Health Watch Table — Fetal Alcohol Spectrum Disorder (FASD)

Tao, Temple, Casson and Kirkpatrick 2013

Overview:
Fetal Alcohol Spectrum Disorder is an umbrella term for the range of effects that can occur in an individual exposed to alcohol in utero. These effects can include various physical, intellectual and neurobehavioural deficits that vary widely in severity. Fetal alcohol syndrome (FAS), partial fetal alcohol syndrome (pFAS) and alcohol-related neurodevelopmental disorder (ARND) are now used to refer to each of the three sub-categories subsumed under FASD.[1,2] Prenatal alcohol exposure does not always lead to FASD.

CONSIDERATIONS	RECOMMENDATIONS
1. PREVALENCE	
The reported incidence of full FAS 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]	
2. AETIOLOGY	
Prenatal alcohol exposure 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.	
3. DIAGNOSIS	
Children: Diagnosis is based on a combination of: - history of prenatal alcohol exposure; - characteristic facial features (smooth philtrum, thin vermilion border of the upper lip and small palpebral fissures); - perinatal growth deficit (<10th percentile for height or weight); - central nervous system abnormalities, whether structural (microcephaly), neurologic (seizures, motor problems or soft neurologic findings), or neurobehavioural problems.[5] 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] Experts call for early diagnosis and intervention with families of alcohol-affected children to: - promote their development; - minimize the occurrence of secondary disabilities (see list below in "Adult Diagnosis –	☐ Consider referral for assessment to an appropriate resource for your community, preferably a multidisciplinary FASD team. ▪ Referral guidelines include: - known substantial prenatal alcohol exposure (maternal intake ≥7 drinks per week or ≥3 drinks on multiple occasions), or if there is - unknown prenatal alcohol exposure, but - caregiver or parental concern, or - three facial features (as above), or - ≥1 facial feature plus height or weight deficit, or - ≥1facial 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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Recommendations"); - identify and support previously unidentified siblings, and - seek to prevent subsequent pregnancies affected by alcohol.[7]	
Adults: Separate criteria for adults do not exist, but diagnosis is more challenging because: - facial features in children with FAS may not persist into adulthood;[1] - growth deficiency likely does not persist past 18 months;[11] - 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.	☐ In addition to the data required for diagnosis, consider assessment of adaptive functioning[13] and disabilities that could be considered secondary to FAS: - 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 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]
Most individuals with FASD have an 'invisible' disease and <50% meet current definitions of developmental/intellectual disability.[12] 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]	☐ 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: - 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 placements[14]
4. COGNITIVE FUNCTION/COMMUNICATION	
Children: Intellectual ability may vary by individual from average IQ to severe intellectual disability. Diagnostic category does not necessarily predict severity of cognitive deficits, (i.e., deficits of FAS, pFAS and ARND can all be substantial).[15]	☐ 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.
Learning disabilities, language and communication deficits are common.[1] Executive functioning skills are	☐ 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

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often a significant weakness. This can lead to problems with emotional regulation, impulse control, and deficits in planning, organization, and attention.[16, 17]	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).
Adults: Cognitive skills may increase further or decline during childhood and into adulthood.[12]	☐ Refer for comprehensive assessment in late adolescence or early adulthood to establish cognitive level and to plan for future needs.
Significant deficits in mathematical ability often persist into adulthood.[12, 19]	☐ Consider the need for assistance with financial management from family members, support staff or Public Guardian and Trustee.
It is common to face challenges in transition to adult care; there are often gaps in services transition from childhood to adulthood.[12]	☐ Consider services provided by Developmental Services Ontario (DSO); and/or adult mental health services.
5. ADAPTIVE DAILY LIVING SKILLS	
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.	☐ 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.
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]	
Structured activities and routines can help with organizational deficits.	
6. PHYSICAL HEALTH ISSUES[1]	
Children and Adults: Conductive and sensorineural hearing loss and vision abnormalities are common in FAS.[5]	☐ 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.
Dental problems, including malformations and caries, are common in FAS.[5]	☐ Counsel re dental hygiene and prompt treatment of caries.
Neurological assessment is part of the diagnostic work-up. Typical and atypical seizures may be present.[13]	☐ Neurologic issues may need periodic assessment.
Inappropriate sexual behavior may be more common than anticipated. "Virtually every malformation has been described in patients with	☐ Take a sexual history and provide counselling regarding contraception and sexually transmitted infections. ☐ Be aware of the possibility of congenital abnormalities

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FAS."[13]	
Growth deficiency is common.	☐ Measure growth parameters, assure adequate nutrition and manage feeding difficulties.[13]
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.	☐ Address other physical health issues as in the general population, keeping in mind these deficits may interfere with optimal health care.[13]
7. MENTAL HEALTH AND BEHAVIOURAL ISSUES[1]	
Children: Attention disorders (e.g., ADHD) occur in many cases.[21]	☐ 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]
Childhood trauma and attachment disorders are common. Many individuals experience multiple home/foster home placements, neglect, and abuse.[19]	☐ Consider individual counselling and/or positive mentorship programs (e.g., Big Brothers or Sisters, community support programs).
Adults: Psychiatric disorders occur in a large percentage of cases. Mood, anxiety and conduct disorders are common[23]. Underlying neurological deficits can lead to increased emotional reactivity.[16]	☐ 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.
Adolescents and adults with FASD may have difficulty with cognitive-types of therapy, partly due to language processing difficulties.[12]	☐ Refer to social services for ongoing case management and support. ☐ Focus counselling on concrete suggestions around behavioural strategies with close supervision. ☐ Monitor for impulsivity, adult hyperactivity and depression with suicidal tendencies.
Addiction problems are common. They can begin in teenage years and continue into adulthood.[14]	☐ Monitor for substance abuse and refer for treatment as necessary. Identify/ monitor women at risk for alcohol use during pregnancy.
Interactions with the justice system often occur.[14]	☐ Refer to Mental Health Court Services or Victim's aid to assist with court processes.
8. SLEEP	
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]	☐ Consider referral for sleep evaluation, if clinically indicated.
Sleep disturbances, including bedtime resistance, shortened sleep duration, increased sleep anxiety and night awakenings, are common.[24]	☐ Screen for sleep-related disorders and consider referral to sleep medicine professionals, Occupational Therapy or Behaviour Therapy for environmental adaptations.

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9. SENSORY ISSUES[1]	
Children and Adults: May have sensory processing (integration) disorder, "clumsiness", or mild neurological or sensorimotor abnormalities. They may present with difficulties in performing activities of daily living, extreme avoidance of activities and/or agitation.[25]	☐ 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.
PROFESSIONAL RESOURCES	
FASD Screening Tool Kit: Includes resources and screening tools for Primary Healthcare professionals.	☐ 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
Centre for Excellence on FASD: Website contains general information and educational materials.	☐ SAMSA website: www.fasdcenter.samhsa.gov/
FASD and Justice: Contains information on FASD for legal professionals.	☐ FASD-Ontario Network of Expertise website on FASD and the legal system in Canada: www.fasdjustice.ca/
Understanding Fetal Alcohol Spectrum Disorder – A Resource for Education Practitioners in Ontario: Contains resource materials for teachers and families.	☐ Copies can be purchased from MOTHERISK, the Hospital for Sick Children 123 Edward Street, Suite 401, Toronto, ON, M5G 1E2 Website: www.motherisk.org/prof/index.jsp
CAREGIVER ISSUES AND RESOURCES	
Let's Talk FASD Caregiver guide with recommendations for both children and adults with FASD.	☐ www.von.ca/FASD/
FASD Connections Website for adolescents and adults with FASD and their families with information about management, helpful tips, and advice from parents and professionals.	☐ www.fasdconnections.ca/index.htm
FASD|ONE A website with information regarding diagnostic clinics across Ontario, FASD support groups, and general information about FASD in Canada.	☐ www.fasdontario.ca/cms/
ADDITIONAL CANADIAN AND INTERNATIONAL WEBSITES OF INTEREST	
Canada's first comprehensive, collaborative and interdisciplinary national FASD research network.	☐ www.canfasd.ca/
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	☐ www.fasdchildwelfare.ca/

child welfare jurisdictions and agencies, as well as early intervention practices.	
Lakeland Centre for FASD	☐ www.lcfasd.com/
Manitoba FASD Centre: Multidisciplinary assessment, education, training and research service of the Winnipeg Regional Health Authority Child Health Program.	☐ www.fasdmanitoba.com/
Healthy Child Manitoba – FASD Resources	☐ www.gov.mb.ca/healthychild/fasd/index.html
FASD Support Network of Saskatchewan Inc.	☐ www.skfasnetwork.ca/main/resources/communityresources/
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.	☐ www.nofas.org/ ☐ www.nofas-uk.org/
FAS DPN Center on Human Development and Disability University of Washington, Seattle WA	☐ http://depts.washington.edu/fasdpn/

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