

Health Watch Table — Fetal Alcohol Spectrum Disorder (FASD)

Tao, Temple, Casson and Kirkpatrick 2013

Overview:

Fetal Alcohol Spectrum Disorder (FASD) may occur when an individual is exposed to alcohol in utero. Symptoms include physical, intellectual and neurobehavioural deficits that can vary widely in severity. The 2016 Canadian guidelines for diagnosis of FASD describe 2 categories: FASD with Sentinel Facial Features and FASD without Sentinel Facial Features²⁶. Prenatal alcohol exposure does not always lead to FASD.

CONSIDERATIONS	RECOMMENDATIONS
<h3>1. PREVALENCE</h3>	
<p>The reported incidence of FASD with Sentinel Facial Features currently ranges from 0.2 to 2.0 cases per 1,000 live births and up to 43 per 1,000 among “heavy” drinkers (different population surveyed or different methods used). There are now an estimated 300,000 cases of FASD in Canada ,(an incidence of 9/1,000 live births).^{3, 4}</p>	
<h3>2. AETIOLOGY</h3>	
<p>Prenatal alcohol exposure</p> <p>The range of deficits in FASD is associated with many factors, including the amount, time and frequency of exposure, as well as the state of health/nutrition of the mother and the genetic makeup of the mother and the fetus.</p>	
<h3>3. DIAGNOSIS</h3>	
<p>Children: Diagnosis is based on a combination of:</p> <ul style="list-style-type: none"> - history of prenatal alcohol exposure; - characteristic facial features (smooth philtrum, thin vermilion border of the upper lip and small palpebral fissures); - central nervous system abnormalities, whether structural (microcephaly), neurologic (seizures, motor problems or soft neurologic findings), or neurobehavioural problems.⁵ <p>Manifestations of FASD may overlap with other disorders of environmental or genetic (e.g., 22q11 del syndrome) etiology. It is essential to rule out such differential diagnoses, especially in the absence of confirmed prenatal alcohol exposure.^{1,6}</p> <p>Experts call for early diagnosis and intervention with families of alcohol-affected children to:</p> <ul style="list-style-type: none"> - promote their development; - minimize the occurrence of secondary disabilities (see list below in “Adult Diagnosis – Recommendations”); - identify and support previously unidentified siblings, and 	<ul style="list-style-type: none"> ▪ Consider referral for assessment to an appropriate resource for your community, preferably a multidisciplinary FASD team. <ul style="list-style-type: none"> ▪ Referral guidelines include: <ul style="list-style-type: none"> - known substantial prenatal alcohol exposure (maternal intake ≥ 7 drinks per week and/or 2 or more binge episodes of ≥ 4 drinks per occasion), or if there is - unknown prenatal alcohol exposure, but <ul style="list-style-type: none"> - caregiver or parental concern, or - three facial features (as above), or - ≥ 1 facial feature plus central nervous system abnormalities^{8,9} ▪ Consider the use of screening tools, such as the “Neurobehavioural Screening Tool” and “Maternal Drinking Guide: Factsheet and Tool”¹⁰. (Be aware of the lack of demonstrated validity and reliability of existing FASD screening tools and the potential adverse effects of screening in the absence of, or long delays in, access to facilities able to provide diagnostic evaluation.)⁷ ▪ Consider consultation with a medical geneticist to rule out other conditions of environmental or genetic etiology.^{1,6}

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<p>- seek to prevent subsequent pregnancies affected by alcohol.⁷</p>	
<p>Adults: Diagnosis maybe more challenging because:</p> <ul style="list-style-type: none"> - facial features in children with FASD may not persist into adulthood;¹ - motor problems seen at age 4 may not be seen by age 25;¹¹ - cumulative environmental influences (e.g., traumatic brain injury, alcohol and drug abuse, mental health problems) may distort the evaluation of brain function. <p>Most individuals with FASD have an ‘invisible’ disease and <50% meet current definitions of developmental/intellectual disability.¹²</p> <p>However, “The diagnosis can lead to a paradigm shift in attitude and perception towards the affected individual from one of a lazy, lying, obstinate and difficult individual or sociopath to that of an individual who is neurologically impaired and who needs appropriate assistance with specific management and treatment”.¹²</p>	<ul style="list-style-type: none"> ▪ In addition to the data required for diagnosis, consider assessment of adaptive functioning¹³ and disabilities that could be considered secondary to FAS: <ul style="list-style-type: none"> - mental health problems - disrupted school experience - trouble with the law, incarceration - inappropriate sexual behavior - alcohol and drug problems - dependent living - problems with unemployment - problems with parenting <p>These disabilities might manifest themselves as: depression, anxiety or psychosis, poor judgement, poor impulse control, sexual promiscuity, restlessness, poor problem-solving skills, resistance to change, difficulty forming meaningful or lasting relationships, gullibility and victimization, inability to understand or to conform to social norms, unemployment.¹²</p> <ul style="list-style-type: none"> ▪ Because a history of prenatal alcohol exposure may be difficult to obtain for adults, consider the possibility in persons who have experienced one or more of the following: <ul style="list-style-type: none"> - premature maternal death related to alcohol use - living with an alcoholic parent - abuse or neglect - involvement with child protective services agencies - a history of transient caregiving situations - foster or adoptive placements¹⁴
<p>4. COGNITIVE FUNCTION/COMMUNICATION</p>	
<p>Children: Intellectual ability may vary by individual from average IQ to severe intellectual disability.</p> <p>Learning disabilities, language and communication deficits are common.¹</p> <p>Executive functioning skills are often a significant weakness. This can lead to problems with emotional regulation, impulse control, and deficits in planning, organization, and attention.^{16, 17}</p>	<ul style="list-style-type: none"> ▪ Refer for comprehensive assessment of cognition, communication, sensory function, daily living skills and academic abilities in order to identify strengths and deficits and to make a comprehensive support plan for families and schools.¹⁸ Individualized management plan can be based on the results of comprehensive assessments to enhance strengths and provide support for deficits. ▪ Monitor individual education plan, educational testing, balance of special education and inclusion, academic progress, behavioural differences, later vocational planning. ▪ Consider therapeutic programs based on deficits identified by assessment, such as speech language therapy, and memory/attention remediation programs. ▪ Comprehensive assessments should always include measures of executive functioning, as this area is very important for the application of cognitive skills in everyday life (see Adaptive Daily Living skills below).

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<p>Adults: Cognitive skills may increase or decline during childhood and into adulthood.¹²</p> <p>Significant deficits in mathematical ability often persist into adulthood.^{12, 19}</p> <p>It is common to face challenges in transition to adult care; there are often gaps in services transition from childhood to adulthood.¹²</p>	<ul style="list-style-type: none"> ▪ Refer for comprehensive assessment in late adolescence or early adulthood to establish cognitive level and to plan for future needs. ▪ Consider the need for assistance with financial management from family members, support staff or Public Guardian and Trustee. ▪ Consider services provided by Developmental Services Ontario (DSO); and/or adult mental health services.
<p>5. ADAPTIVE DAILY LIVING SKILLS</p>	
<p>Children and Adults: Support and supervision from care providers or family members is necessary to help individuals make and follow through on treatment plans and appointments.</p> <p>Functional daily living skills are often significantly lower than cognitive skills. Individuals with relatively high IQ scores may still struggle with social skills, financial and time management, and organization of daily life.^{12, 20}</p> <p>Structured activities and routines can help with organizational deficits.</p>	<ul style="list-style-type: none"> ▪ Consider inviting care providers or family members to appointments to help facilitate follow through. ▪ Consider referral to vocational support services (e.g., job coaches, supported employment services) to help adults find and retain employment. ▪ Consider structured social skills training programs to improve skills. ▪ Refer to Occupational Therapy or Behaviour Therapy for help with setting up schedules and environmental supports. Specific intervention strategies might include using visual schedules, memory aids, checklists, sensory-motor interventions. ▪
<p>6. PHYSICAL HEALTH ISSUES¹</p>	
<p>Children and Adults: Conductive and sensorineural hearing loss and vision abnormalities are common in FASD with Sentinel Facial Features.⁵</p> <p>Dental problems, including malformations and caries, are common in FASD with Sentinel Facial Features.⁵</p> <p>Neurological assessment is part of the diagnostic work-up. Typical and atypical seizures may be present.¹³</p> <p>Inappropriate sexual behavior may be more common than anticipated.</p> <p>“Virtually every malformation has been described in patients with FASD.”¹³</p>	<ul style="list-style-type: none"> ▪ Screen for hearing and vision problems at time of diagnosis. Follow up should be guided by clinical findings. ▪ Brain stem auditory evoked response testing between 6 and 12 months may help in early identification of hearing loss. ▪ Counsel re dental hygiene and prompt treatment of caries. ▪ Neurologic issues may need periodic assessment. ▪ Take a sexual history and provide counselling regarding contraception and sexually transmitted infections. ▪ Be aware of the possibility of congenital abnormalities ▪ Measure growth parameters, assure adequate nutrition and manage feeding difficulties.¹³

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<p>Growth deficiency may occur.</p> <p>Learning difficulties, poor capacity for abstraction, deficits in higher level receptive or expressive language, problems in memory, attention and judgement may compromise access to health care services.</p>	<ul style="list-style-type: none"> ▪ Address other physical health issues as in the general population, keeping in mind these deficits may interfere with optimal health care.¹³
<p>7. MENTAL HEALTH AND BEHAVIOURAL ISSUES¹</p>	
<p>Children: Attention disorders (e.g., ADHD) occur in many cases.²¹</p> <p>Childhood trauma and attachment disorders are common. Many individuals experience multiple home/foster home placements, neglect, and abuse.¹⁹</p>	<ul style="list-style-type: none"> ▪ Evaluate and refer for attention-related disorders. ▪ Structured environments and structured tasks used in the treatment of children with ADHD may also assist children with FASD. ▪ Consider stimulants for FASD as help in managing some symptoms.²² ▪ Consider individual counselling and/or positive mentorship programs (e.g., Big Brothers or Sisters, community support programs).
<p>Adults: Psychiatric disorders occur in a large percentage of cases. Mood, anxiety and conduct disorders are common²³. Underlying neurological deficits can lead to increased emotional reactivity.¹⁶</p> <p>Adolescents and adults with FASD may have difficulty with cognitive-types of therapy, partly due to language processing difficulties.¹²</p> <p>Addiction problems are common. They can begin in teenage years and continue into adulthood.¹⁴</p> <p>Interactions with the justice system often occur.¹⁴</p>	<ul style="list-style-type: none"> ▪ Monitor for psychiatric disorders and refer to psychiatric /mental health services as needed. ▪ Refer to counselling and/or behaviour management as needed. ▪ Provide or arrange medication management for known diagnosis and symptoms such as for depression, anxiety. ▪ Refer to social services for ongoing case management and support. ▪ Focus counselling on concrete suggestions around behavioural strategies. Make routine appointments and provide structure. ▪ Monitor for impulsivity, adult hyperactivity and depression with suicidal tendencies. ▪ Monitor for substance abuse and refer for treatment as necessary. Identify/monitor women at risk for alcohol use during pregnancy. ▪ Refer to Mental Health Court Services or Victim's aid to assist with court processes.
<p>8. SLEEP</p>	
<p>Children and Adults: Sleep disturbance is common with prenatal alcohol exposure, and medical problems related to obstructive sleep apnea may have been overlooked previously.¹³</p> <p>Sleep disturbances, including bedtime resistance, shortened sleep duration, increased sleep anxiety and night awakenings, are common.²⁴</p>	<ul style="list-style-type: none"> ▪ Consider referral for sleep evaluation, if clinically indicated. ▪ Screen for sleep-related disorders and consider referral to sleep medicine professionals, Occupational Therapy or Behaviour Therapy for environmental adaptations.
<p>9. SENSORY ISSUES¹</p>	

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<p>Children and Adults: May have sensory processing (integration) disorder, “clumsiness”, or mild neurological or sensorimotor abnormalities. They may present with difficulties performing activities of daily living, extreme avoidance of activities and/or agitation.²⁵</p>	<ul style="list-style-type: none"> ▪ Occupational therapy assessment using a variety of tools may identify particular deficits. ▪ A sensory screening questionnaire completed by a caregiver may reveal sensory processing disorder, areas including visual, auditory, tactile, olfaction, gustatory, vestibular, and proprioception. ▪ Once sensory processing disorder is identified, a sensory integration therapy designed by an occupational therapist may help the person to use sensory information in meaningful and natural ways.
10. PROFESSIONAL RESOURCES	
<p><i>FASD Screening Tool Kit</i>: Includes resources and screening tools for Primary Healthcare professionals.</p>	<ul style="list-style-type: none"> ▪ Information and copies of the entire Tool Kit: http://ken.caphc.org/xwiki/bin/view/FASDScreeningToolkit/National+Screening+Tool+Kit+for+Children+and+Youth+Identified+and+Potentially+Affected+by+FASD
<p><i>Centre for Excellence on FASD</i>: Website contains general information and educational materials.</p>	<ul style="list-style-type: none"> ▪ SAMSA website: http://www.fasdcenter.samhsa.gov/
<p><i>FASD and Justice</i>: Contains information on FASD for legal professionals.</p>	<ul style="list-style-type: none"> ▪ FASD-Ontario Network of Expertise website on FASD and the legal system in Canada: http://www.fasdontario.ca/cms/service-areas/justice/
11. CAREGIVER ISSUES AND RESOURCES	
<p><i>Let's Talk FASD</i> Caregiver guide with recommendations for both children and adults with FASD.</p>	<ul style="list-style-type: none"> ▪ http://www.faslink.org/_fasdtool_fullproof2.pdf
<p><i>FASD ONE</i> A website with information regarding diagnostic clinics across Ontario, FASD support groups, and general information about FASD in Canada.</p>	<ul style="list-style-type: none"> ▪ http://www.fasdontario.ca/cms/
12. ADDITIONAL CANADIAN AND INTERNATIONAL WEBSITES OF INTEREST	
<p>Canada's first comprehensive, collaborative and interdisciplinary national FASD research network.</p>	<ul style="list-style-type: none"> ▪ http://www.canfasd.ca/
<p>FASD and Child Welfare Community of Practice: Network to inform policy makers, program developers and practitioners about the needs of children with FASD in the care of child welfare jurisdictions and agencies, as well as early intervention practices.</p>	<ul style="list-style-type: none"> ▪ http://www.fasdchildwelfare.ca/
<p>Lakeland Centre for FASD</p>	<ul style="list-style-type: none"> ▪ http://www.lcfasd.com/
<p>Manitoba FASD Centre: Multidisciplinary assessment, education, training and research service of the Winnipeg Regional Health Authority Child Health Program.</p>	<ul style="list-style-type: none"> ▪ http://www.fasdmanitoba.com/
<p>Healthy Child Manitoba – FASD Resources</p>	<ul style="list-style-type: none"> ▪ http://www.gov.mb.ca/healthychild/fasd/index.html

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National Organization on Fetal Alcohol Syndrome Washington, DC; London, England Devoted to preventing alcohol use during pregnancy and supporting individuals and families living with FASD.	<ul style="list-style-type: none"> ▪ http://www.nofas.org/ ▪ http://www.nofas-uk.org/
FAS DPN Center on Human Development and Disability University of Washington, Seattle WA	<ul style="list-style-type: none"> ▪ http://depts.washington.edu/fasdpn/

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