ANTICIPATORY GUIDANCE FOR CHILDREN AND ADOLESCENTS WITH FETAL ALCOHOL SPECTRUM DISORDER (FASD): PRACTICE POINTS FOR PRIMARY HEALTH CARE PROVIDERS

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ABSTRACT

Background
Fetal Alcohol Spectrum Disorder (FASD) is an umbrella term that describes the range of effects that can occur in an individual who was prenatally exposed to alcohol and includes an array of complex neurodevelopmental and physical findings.

Objectives
To give primary healthcare providers (PHCP) evidence-based recommendations for supporting and managing the symptoms of FASD *after* patients have received a diagnosis.

Methods
Primary health recommendations for the management of children and adolescents with FASD were developed based on expert clinical judgment and supported by evidence-based research, where appropriate. The format was adapted from other health supervision practice guidelines as developed by the American Academy of Pediatrics. Clinical practice "Points" for the PHCP are highlighted. A reference table of anticipatory recommendations by age is presented.

Results
In most cases, the initial screening and referral for diagnosis will be made by the PHCP, and they will be responsible for ongoing management. It is anticipated that these recommendations will provide the PHCP with evidence to support the longitudinal health care of children and adolescents with FASD and their families as they transition throughout all developmental stages.

Conclusion
There is a pressing need for the involvement of PHCP in the active care of children and adolescents with FASD and their families over the lifespan. PHCP are trained in screening, prevention, and management of health needs, and are in the position to coordinate sub-specialty referrals as needed. Engaging PHCP will provide a truly integrated care system for individuals with FASD and their families.

Key Words: *Fetal Alcohol Spectrum Disorder (FASD); children; adolescents; anticipatory guidance*

What is FASD?
Fetal Alcohol Spectrum Disorder (FASD) is an umbrella term that describes the range of effects that can occur in an individual who was prenatally exposed to alcohol and includes an array of complex neurodevelopmental and physical findings.[1] These effects can include lifelong physical, mental and behavioural difficulties, as well as learning disabilities. Alcohol exposure during pregnancy results in changes to the developing brain at both the neurochemical and structural levels. Often, these changes are not

detected until a child reaches early or middle school age when problems at school and at home become increasingly apparent. These challenges can include difficulties in adaptive functioning, social communication and attention, motor and sensory problems, memory deficits, and trouble learning from consequences. As the child grows and develops, they are at an increased risk for developing depression, anxiety and/or other mental health conditions, particularly if their symptoms and deficits are not appropriately identified and managed.

Scientific evidence has conclusively shown that alcohol consumption during pregnancy can cause fetal harm[2-5]; however, there is insufficient data to define any threshold for safe low-level drinking during pregnancy or when planning to become pregnant. Because the brain injury is the most common and serious consequence of prenatal exposure to alcohol and can occur at any time during a pregnancy, the safest choice for a woman who is pregnant or planning to become pregnant is **not to drink alcohol**.

It is possible for individuals with FASD to experience differences in their challenges due to the wide variation of alcohol-mediated effects on brain development. Some of the more common difficulties include:

- Cognitive functioning/learning disabilities.
- Executive functioning – difficulty with judgment; planning; delaying gratification; inhibition; cognitive flexibility; learning from consequences; organization and impulsivity.
- Memory – short and long term; verbal and visual information.
- Communication – can be highly verbal, but lack comprehension skills for both the verbal and nonverbal cues; deficits in social communication (pragmatics) impacts daily adaptive and social function.
- Neuromotor Deficits – impaired balance and coordination; and poor motor planning.
- Sensory Dysregulation – hyper- or hyposensitivities or combinations of both to touch (e.g., low/high pain threshold, heat/cold); light; sound; taste and smell.

If these are not appropriately understood and addressed, children and adolescents with FASD are at increased risk for early school failure, involvement with the law, family disruption and homelessness.

In 2005, Loock and colleagues published *"Identifying fetal alcohol spectrum disorder in primary care"* as a guideline for diagnosis.[6] These recommendations provided a simple, straightforward approach to identifying patients at risk for FASD and outlined the appropriate screening tools for assessing problematic alcohol use in women. This reflected the operationalization of the Canadian Diagnostic Guidelines for FASD[1] and aimed to improve diagnosis of FASD in the clinical setting. However, they did not include specific guidance for follow-up, monitoring and ongoing health support, in which the responsibility falls predominantly to the primary healthcare providers (PHCP). Thus, based on the expectation that PHCP can now screen women at-risk of having children with FASD and the availability of diagnostic services, the purpose of this paper is to provide PHCP with evidence-based anticipatory guidance for supporting and managing the symptoms of FASD *after* patients have received a diagnosis. These practice points support the non-peer reviewed literature on medical management of FASD[7,8], and which can be reviewed for more in depth background.

In a survey conducted by the American Academy of Pediatrics, pediatricians reported knowledge about FASD, but did not feel adequately trained to integrate the management of the diagnosis in their everyday practice.[9] Pediatricians and other PHCP are often required to coordinate appropriate mental health services, provide consultation to special education programs, and manage medication for comorbid health conditions. Thus, the goal of this document is to present best practice anticipatory recommendations that can be used by PHCP to better meet the challenges of ongoing management for patients with FASD after providing appropriate referrals for FASD diagnosis (*please see **Appendix I:** Anticipatory Guidance for Children and Adolescents with FASD template).*

Prevalence of FASD

Although exact prevalence rates for FASD remain largely unknown, from the estimates that do exist, it is clear that FASD is an important global health issue. In the United States, FASD has been estimated to occur at a rate of 9.1 per 1000 live births[10-13], and may be as high as 2-5% in some parts of the United States and in some Western European countries.[14] Currently, countries from Central and Eastern Europe, Africa, Asia and Canada are working with the World Health Organization to determine accurate prevalence rates for FASD.[15]

It has been well-documented that alcohol consumption among women of child-bearing age is increasing[16] and that drinking patterns leading to adverse health outcomes are also increasing, including those associated with prenatal alcohol exposure. In the developed world, approximately 40% of women of childbearing age drink alcohol, and many are drinking at or around the time of conception.[17,18]

The economic and societal costs associated with FASD are significant. In Canada, the *total* adjusted annual cost associated with FASD at the individual level is an ~$21,642[19], with a lifetime cost from day of birth to 53 years old of ~$5.3 billion.[19,20] There are also the unmeasured indirect costs associated with stress and financial burden to the caregiver, as well as the loss of full potential for the individual with FASD. The costs associated with supporting individuals with FASD span many systems including education, child welfare, health, mental health, justice and social support (e.g., housing).

Speaking to Patients About Alcohol

PHCP are well positioned to counsel their patients about problematic alcohol use. They play an important role in providing education and information, as well as, communicating appropriate low-risk alcohol drinking guidelines.[21] However, a recent US report revealed that health professionals do not routinely discuss problematic alcohol use (such as binge drinking) with their patients.[22] PHCP may feel uncomfortable asking their patients about alcohol use; lack the time; receive inadequate remuneration; are influenced by issues of societal stigma; perceive professional or systemic inadequacies; and/or lack information on how to manage a discussion on alcohol use and intervention strategies.[22,23] Recent meta-analytic evidence supports the effectiveness of preconception interventions such as screening, education, motivational interviewing, and referral to reduce alcohol use in pregnancy.[24] These conversations need to be respectful, compassionate, and informed. PHCP thus have an important role in screening for problematic alcohol use, offering harm reduction, implementing brief intervention strategies, and/or providing referrals for diagnosis and treatment.[22,25]

Screening for Problematic Alcohol Use

It is critical for PHCP to feel comfortable and confident screening for problematic alcohol use, especially during pregnancy. Currently, there are several screening tools available that are both sensitive and specific for both males and females.[26] Screening tools for problematic alcohol use that are specific to women include the "CRAFFT" for adolescents, the "modified CAGE" (T-ACE and TWEAK) for pregnant and non-pregnant women[1,6] or the AUDIT (Alcohol Use Disorder Identification Test).[27] Motivational interviewing is also an important skill set for conducting these types of investigations and is effective in reducing alcohol use in pregnancy.[25]

FASD Screening Tool Kit

In partnership with the Public Health Agency of Canada (PHAC), the First Nations Inuit Health Branch (FNIHB) of Health Canada, and *many* FASD experts, practitioners *and* researchers, the Canadian Association of Pediatric Health Centres (CAPHC) facilitated the development of a National FASD Screening Tool Kit.[28,29] The tool kit is comprised of the Neurobehavioural Screening Tool (NST); Meconium Fatty Acid Ethyl Esters (FAEE) Testing; Maternal Drinking Guide – Fact Sheet and Tool; Medicine Wheel Student Index and Medicine Wheel Developmental History; and the FASD Screening & Referral Form for Youth Probation Officers. The use of these tools, such as the NST, continue to be evaluated across different clinical populations.[30] Ethical questions have been raised about biomarkers for prenatal alcohol exposure[31,32], which identify risk for developmental

disability in the child, but are not diagnostic. The child will need developmental monitoring and access to a supportive environment. These tests also extend a certain degree of culpability to the biological mother, and positive screens need to be carefully communicated[33] and the mother provided with supports for her own needs.[33,34]

HOW IS THE DIAGNOSIS MADE?

Multidisciplinary Approach

FASD may be diagnosed in an individual with a history of prenatal alcohol exposure and a pattern of neurobehavioural characteristics with or without facial features. The Canadian diagnostic guidelines for FASD[1] describe a multidisciplinary process that consists of screening and referral, neurodevelopmental and physical assessment, diagnostic formulation, recommendations for management, and follow-up. The multidisciplinary team varies based on resources, but typically includes a coordinator, physician, psychologist, occupational therapist, speech therapist, and social worker. The team collects information from the individual and their family to determine the specific needs and goals of the assessment, to ascertain their readiness, and to identify community and cultural influences that may impact the assessment and subsequent resources available to the family. PHCP can provide important support, education, and advocacy to the family during the process of data gathering. Confirmation of prenatal alcohol exposure is a complex process that involves reliable sources, ideally the birth mother. The multidisciplinary assessment provides data on cognitive and adaptive functioning across multiple domains of brain function. A differential diagnosis is considered along with the physical examination and dysmorphology assessment to determine the functional strengths and needs that can inform the most appropriate management plan. The final report outlines the basis for diagnosis, details specific areas of strength and weakness, and provides concrete recommendations for follow-up and support. The PHCP receives a copy of the report and plays an important role in following-up on recommendations with the family, providing on-going education and support in the community, advocating for services and supports, and for a culture of acceptance and understanding.

METHODS

Primary health recommendations for the management of children with FASD were developed based on expert clinical judgment and supported by evidence-based research, where appropriate. The format was adapted from other health supervision practice guidelines as developed by the American Academy of Pediatrics (e.g., AAP Committee on Genetics. American Academy of Pediatrics: Health supervision for children with Down syndrome[26]).

RESULTS & DISCUSSION

Key Points about FASD for PHCP

Social and environmental factors

There are a number of potential factors that can influence the presentation and severity of FASD, including: maternal nutrition and stress in pregnancy, exposure to other drugs in utero, as well as, genetic and epigenetic influences.[5,35-39]

Early postnatal adversity such as unstable home environment and exposure to neglect, abuse and domestic violence have a negative effect on early brain development. This is mediated largely through the stress response involving the hypothalamic pituitary axis leading to altered cortisol secretion and lifelong implications.[38,40] These effects have been well studied in the Adverse Childhood Experiences (ACE) study[41] and in the Harvard Early Brain Development work.[42] Attachment disorders need also to be considered in children who have had chaotic early life experiences with multiple caregivers, as this can have a negative impact on development.[43-48] Many children with prenatal exposure to alcohol will come into the foster care system due to the systemic issues that contributed to the maternal drinking. These children are at risk for developmental disability from both the prenatal alcohol exposure and early life adversity. All children in foster care require developmental screening including the investigation of prenatal alcohol exposure. These should be evaluated by history and documented.[49,50] Ultimately, an early

diagnosis, access to appropriate services, and stability of home environment are critical protective factors against negative outcomes in later years.[51,52]

PRACTICE POINT #1: ***PHCP are in a position to screen for child maltreatment and to advocate for stability of placement for the child and education for their families to minimize or prevent further trauma.***[53,54]

Behaviour and Learning

Current research on the brain dysfunction associated with FASD supports a diffuse information processing, integration and self-regulation model that underlies many of the problems observed in this population.[55-58] Clinically, affected children present with complex difficulties in adaptive function that becomes increasingly evident with age as natural societal expectations increase.[59-61] The measure of intellectual ability alone often fails to reflect the extent of dysfunction associated with FASD and many children score in the low-average range.[62] Executive functioning deficits describe significant areas of difficulty that include: cognitive flexibility, planning and organization, reasoning, inhibition, shifting, working memory and abstract reasoning.[63-65] Memory deficits in both verbal and visual information have also been documented.[55,66] Attention difficulties are common and studies support a comorbid attention deficit/hyperactivity disorder (ADHD) diagnosis in >65% of children with FASD.[67,68] Sustained attention appears to be more significantly impaired than immediate attention in children with FASD compared to children with ADHD.[69] Academic difficulties have been identified in the areas of mathematics and reading comprehension, both critical to functional numeracy of money, time management and learning through reading.[70,71] In later school years, a shift from academics to basic life skills and employability options is more supportive and reduces the frustrations of being overwhelmed in a classroom setting.[72]

Management of ADHD and Mood Disorders Comorbid with FASD

Educating caregivers on the complex impact of prenatal alcohol exposure on brain development is the initial step in the management of comorbid ADHD and mood dysregulation diagnoses.

Pharmacotherapeutics

The first line pharmacotherapeutics for ADHD are the stimulant medications (e.g., methylphenidate) in short or long acting formulations as described in the Multimodal Treatment of ADHD[73] and in the American Academy of Pediatrics guidelines for ADHD treatment.[74] Common side effects include loss of appetite and difficulty settling to sleep that requires ongoing monitoring of growth, nutrition planning and sleep management. Emotional lability can present as the medications wear off and is often a reason to discontinue the stimulant medication. Switching from one stimulant to another may result in fewer side effects. Consideration must be given if the adolescent or their family members are at risk of abuse, misuse or diverting the stimulant medication to a street drug when choosing to prescribe stimulants. If there is a family history of sudden death from cardiac arrhythmias or a known cardiac concern in the patient, a baseline electrocardiogram with measure of QT interval is recommended.

An alternative non-stimulant medication for ADHD management is Atomoxetine a selective norepinephrine transport inhibitor, which has been effective for the inattentive ADHD subtype and anxiety.[75,76] This requires daily dosing and more than four weeks of administration to determine effectiveness. The most common side effects include nausea and abdominal discomfort.

Alpha 2 adrenergic agonists (e.g., short acting clonidine and long acting guanfacine, under the trade name of Intuniv), which facilitate dopamine and norepinephrine neurotransmission have been beneficial for the medical management of ADHD as an adjunct to stimulants or as a primary therapy.[77] Cardiac, including electrocardiogram with QT interval and blood pressure monitoring is required for this family of

drugs. Side effects reported are initial sedation that improves over time.

Medication management for anxiety, depression and other mood disorders comorbid with FASD frequently involves the use of Selective Serotonin Reuptake Inhibitors or SSRIs.[78-80] However, there are no randomized control trials specific to FASD. Atypical antipsychotics are often prescribed for individuals with FASD for a variety of disruptive behaviours but there is no research evidence to support this. This raises an urgent call to researchers to do more in FASD intervention research, especially with the suspected prevalence of FASD in the population and the high incidence of comorbid mental health disorders. A recent panel of experts on therapeutic products for children in Canada led by Dr. Stuart MacLeod has raised these issues.

Dose guidelines are provided based on body weight with a "start low go slow" rule when changing doses based on clinical responses. It is essential to obtain information from caregivers and teachers on the responses in all environments by either a questionnaire or qualitative description. It is also important to ask the older child or youth how they feel the medication is working for them.

Interventions

Medications must be accompanied by classroom accommodations such as preferential seating, reducing over stimulation, reduced task length, extra time for tests, access to a scribe, reminders for organizational skills and modified learning if a learning disability is also present.[81] Nonmedical approaches to ADHD management have been developed such as computer-based attention training[82] and neurofeedback[83] programs. However, these therapies are not readily available and can be very expensive and require a time commitment.

Parent coaching programs that teach how to provide positive discipline for negative behaviours and rewards for appropriate behaviours, such as the Triple P or Incredible Years programs have been beneficial for children and adolescents with ADHD and other disruptive behaviours.[74] However, they have not been evaluated in the FASD population specifically but provide caregivers with basic parenting tools that are important. Anxiety and other internalizing disorders can be managed with non-pharmaceutical interventions including behavioural parenting interventions or cognitive behavioural therapy for the affected child or youth.[84] These interventions require a skilled therapist who can modify the strategies according to the cognitive, communication and other challenges associated with FASD. However, it is unclear whether individuals with FASD can generalize from the therapy session to using the skills acquired in real life situations, as adaptive functioning is a fundamental deficit in FASD.

PRACTICE POINT #2: ***PHCP should provide ongoing monitoring of academic and social functioning with the family and education system. They are in a position to provide education and consultation to the schools and to interpret behaviour with an understanding of the neurological basis of FASD and the associated behaviours.***

Self-Regulation

Difficulties with self-regulation have been considered a core deficit of FASD and describe problems with sustaining attention, difficulties with impulse control and inhibition, difficulty regulating appropriate responses to stress, mood and affect dysregulation, sleep disturbance and other mental health disorders. Disturbances in self-regulation can be noted as early as the neonatal and early infancy period.[85,86] Presentations can include irritability, under-or over-responsiveness to stimulation, poor habituation, disorganized suck and swallow and disrupted sleep patterns.[87,88] Self-regulation problems can often be overlooked and further underscore the need for comprehensive history taking. During toddlerhood and into early school age, self-regulation difficulties present as hyperactivity, inattention, oppositional defiance and mood swings. ADHD may be diagnosed prior to identifying the history of prenatal alcohol exposure. This emphasizes the importance of asking about the possibility of alcohol use in the pregnancy when taking the history of any child presenting with developmental or behavioural disability.[68] During adolescence and adulthood continued problems can lead to risk-taking and

impulsive behaviours that may lead to problems with the law.[60,61,72,89,90] When managing problems with self-regulation, environmental adaptation with an understanding of triggers is a good initial approach that may benefit from the involvement of an appropriate therapist. Medications that target the symptoms may be also considered along with a comprehensive behavioural management plan and appropriate supports. Medication management in FASD can be challenging and may require consultation with mental health services.[91,92]

PRACTICE POINT #3: ***PHCP should evaluate children with FASD for other mental health disorders (or refer for assessment). They should educate families on the behavioural and medication management when appropriate, in consultation with mental health specialists as needed.***

Social Situations

While basic language may appear to be intact, higher order language deficits are common in the FASD population.[93] This includes communication functions such as predicting, referencing, inferencing, reasoning and narrative generation[94], which can impact social function, and the ability to understand instructions and information.[70,95-97] Children with FASD can be talkative, but tangential, making it difficult for the listener to follow what the individual is trying to say. This type of communication can present as "lying" or "telling stories"[70,98], and must be considered when individuals are in different social situations (e.g., legal statements in court). Due to the fact that individuals with FASD often experience impairments in their understanding of social use of language and nonverbal social communication cues, they are at an increased risk of victimization.[96,97,99]

PRACTICE POINT #4: ***PHCP should screen communication skills of children with prenatal alcohol exposure and refer early to speech and language therapists.***

Family Support

By framing FASD as a neurodevelopmental condition, the focus shifts from "changing" the child to "providing" them with the most supportive environment. Stable home placement that includes positive stimulation leading to healthy attachments and learning opportunities provide the foundation for successful outcomes. It is critical that all caregivers receive training, support and respite to provide them with important tools for managing children and adolescents with FASD and to help reduce stress and prevent burnout.[100-102] Interventions for children with FASD that focus on a quality caregiving environment and integrate the role of family have been suggested[103], and caregiver training has been a repeated key to success across many research studies.[100,102,104] An online caregiver-training program has recently been developed and is currently undergoing larger field trials to provide caregivers with education, training and support to meet their needs, the needs of their child with FASD and their family based on caregiver and clinician input.[105] When children with FASD encounter non-supportive environments, their learning is impeded and this can lead to externalizing behaviours (e.g., aggression, acting out) or internalizing behaviours (e.g., shut down, withdrawal, anxiety). Training of foster care providers about FASD has been shown to improve stability of placement and reduce caregiver stress.[101,102]

PRACTICE POINT #5: ***PHCP should be aware of FASD support services in their community and refer families to educational and family supports early.***

Medical Review Including Medication Management

Children with FASD can have significant health concerns requiring coordination of care by a PHCP who understands their unique needs and provides continuity of care over the lifespan. A thorough medical history must be obtained from the individual or reliable caregiver, and a general physical and neurological exam are the gold standard. Screening for mental health disorders is also needed, as well as, screening for addictions for adolescents and young adults. Importantly, the majority of health issues are not specific to FASD and can present as other neurodevelopmental disabilities, which underscores the importance of

continuity of care. For example, if the child is in the foster care system, every effort should be made to maintain the same PHCP. For adolescents and young adults with FASD, having easy access to a PHCP with whom they have a trusting and nonjudgmental relationship can significantly improve quality of life and prevent many health complications.

The following list highlights the most frequent health issues associated with FASD requiring ongoing monitoring by their primary care provider:

Growth

Growth may be impaired in some children or may be normal, even with significant neurodevelopmental impairment. Growth should be monitored at each visit using standardized growth curves. The growth curves produced by the Canadian Pediatric Endocrinology Group (CPEG) based on the 2010 WHO curves with some modifications are recommended. The Canadian Pediatric Society has endorsed these growth curves.[106] The detection of small stature (i.e., less that the 10%) is one criterion of full Fetal Alcohol Syndrome (FAS)[1], however it is important to rule out other causes of growth deficiency, such as malabsorption (celiac, short gut syndrome); pituitary growth hormone deficiency; nutritional deficiencies; other in utero drug exposures; gastroesophageal reflux; feeding disorders, including those related to sensory processing or emotional disturbances; other systemic chronic disease (e.g., cardiac, renal); genetic syndromes; or familial small stature (if biological parental stature is available).

Facial Dysmorphology

Elements of the characteristic face of FAS, with flat philtrum, thin upper lip and small palpebral fissures, may be observed in approximately 10% of patients who experienced prenatal exposure to alcohol. Facial analysis can be completed using a photographic software program from the University of Washington.[107,108] However, there are a number of genetic syndromes that produce similar facial dysmorphology and must be investigated by appropriate genetic testing (e.g., Williams syndrome, Aarskog, syndrome 22q11.2 deletion syndrome).[1,109]

Other Physical Effects of PAE

A number of birth defects have been described to recognize developing organ systems that can be damaged or disrupted by prenatal exposure to alcohol. While there is a long list of possibilities, the most important organ systems to screen include: vision (strabismus and myopia); hearing (malformations, sensorineural hearing loss that can impact language development); heart (septal defects needing surgery, arrhythmias that have major implications of side effects to certain medications); and palate (requiring plastic surgery to repair). It should be noted that these malformations are common in the general population and in other genetic syndromes, and therefore ***not*** specific to prenatal exposure to alcohol.[109] Additional minor dysmorphic features have also been documented such as a hockey stick palmar crease.[109] Thus, before an FASD diagnosis is made, it is critical to determine the etiology of these features (e.g., prenatal alcohol, genetic abnormality). Current genetic testing has revealed an increasing number of chromosomal abnormalities that may be linked to the observed birth defects. Physicians can now request a microarray through genetic labs, if indicated, and refer for further genetic assessment and counselling as appropriate.[109]

Seizures

A retrospective chart review revealed that individuals with FASD are at increased risk of having a seizure disorder (~prevalence of 17.7%) compared to the general population.[110] Clinical presentation of the seizures can be subtle necessitating a thorough examination when conducting the child's history. An electroencephalogram (EEG) is recommended if there is a clinical suspicion. Atypical behaviours reported in sleep may require additional video EEG investigation and/or sleep deprived EEG. Epileptic abnormalities on the EEG need clinical correlation and may need treatment with an anticonvulsant. These medications need to be titrated with the same precautions as those used for other co-morbidities (e.g., ADHD).

Additionally, the knowledge of confirmed prenatal exposure to alcohol may also impact the efficacy of prescribed medications, rendering the patient more or less sensitive to the effects. Frequent monitoring is recommended. Any abnormalities on EEG also need to be considered in the context of the differential diagnosis of comorbid conditions, especially if medications such as stimulants for ADHD or selective serotonin reuptake inhibitors for mood have been prescribed.

Neuroimaging is not indicated in the diagnosis of FASD but can be considered as part of the differential diagnosis if there are abnormal hard neurological findings such as spasticity or microcephaly. Research level MRI studies are providing further information on the impact of alcohol on brain development.[111]

Immune System

The effects of prenatal alcohol exposure on the developing neuroimmune system are complex and not fully understood. Longitudinal population based studies such as the Adverse Childhood Experiences Study, demonstrate that pre- and postnatal toxic stress can alter the immune system responses and the effects can be life-long.[41,112-114] Prenatal alcohol exposure and/or exposure to traumatic stress is often linked to psychosocial determinants of health such as poverty; malnutrition and environmental exposure, which can further impact the developing immune system. With lower immune responses, the individual may be more prone to common infections.

Sleep

Disrupted sleep, both difficulties in falling asleep and staying asleep, is very common in FASD.[115-118] A description of the child's sleep patterns, the sleep environment and medications that are used throughout the day are essential pieces of the history that need to be collected by the PHCP. The causes of the sleep problems can be multiple and complex including the effects of prenatal alcohol exposure on the normal sleep cycle. Trauma and adverse life events, low iron levels (as found in restless leg syndrome), mental health issues such as anxiety or depression, school frustrations and bullying, chaotic home environment, technology in the bedroom, personal substance abuse in older teens and young adults, and side effects of prescribed medications can all contribute to disrupted sleep patterns. Initial management steps include counselling regarding appropriate sleep hygiene and a stable emotional environment. Melatonin may be appropriate in conjunction with strict sleep hygiene and environmental modifications.

PRACTICE POINT #6: ***PHCP should screen children and adolescents with FASD for sleep disorders using a simple screen such as the 5-item pediatric sleep screening instrument, the BEARS (B=Bedtime Issues, E=Excessive Daytime Sleepiness, A=Night Awakenings, R=Regularity and Duration of Sleep, S=Snoring.[119] PHCP should provide early referrals to occupational therapists that can provide consultation on sensory processing, sleep and self-regulation. If Obstructive Sleep Apnea is suggested by clinical history, referral to a Sleep Clinic or an Ear, Nose and Throat Specialist is indicated. If nocturnal seizures are suspected, a sleep deprived EEG and/or referral to Neurologist is indicated.***

Nutrition

Feeding difficulties often present during infancy where there has been prenatal exposure to drugs and alcohol. Symptoms may include poor coordination of suck and swallow, irritability associated with pain from gastroesophageal reflux, or coughing with intake of liquids. Feeding difficulties may also be related to environmental neglect and poor infant-maternal bonding. Early identification and management can prevent failure to thrive and other medical complications. Referral to services such as a Dietician, Occupational Therapist, Speech and Language Pathologist or a multidisciplinary feeding team may be indicated. In the preschool age group, sensitivities to different textures and tastes of foods can lead to food refusals. Nutritional deprivation in the early years can develop into lifelong unhealthy habits such as hoarding and stuffing of foods and not recognizing limits. Many medications prescribed for behaviour management can have side effects such as loss of appetite or excessive food cravings. The PHCP needs to use good judgment in choosing the appropriate

medications and frequently monitor weight, Body Mass Index and blood testing if indicated.[120,121]

Elimination

Constipation is a frequent problem for all children and adolescents with disabilities including those with FASD. There are many factors to consider, including food choices, behavioural stool retention, gut motility, side effects of medications, and lack of home routines that must be contemplated in developing an appropriate management plan. Additional problems with urine control can be related to renal and bladder function. The PHCP needs to also be aware that trauma, especially sexual abuse, can trigger these problems and further investigations need to be approached with extreme sensitivity.

Mental Health Disorders

Over 90% of individuals with FASD have a coexisting mental health disorder[52,122], where ADHD is one of the most prevalent.[67] In teens and young adults there are often multiple conditions, such as depression, anxiety and substance abuse. These conditions may be primarily due to the impact of in utero alcohol exposure or secondary to adverse life experiences, or both. There is no evidence-based literature supporting unique management of mental health disorders in FASD. Anecdotal evidence suggests that the responses to medication are not predictably robust and may result in the prescribing of multiple medications. In recent years there has been an increase in the use of atypical antipsychotic drugs to manage aggression and "out of control" behavioural responses. General practice guidelines on the management of mental health conditions in the general population provides the PHCP with guidance in their management, recognizing that the neurobehavioural complexity of FASD may result in atypical responses to medications and thus close monitoring is recommended.[120,121] Cognitive therapy may be of limited efficacy when there are significant functional limitations in communication and cognitive function as is seen in FASD. Therapy that is trauma-informed and based on attachment theory is often recommended.[33] Access to a mental health team that has received FASD training and who can help manage these complex cases is helpful in these situations.

PRACTICE POINT #7: ***The PHCP must evaluate the environment prior to prescribing medication for presenting behaviours. When doing so, they must follow patients closely for side effects as their responses may differ from children with no underlying FASD.***

Dental Health

Although prenatal exposure of alcohol alone may not affect the development of dental enamel in utero, maternal malnutrition can play a role. A recent population based study suggests that children of mothers with an alcohol-related diagnosis have increased dental disease including dental admissions.[123] More importantly, the postnatal diet with inappropriate bottle feeding and high sugar intake compounded by poor oral hygiene can cause cavities. Individuals with FASD have difficulty remembering routines for daily living, especially personal hygiene without constant reminders. A picture list for daily routines on the bathroom mirror can be very helpful. Dental cavities and abscesses are painful and can contribute to irritable behaviours and disrupted sleep. Early recognition is very important. Regular six month routine dental monitoring is recommended. In the adolescent years, many teens with FASD have dental malocclusion related to midfacial under-development and may require orthodontic treatment.

PRACTICE POINT #8: ***The PHCP should be vigilant in assessing for health issues that may occur more frequently in individuals with FASD. Early identification and treatment of co-morbid health conditions will reduce the burden of care for individuals with FASD and the families caring for them. The PHCP has an important role in the early identification of individuals who may have experienced prenatal alcohol exposure by conducting a complete and sensitive medical and prenatal history.***

COMMUNITY PARTNERSHIPS

What Partnerships Are Needed?

An integrated network of multidisciplinary, community-based care providers is fundamental to the management of children with FASD. Children with FASD and their families often have complex needs that span multiple systems (e.g., health, education, social services etc.) As FASD is a lifelong condition, supports and services will change over time, making continuity of care a major contributor to ongoing success. It is important to foster partnerships across all systems early in the diagnostic process, as they will be critical for supporting children and their families throughout the lifespan. The spectrum of services in a community may include screening; early intervention; access to a multidisciplinary diagnostic team; developmental, educational and behavioural interventions; primary health care; mental health and addiction services; rehabilitation services; tiered prevention services; and employment and housing support (for older individuals with FASD).

PRACTICE POINT #9: ***A coordinated team approach, with the PHCP as a key player, should be based on the principles of child-centered and family-centered care, inter-professional collaboration, evidence-based knowledge, flexible care provision, shared communication, effective resource coordination, and integration of care.***

Role of the PHCP (e.g., Pediatrician, Family Physician)

The complexity of FASD requires a PHCP who is knowledgeable about FASD and has access to a collaborative multidisciplinary team. The PHCP may be a resource to help navigate the systems for the family and individual with FASD. A key element of providing care to families of children with FASD is providing education to caregivers including a discussion about the behavioural and cognitive effects of FASD, goals for intervention, and how to advocate for supports and services for their children.[124] The supports will naturally need to change at different ages and life stages, and an anticipatory guidance approach is needed.

PRACTICE POINT #10: ***The PHCP and support team will play a key role in ensuring a successful transition from childhood to adulthood. This will include transition planning and helping families secure the services and resources their child will need in adulthood.***

FASD AND Alcohol Resources in the Community

It is important to identify community-based resources related to FASD, alcohol, addictions, and prevention for each region.[1,100] These resources should be readily available to families from their PHCP and/or community team and/or shared through community partnerships.

PRENATAL MANAGMENT

Education and Counselling from PHCP (e.g., Pediatrician, Family Physician)

All PHCP need to be aware of the risks associated with alcohol use during pregnancy and to provide prevention messaging to all women of childbearing age and their partners. There are many resources for primary prevention messaging such as posters, pamphlets and other media. Primary prevention messages displayed in a health care setting may not change behaviour, but can be used to start the conversation about "how to have a healthy pregnancy" by the PHCP.

Counselling

PHCP are in an ideal position to talk to all women about their alcohol use at multiple points in their lifespan. Alcohol use in pregnancy crosses all ethnic and economic strata. The question of alcohol use should be asked without judgment and with the offer of positive support. Women may be fearful about disclosing their alcohol use during pregnancy, as they may lose their child to Child Welfare authorities. Many women with problematic alcohol use have also experienced multigenerational trauma, loss and grief, undiagnosed mental health issues, lack of educational opportunities, stressful home environments, unplanned pregnancies and intimate partner violence. It is incumbent that the PHCP recognizes these compounding factors. The Society Obstetricians and Gynecologists of

Canada have published *Alcohol Use and Pregnancy Consensus Clinical Guidelines* that describe best practices for counselling women about alcohol use and pregnancy, and provide evidence-based recommendations to help PHCP provide the best care in these sensitive situations.[125]

An emerging "high risk" group for alcohol use in pregnancy may be professional women, who may not be planning pregnancy, and who may use alcohol as a means to cope with stress and mental health issues. Binge drinking in adolescent girls is a concern, as this is an at-risk age group for unplanned and late recognition of pregnancy. The PHCP needs to feel comfortable asking questions about problematic alcohol and/or substance use to ***all*** women of childbearing age. Screening tools (e.g., TWEAK, T-ACE, CAGE) can be extremely useful for identifying "at-risk" populations, who would benefit from further counselling, referral, intervention, and/or treatment for problematic alcohol and/or substance use. The PHCP is in a position to provide prevention messaging to male partners to help them understand the male's role in having a healthy pregnancy, including information on alcohol and stress in pregnancy.

Harm Reduction

There are many women who are unable to change their behaviour even after they receive information about problematic alcohol and/or substance use and may require a more personalized approach. This approach needs to be framed within a social determinants of health context and based on harm reduction. Brief interventions, such as motivational interviewing, have been effective. The PHCP needs to know the next level of tertiary prevention and how these patients can access more intensive supports and programs that provide access to contraception, physical and mental health care and targeted educational resources for women. Although the primary goal is less prenatal alcohol exposed-pregnancies, if this cannot be achieved, harm reduction is supported without blaming or shaming.[33,34,86]

Prenatal Investigations

Prenatal fetal ultrasound may identify differences in limb length, congenital cardiac defects, and other alcohol-related birth defects, if present. However, most cases of FASD show no specific features on prenatal imaging that would identify FASD. At this time, there are no specific genetic tests that would identify FASD.

Maternal Nutrition

FASD has been associated with the "poverty trap[126]", which is associated with a lack of resources leading to poor nutrition during pregnancy, including decreased folate, vitamin, iron and protein intake. Additionally, the calories from alcohol reduce food intake and monies may be directed to the purchase of alcohol rather than nutritious foods.[127] These factors, along with lack of antenatal care, can also adversely impact the management of gestational diabetes.

Nutrient deficiencies compound the effects of prenatal alcohol exposure[128], and the potential of using nutrient supplementation as a protective factor, is currently under investigation.[129-131] Maternal iron deficiency contributes to poor iron stores in the newborn, which can impact cognitive development.[132,133] Micronutrient supplements, such as choline[134], may also improve cognitive function following prenatal alcohol exposure. However, diet enrichment does not replace the need to provide the woman and her partner with advice on avoiding alcohol in pregnancy.

CONCLUSION

There is a pressing need for the engagement of PHCP in the active care of individuals with FASD and their families over the lifespan. PHCP are trained in screening, prevention, and management of health needs, and are in the position to coordinate sub-specialty referrals as needed. They can also provide families and their communities with education and interdisciplinary coordinated care. Individuals with FASD are often involved with multiple systems such as health, education, social services, and justice. The role of a PHCP can include critical consultation and advocacy for affected individuals. Finally, subspecialty care

may not always be easily accessible to individuals and families in remote areas, and the PHCP can provide an important link to expert care. The purpose of these guidelines is to provide PHCP with the best evidence for the medical, behavioural, and mental health recommendations for the care of individuals with FASD in their communities (see worksheet template in Appendix I). Engaging PHCP will provide a truly integrated care system for individuals affected by prenatal alcohol exposure and their families.

Acknowledgements

The authors wish to thank Dr. Hasu Rajani and Dr. Leigh Wincott from the Department of Pediatrics at the University of Alberta for their contributions to the section describing the most frequent health issues associated with FASD, and Dr. Lee Green from the Department of Family Medicine at the University of Alberta and Dr. Sally Longstaffe from the Manitoba FASD Centre, Child Development Clinic and Department of Pediatrics at the Manitoba Institute of Child Health for reviewing the manuscript as representatives from the PHCP practice community.

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APPENDIX I: Anticipatory Guidance for Children and Adolescents with FASD (modeled after Appendix I from[135])

	Prenatal	Infancy Birth to 1 y					Early Childhood, 1 to 5 y						Late Childhood (6 to 13 y)	Adolescence (14 to 21 y)
m = months; y = years		Neo-natal	2 m	4 m	6 m	9 m	12 m	15 m	18 m	24 m	3 y	4 y		
Maternal Alcohol Use Screening	S	S – screen as required for referral and/or treatment required; interview/information gathering for multidisciplinary FASD assessment should be done by appropriately trained individual working with team												
Diagnosis		•	•	•	•	•	•	•	•	•	•	•	•	•
Medical Evaluation														
Growth (Length, weight, head circumference)	o	o	o	o	o	o	o	o	o	o	o	o	o	o
Hearing Screening		S/o	S/o	S/o	S/o	S/o	S/o	S/o	S/o	S/o	S/o	S/o	S/o	S/o
Vision Screening		S/o	S/o	S/o	S/o	S/o	S/o	S/o	S/o	S/o	S/o	S/o	S/o	S/o
ARBD (complete review of systems, e.g., cardiac, musculoskeletal, spina bifida etc.)		o	o	o	o	o	o	o	o	o	o	o	o	o
Seizures		S/o	S/o	S/o	S/o	S/o	S/o	S/o	S/o	S/o	S/o	S/o	S/o	S/o

DCD										S	S/o	S/o	S/o	S/o
Toileting/Enuresis/ Encopresis									S	S	S	S	S	
Eating/Feeding		S/o	S/o	S/o	S/o	S/o	S	S	S	S	S	S		
Sleeping		S	S	S	S	S	S	S	S	S	S	S	S	S
Sexuality													S	S
Psychiatric/ Behavioural														
ADHD											S/o	S/o•	•	•
Mood disorder (anxiety/depression)	S/o										S/o	S/o	S/o	•
ASD									S/o •	S/o •	S/o •	S/o •	S/o •	S/o •
Substance Use	S/o												S/o	S/o
Psychosocial														
Development		S/o	S/o	S/o	S/o	S/o	S/o	S/o	S/o	S/o	S/o	S/o	S/o	S/o
Behaviour		S/o	S/o	S/o	S/o	S/o	S/o	S/o	S/o	S/o	S/o	S/o	S/o	S/o
Preschool/School Performance										o	o	o	o	o
Socialization/Peers										o	o	o	o	o

Referrals (at any appointment as needed)														
SLP							•	•	•	•	•	•	•	•
OT		•	•	•	•	•	•	•	•	•	•	•	•	•
PT		•	•	•	•	•	•	•	•	•	•	•	•	•
Early Intervention		•	•	•	•	•	•	•	•	•	•	•	•	•
FASD Family Support		•	•	•	•	•	•	•	•	•	•	•	•	•
FASD Community Support		•	•	•	•	•	•	•	•	•	•	•	•	•
Justice													•	•

tion Disorder; OT = Occupational Therapist; PT = Physiotherapist; SLP = Speech & Language Pathologist.

TABLE 1 Anticipatory Recommendations by Age

	Physical Examination	**Discuss and Review**	**Evaluate for**	**Anticipatory Guidance**
Birth to 1 month	- Measure and plot growth parameters (weight, length, head circumference), including growth at birth using appropriate growth curves - Complete dysmorphology examination. This may be conducted by geneticist/ dysmorphologist experienced in FASD. Palpebral fissure lengths (PFL) should be plotted on PFL curves. An assessment of lip fullness and development of philtrum should be conducted using the Washington lip-philtrum guide. - Complete systems exam including but not limited to intraoral/palate, vision, hearing, skin (e.g., hemangiomas, other birthmarks, neurocutaneous abnormalities), cardiac (septal defects, patent ductus arteriosus, other), orthopedic/skeletal (e.g., congenital hip dislocation, scoliosis, limb/digit anomalies), genitourinary (e.g., hydronephrosis, labial hypoplasia, sphincter tone, tufts), neurological	- Prenatal alcohol use - Maternal substance use patterns including screening for current substance misuse using screening tool such as CRAFFT or modified CAGE (T-ACE and TWEAK) [6] - Mental health screening for depression, post-partum depression or other mental health disorders - Social screening for risk factors such as intimate partner violence, mental health disorder such as depression, and poverty	- Alcohol Related Birth Defects (ARBD): cardiac defects, gastrointestinal defects, cleft lip and palate, orthopedic anomalies (e.g., radioulnar synostosis), spina bifida - *see Table 2 from [136])* - Growth retardation, especially symmetric growth retardation - Vision (e.g., optic nerve hypoplasia, abnormal retinal vessels, coloboma, microphthalmia [137]) - Hearing: universal newborn hearing recommended - Newborn metabolic screening - Iron deficiency [132] - Microcephaly: if present, recommend head ultrasound and consider MRI - Seizure disorder	- Self-regulation: Infants with prenatal alcohol exposure and/or other prenatal substance exposure may have difficulty regulating their body temperature, movements, and reactions to their environment. They may be jittery, irritable, and show tone abnormalities. Infants may respond to swaddling, calm quiet environments, and patient well-regulated caregiving. Parents may benefit from counselling and respite care. - Sleep: Further evidence of abnormal self-regulation may be poorly regulated sleep, reduced sleep, or disrupted sleep patterns. Parents may benefit from sleep consultation and respite. - Feeding: Infants may have poorly coordinated suck and swallow, regurgitate more frequently. They benefit from patient responsive feeding

	(e.g., head shape, microcephaly, focal abnormalities, tone abnormalities)			practices. Parents may need consultation from feeding specialists and occupational therapists.
1 month to 1 year: Infancy	- Measure and plot growth parameters (weight, length, head circumference), including growth parameters at birth using appropriate growth curves. - Complete dysmorphology examination. This may be conducted by geneticist/ dysmorphologist experienced in FASD. PFL should be plotted on PFL curves. An assessment of lip fullness and development of philtrum should be conducted using the Washington lip-philtrum guide. - Complete systems exam, including oral/dental/palate, vision, hearing, cardiac, hips, orthopedic/skeletal abnormalities, genitourinary, neurologic (e.g., abnormalities of tone, persistent primitive reflexes, motor deficits) - Complete developmental assessment looking for delays in expressive and receptive language, problem solving delays, fine and gross motor delays, social and emotional delays, self-regulatory delays	- Developmental milestones and behaviour[138] - Parent child relationship and stressors - Social behaviour and development - Parenting stress and sources of support	- ARBD as above - Vision – refer for formal ophthalmologic evaluation if any visual concerns [137] - Hearing – refer for formal audiologic evaluation if newborn screen has not been done, if there are any speech or language delays, or if there are any concerns regarding hearing or speech development [139] - Developmental delay[138] – refer for formal developmental assessment - Iron deficiency, other nutritional deficiency	- Behavioural disturbance including difficulties with self-regulation, disorganization, emerging hyperactivity, emotional dysregulation - Discuss attachment behaviours and healthy parent child interactions; refer for supports in high risk groups and as needed - Feeding disturbances including food selectivity and atypical feeding behaviours - Screen for sleep disturbances - Daycare: issues related to sensitivity to environmental change, behavioural management - Discuss early intervention supports in the community including developmental supports, mental health services, and therapy supports including physiotherapy, occupational therapy, and speech and language therapy

				- Caregiver support and respite
1 to 5 years: Early Childhood	- Continue to monitor growth parameters (weight, length, head circumference) using appropriate growth curves. - Complete systems exam, including oral/dental/palate, vision, hearing, cardiac, hips, orthopedic/skeletal abnormalities, genitourinary, neurologic (e.g., abnormalities of tone, persistent primitive reflexes, motor deficits), and minor dysmorphic features particularly in the child who has previously been assessed as non-dysmorphic as minor findings may still be found - Complete developmental assessment looking for delays in expressive and receptive language, problem solving delays, fine and gross motor delays, social and emotional delays, self-regulatory delays – follow-up should include a pre-kindergarten developmental assessment for the purpose of informing school supports and programming	- Developmental milestones and behaviour [138,140-142] - Parent child relationship and stressors - Social behaviour and development [142,143] – risk for internalizing and externalizing behaviours - Sensory differences and influence on self-regulation/behaviour, sleep, eating, toileting [118,144] - Parenting stress and support	- Vision – refer for preschool vision screening - Hearing – refer for formal audiologic screening/ evaluation if newborn screen has not been done, if there are any speech or language delays, or if there are any concerns regarding hearing or speech development [139] - Developmental delay [138,140] – refer for formal developmental assessment - Iron deficiency, other nutritional deficiency	- Discuss school readiness and support early intervention programs aimed at academic and social emotional health - Discuss neurobehavioural differences in learning and social behaviour and need for continued and increased supports with age as adaptive gaps widen [142,145] - Education re: behaviour in context of prenatal alcohol exposure "reframing behaviour" [146-148] - Education and support re: sleep disorder – refer for consultation as needed - Discuss need for caregiver support and respite - Advocate for educational and community based supports for child
6 to 13 years: Late Childhood	- Continue to monitor growth parameters (e.g., weight, length, head circumference) using appropriate growth curves.	- Evolution of comorbid diagnoses such as ADHD, ODD and Conduct Disorder Pharmacological interventions	- Vision – refer for preschool vision screening - Hearing – refer for formal audiologic screening/ evaluation if	- Collaborate with education system, social services, and other service providers that have contact with the patient

	- Complete systems exam, including oral/dental/palate, vision, hearing, cardiac, hips, orthopedic/skeletal abnormalities, genitourinary, neurologic (e.g., abnormalities of tone, persistent primitive reflexes, motor deficits), and minor dysmorphic features particularly in the child who has previously been assessed as non-dysmorphic as minor findings may still be found - Assess Tanner Stage and evolving pubertal development - Comprehensive neuropsychological assessment looking for delays and/or deficits in the following domains: Motor; Neurophysiology/Neuroanatomy; Cognition; Communication; Academic Achievement; Memory; Attention; Executive Function; Anxiety and Depression; Adaptive Behaviour, Social Skills and Social Communication	- Early presentations of mental health issues such as depression, low self-esteem, anxiety and mood regulation Pharmacological interventions - Determinants of health (housing, food security) - Parent child relationship and stressors - Social behaviour and development [142,143] – risk for internalizing and externalizing behaviours - Sensory differences and influence on self-regulation, sleep, eating[118,144] - Parenting stress and support - New contact with the justice system - Understanding of puberty, sexual activity, contraception	newborn screen has not been done, if there are any speech or language delays, or if there are any concerns regarding hearing or speech development [139] - Cognitive disability or learning difficulties/disability – refer for formal psychoeducational assessment - Iron deficiency, other nutritional deficiency Evidence of abuse (physical, emotional, sexual) - Refer for follow-up based on physical findings, when indicated - Existence of trusting and stable relationships and/or primary advocate for the individuals (caregiver) - Drug and/or alcohol abuse and subsequent referral to appropriate treatment centres and programs	- Identify potential advocates and/or mentors, if needed - Discuss neurobehavioural differences in learning and social behaviour and need for continued and increased supports with age as adaptive gaps widen [142,145] - Education re: behaviour in context of prenatal alcohol exposure “reframing behaviour” [146-148] - Advocate for educational and community based supports for child - Drug and/or alcohol education - Sex education, personal safety/abuse, and contraception when needed
13-21 years or older: Adolescence to Early Adulthood	- Depending on the age and cognitive capacity of the teen, choose to do the exam with or without the caregiver present, include teen in the decision. - Corroborate information from the teen in a separate interview	- Transition to adulthood -School transitions to higher grades and need for assessment and supports that may not have been previously identified	- Vision and hearing - Oral health as many teens have significant malocclusions needing orthodontic work - Blood work for iron deficiency, other nutritional deficiencies based	- Discuss physical health needs, and pubertal changes - Discuss medication including transitioning to independence, medication preferences (e.g., stimulants), side effects of medications.

	with the caregiver, keeping in mind how long they have had a relationship. - Continue to monitor growth parameters (weight, height, head circumference) using appropriate growth curves. Note growth impact of prescribed medications: weight loss with stimulants, excessive weight gain with atypical antipsychotics and antidepressants - Complete systems exam, especially if assessment for birth defects or acquired health conditions have not been previously conducted. Include oral/dental/palate, vision, hearing, cardiac, orthopedic/skeletal abnormalities, genitourinary, neurologic (e.g., abnormalities of tone, balance and coordination with eyes open and closed, motor planning, soft signs such as past pointing on finger nose testing), and minor dysmorphic features, Tanner staging of pubertal development with note of gynecomastia in males treated with atypical antipsychotics. - Complete developmental/mental status assessment by history and current report: Previous mental health diagnosis and interventions (ADHD is the	- Current behavioural and mental health concerns and management - Sleep hygiene - Nutrition and self care - Caregiver child relationship and stability of placement - Caregiver stress and supports, knowledge about FASD and role as advocate in transition years to adulthood	on diet history - Monitor side effects of medications, if applicable - Blood work for fasting insulin and glucose, prolactin, thyroid function with atypical antipsychotics; electrocardiograms for arrhythmia in teens with positive family history or taking stimulants - History to suggest seizures and need for electroencephalography - Sexual activity and knowledge about pregnancy - Substance use - Current and merging concerns about mental health	- Discuss sexual health, especially around contraception for both male and female teens to prevent unplanned pregnancy and sexually transmitted diseases. - The harm of alcohol use in pregnancy needs to be emphasized repeatedly and at a level understood by the teen. - Discuss mental health concerns and refer to an Adolescent Psychiatrist or mental health therapist as needed - Trauma-informed therapy might be indicated. - Advocate for education supports and, if needed, an updated assessment of function - Advocate for community supports and high level of supervision to ensure safe and meaningful participation and prevention of victimization, as appropriate - Discuss with caregiver(s) the process of transition to adult services. Current guidelines recommend that

	most common comorbidity in FASD). Past history of maltreatment or trauma, number of placements, relationship to current caregiver(s). Impairments in communication (not understanding what is requested, responses that are vague, not connected, tangential and immature) Problems in the area of executive function (e.g., problem solving, inhibition, flexible thinking, predicting, using judgment) Social and emotional difficulties (including bullying or being victimized by others, positive participation with peers in community-based and sports activities) Self-regulatory difficulties with externalizing behaviours of aggression or internalizing behaviours of low self- esteem and anxiety Sexual activity including past or present history of abuse Substance use Suicidal ideation or attempts Sleep pattern and diet School experiences (i.e., extra supports in the classroom, cognitive and academic assessments) Ability to perform daily living and self-care activities independently.			this start at the age of 12 years with ongoing assessment of the teens' ability to become independent in decision making, shared decision-making or the need for legal guardianship as an adult. Documentation and paperwork will be different in different jurisdictions. This may require navigation of the system by an informed person or trustee to ensure safe living, financial management, employment options and ongoing maintain of health care. Special time allocations needed to be considered for these visits. - Teens living with FASD need to be informed about their diagnosis and need for life long mentors and supports. - Timing and process to be determined in consultation with primary caregiver. Care is needed to prevent blaming. - Discuss need for caregiver support and respite, especially if there are increasing mental health issues for the teen and stress within the family

				- Advocate for the teen to enter foster or group home care, where they can develop positive and trusting relationships and set realistic goals for the future. Care agreements can be extended to age 21 years in some jurisdictions to plan the transition process to adult services. - Transfer of medical and mental health care to the adult system needs to be planned with appropriate care summaries and training of the adult health care providers on FASD. - Young adults with FASD may become parents themselves and there needs to be consideration of their ability to parent and what supports they will need to be able to care for their children.

ADHD = Attention deficit/Hyperactivity Disorder; ODD = Oppositional Defiant Disorder