASD specified in various guidelines.*

Element of diagnostic criteria	Notes
Prenatal Alcohol Exposure (PAE)	Some guidelines specify a minimum PAE
Neurodevelopmental impairment	Severe, pervasive, with multiple domains of dysfunction. Some guidelines define the number of domains of impairment required and the cut-offs for abnormality
Sentinel facial features (may or may not be present)	Sentinel features: narrow palpebral fissure, flat/smooth philtrum, thin upper lip (See Astley, 2004; Kellerman, 1999)
Growth deficiency (may or not be present)	Required in some, not all guidelines for a diagnosis of FAS
Other birth defects (may or not be present)	Should be documented and for some guidelines contribute to a diagnosis of ARBD
Exclusion of other causes of neurodevelopmental impairment	Genetic disorders, other teratogens
Document co-morbidities	Includes organic diseases, SDoH, ACEs, PTSD, and other pre-existing diagnoses

* Most guidelines recommend use of the University of Washington lip-philtrum guides and facial Dx software (Astley, 2004). Some guidelines recommend us of the 4-digit diagnostic code (Astley, 2004). PAE- prenatal alcohol exposure, FAS - fetal alcohol syndrome; ARBD – alcohol-

related birth defects; SDoH – social determinants of health; ACE – adverse childhood experiences; PTSD post-traumatic stress disorder.

Functional domains included in the assessment for FASD

The criteria for ‘marked’ or ‘significant’ neurodevelopmental impairment differ across international FASD guidelines. The ‘Commonwealth coalition’ has adapted the Canadian guidelines’ approach (Cook et al, 2015), Australia (Bower & Elliott, 2016), New Zealand (Rogan et al 2010,) and Scotland (SIGN, 2019). Functional brain domains require assessment and documentation of significant impairment in at least three of ten specified domains of function, with impairment defined as a score on a validated assessment tool of two or more standard deviations from the mean (Table 4). In the Hoyme guidelines, used by several US teams, the number of domains of impairment required is not specified and the cut-point for abnormality is 1.5 standard deviations.(Hoyme et al., 2005)

Table 4. Ten Common domains for assessment and possible functional outcomes

1.	Brain structure/Neurology	Small head size, low tone, seizures, etc.
2.	Motor Skills	Clumsy, poor coordination, weak pencil grip
3.	Language	Weak receptive and/or expressive language
4.	Cognition	Weak cause/effect and quantitative reasoning
5.	Academic achievement	Mathematics, reading & writing disorders
6.	Memory	Impaired memory
7.	Attention	ADHD, distractible
8.	Executive Functioning	Poor planning, organization, & making choices
9.	Affect (Mood) Regulation	Anxious, depressed, withdrawn, labile
10.	Adaptive function	Weak grooming, selfcare, & safety skills

The DSM-V and Super-Domains for “Pre-screening”

The Diagnostic Statistical Manual (DSM-5) ~~(2013)~~ provides an alternative approach to the diagnosis and classification of FASD under the category Specified Other Neurodevelopmental Disorder, code 315.8. Appendix 3 of the DSM-5 elaborates on Neurobehavioral Disorder Associated with PAE (ND-PAE). Similar to the available diagnostic guidelines, this diagnostic approach requires information on PAE or predictive, sentinel physical features, and a neuro-behavioral constellation of abnormalities in three “Super-Domains”- which must manifest during childhood and cause extensive and significant impairment or distress (Table 5). The 10 domains in Table 4 can be mapped onto the 3 super-domains. The Center for Disease Control (CDC, 2016) explains “Super-Domains” in this way:

> 1. Neurocognitive –Trouble with thinking and memory—does the individual have trouble planning or may forget material he or she has already learned.
> 2. Adaptive--- Trouble with day-to-day living —this can include problems with dressing for the weather, playing with others as a child or social interactions and understanding social cues as an adult
> 3. Self-regulation--. Behavior problems, such as severe tantrums, mood issues (for example, irritability), and difficulty shifting attention from one task to another

The DSM approach may be a useful method for pre-screening and earlier referral by social workers and other allied health professionals, to multidisciplinary diagnostic teams. The DSM-5 diagnostic category 315.8 also has special significance for mental health and social service professionals supporting youth in juvenile justice systems who have been in care, where access to prenatal/early life history and multi-disciplinary diagnosis is often limited. Prior to DSM-5, FASD was often “invisible” to forensic psychologists as it was not recognized nor coded for in their diagnostic manuals and assessments. Inclusion of FASD as ND-PAE in the DSM-5 opens the door for FASD consideration in the courts.

Table 5. DSM-5 criteria for Neurodevelopment Disorder associated with PAE

1.	*Prenatal alcohol exposure (PAE)*
2.	*Neurodevelopmental Disorder*
▯	Self-regulation domain (n=1): attention, mood, behavior, impulses
▯	Neurocognitive domain (n=1): IQ, executive functioning, memory, visual-spatial reasoning skills and their ability to learn
▯	Adaptive domain (n=2): communication, daily living skills, motor skills, and social skills
3.	*Onset in childhood*
4.	Causes *extensive and significant impairment* or distress in *multiple areas of functioning*

If unknown PAE add physical characteristics (biomarkers).e.g.

- Characteristic [Sentinel] Facial features
- Growth Parameters (Height, Weight, Head Size)
- Brain imaging (when available in future)

Costs of FASD

FASD results in enormous financial costs, to both for the individual and society. The economic impact of FASD has been studied in Canada and the US. The loss of productivity due to illness, disability and premature mortality was the highest contributor to the overall FASD-attributable costs (41%), followed by the cost of corrections (29%) and health care (10%). (Stade et al., 2009; Than and Jonsson, 2009; Popova et al, 2011 and 2016). The estimate does not include chronic health and other costs to individuals, their families and communities, especially when diagnosis and interventions are not available.

Functional Needs and Supports for FASD

In supporting the individual with FASD, the social worker should be placed in a key navigating role. Just as diagnosis is multi-disciplinary, support for FASD requires both multidisciplinary and intersectoral approaches, often involving health, education, vocational, legal, child welfare, and other community services.

Social workers should consider the following important principles:

- early diagnosis is crucial and early intervention results in optimal outcomes;
- misdiagnosis can exacerbate problems;
- neurodevelopmental impairments are the key features of FASD - many will not have characteristic facial or other physical signs; and if they do, these may be “unremarkable”, making FASD an ‘Invisible Disability’.

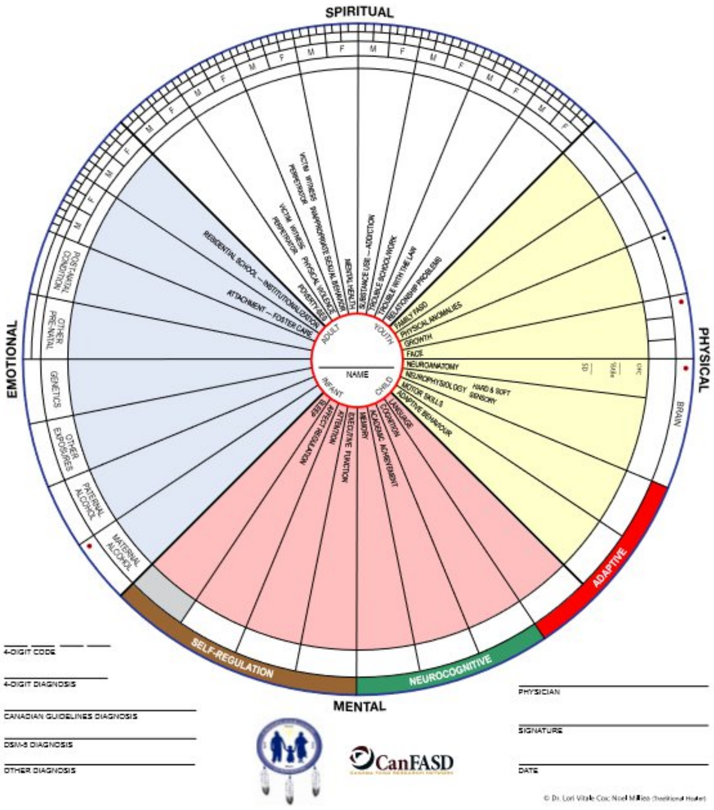
- Significant mental health and behavioral phenomena (e.g. mood and anxiety, impulse control, ADHD, other externalizing behaviors, and suicidality) may also be related to the brain injury in FASD. (O’Connor, 2009; O’Connor, 2014)
- FASD is over-represented in legal and justice settings. (Fast, 1999; ABA, 2012; TRC 2015)
- FASD affects individuals in all aspects of their life and across the lifespan and many struggle to live and work independently.
- FASD is not “genetic”, and the root causes of PAE may be intergenerational.
- Parents with FASD will need increased support, including practical support in how to parent.
- Approaches to diagnosis and support in racialized and oppressed communities must be culturally appropriate and acceptable to families and communities.
- Care of the person with FASD requires respect, understanding, empathy, advocacy, and sustained support. ‘*FASD means you may have trouble making choices. It doesn't mean you can’t succeed.’* (Barr and Streissguth, personal communication to Loock, 1989).

FASD: We Can Change Outcomes

We can help individuals with FASD learn and grow by providing access to the responsive health and allied services. The first step is early screening, recognition and diagnosis. Next is early support, including appropriate interventions for individuals with FASD, and support for parents (birth, foster, and adoptive). Outcomes can be improved by adapting the environment to provide activities and allow meaningful participation; modifying interventions and supports to accommodate particular disabilities; and building on strengths and targeting extra needs identified during assessments. With an accurate diagnosis and individual and family supports, individuals with FASD can achieve their potential and “secondary” adverse outcomes may be mitigated or prevented.

Figure x. The Indigenous Canadian “Two Eyed Seeing” Medicine Wheel

The ‘Two-Eyed Seeing’ Medicine Wheel, developed by Dr Lori Cox and Indigenous elders for use in communities (Figure x), encourages clinicians to consider nature and nurture and transgenerational effects when approaching and supporting individuals and families with FASD. It respects spiritual, physical, emotional and mental spheres, while providing a visual representation of the key components of all current FASD diagnostic systems.



4-DIGIT CODE

4-DIGIT DIAGNOSIS

CANADIAN GUIDELINES DIAGNOSIS

DSM-5 DIAGNOSIS

OTHER DIAGNOSIS

PHYSICIAN

SIGNATURE

DATE

© Dr. Lori Vitale Cox; Noel Milliea (Traditional Healer)

FASD and Community and Family Engagement

It takes a Village to raise a child. Social Pediatrics is an equity-oriented philosophy and practice that seeks to take action on social determinants such as income, housing, education, social capital and environment that are critical mediators of child and youth health. (Tyler, 2018). Working in the FASD field requires a 'RICH' [Responsive, Inter-disciplinary/Intersectoral, Collaborative/Community/individual and family-Centred] and Holistic approach, that spans beyond well beyond pediatrics into adult health and support systems. (Loock, 2016)

Reframing our Shared Approach for FASD

To optimize care for individuals and families with FASD we must re-frame our approach.

1. **We can improve outcomes**: In FASD the primary disability cannot be "cured" but early intervention, diagnosis and support can change outcomes and mitigate "secondary" conditions.
2. **We must adapt our practice and the environment not the person:** If someone is physically challenged, we adapt or modify environment to support their needs and this also applies for individuals with neurodevelopmental disorder associated FASD.
3. **We need to support parents.** Many parents are ostracized or blamed for "poor parenting" and even blame themselves for adverse secondary outcomes. Biological parents, may need higher levels of support.
4. **Some birth mothers may have ongoing mental health and substance use problems,** with high rates of ACEs and untreated mental health needs including agoraphobia and depression,

exacerbated by marked social isolation, and may live with co-dependent partners who don't want them to decrease alcohol use. (Astley, 2000)

5. **FASD is not genetic, but may be epigenetic and also can manifest in an intergenerational pattern**. There may be epigenetic effects that include effects of either parent's substance use. (Kobor, 2011; O'Connor, 2014) Of biological mothers of children with full FAS, up to 50% may themselves have had FASD. (Astley, 2000)
6. **We can help individuals with FASD to learn how to better access services and supports through system navigators.:** by creating supportive environments at home, school and community, where they can have opportunities to be supported in shared decision making and to facilitate making choices.
7. **Individuals with FASD have strengths and interests which must be recognized and nurtured.** Strengths may be identified during the neurodevelopmental assessment and interests reported by the individuals and their family networks.
8. **We have a responsibility to change our approach in all social systems to meet the challenge of FASD:** This may require professional training, adapting professional practice, reframing our language and jargon, and developing community interventions for prevention and support.
9. **Close the gaps in our systems and prevent silos:** We must overcome the lack of diagnostic capacity and current misdiagnosis in health systems; lack of resources to adapt the educational environments including resorting to suspension and exclusion; and lack of outreach and prevention services.
10. **Professional Training is Essential:** It is possible to unknowingly perpetuate structural violence on individuals who do not have access to diagnosis, and whose problem behaviors

are viewed as defiant or deviant, as opposed to part of their disability. **Social workers may require additional training and specific information** on screening for PAE and FASD, referral, and local services.

11. **Social Systems must be responsive and focus on promoting resilience.** Resilience should be viewed as both internal and external, and in FAS it is more about external supports and services than trying to change the underlying neurodevelopmental disorder... *The science of resilience is clear : The social, political and natural environments in which we live are far more important to our health, fitness, finances and time management than our individual thoughts, feelings or behaviours.* (Ungar, 2019)
12. **Healthy public policy applies to FASD:** Sir Michael Marmot recommended that the following six policy objectives can be directly applied to FASD prevention, treatment, and support services:

    Reducing health inequalities will require action on six policy objectives: — Give every child the best start in life — Enable all children young people and adults to maximise their capabilities and have control over their lives — Create fair employment and good work for all — Ensure healthy standard of living for all — Create and develop healthy and sustainable places and communities — Strengthen the role and impact of ill health prevention …[e.g.] Focusing public health interventions such as smoking cessation programmes and alcohol reduction on reducing the social gradient (Marmot, 2010).

Conclusion:

In this chapter we highlight the salient messages regarding PAE and FASD for social workers, summarizing guidelines for the diagnosis and identifying examples of useful approaches for professionals working with individuals and families with FASD. The term FASD encompasses the wide range of physical, mental and behavioral effects that may result from PAE. Ideally, the diagnosis and management of FASD requires a multidisciplinary approach. Although most frequently diagnosed in early childhood, FASD is not a “pediatric” disability, but instead a lifespan condition. As outlined in Chapter 12, it may result in chronic health, mental health and legal-justice problems which require a cross-sectorial response.

The community social worker, in partnership with the primary health care team and specialists, is well positioned to be a catalyst for referrals for diagnostic assessment and for prevention of PAE. The social worker may also play a role in coordinating clinic services, making links with education, justice and other services, and providing resources and referrals for peer-support to improve outcomes and mitigate secondary conditions.

It takes a village to address FASD. Solutions to inequities in outcomes should include a “social pediatric” perspective) with diagnostic and treatment services linked across sectors for more responsive services and supports. (Tyler, 2015, Loock, 2016).

In revisioning our health and social service delivery systems, accessible services must be embedded in “*resource-rich, supportive social environments that foster resiliency*” (Unger 2019) and enable access to earlier identification and support services that reduce inequities, and maximize human potential (Marmot, 2010).

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