# DEVELOPMENT OF CANADIAN SCREENING TOOLS FOR FETAL ALCOHOL SPECTRUM DISORDER

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## **ABSTRACT**

Fetal alcohol spectrum disorder (FASD) is the most common cause of neurobehavioural handicap in North America. Screening for FASD may facilitate diagnosis and hence management of these children. We present a variety of screening tools for the identification of children at risk for FASD.

### Methods

We critically reviewed and evaluated published and practiced methods for their potential of screening suspected cases, their epidemiological characteristics (sensitivity, specificity, positive and negative predictive values) [Phase I], as well as their feasibility [Phase II].

### Results

The following five tools were selected for the FASD screening toolkit: screening fatty acid ethyl esters in neonatal meconium, the modified Child Behaviour Checklist, Medicine Wheel tool, Asante Centre Probation Officer Tool, and maternal history of drinking and drug use.

# Conclusions

The toolkit for FASD screening aims at screening different populations, from the newborns to youth and at-risk mothers. It is anticipated that the toolkit will facilitate diagnosis of FASD.

**Keywords:** Fetal alcohol spectrum disorder, screening

# 1. Project Overview

### 1.1 Project Rationale

On March 1, 2005, Fetal Alcohol Spectrum Disorder: Canadian guidelines for diagnosis were published in the Canadian Medical Association Journal. The development of the guidelines was facilitated by the Public Health Agency of Canada

and Health Canada. The current capacity of diagnostic clinics, however, is low compared to the number of patients referred for diagnosis. In addition, the validity and reliability of FASD screening tools have not been verified. As a result, healthcare and frontline professionals are inconsistent in the criteria in which they use to screen and refer children for assessment and

diagnosis of FASD. The Canadian Association of Paediatric Health Centres (CAPHC), funded by the Public Health Agency of Canada, facilitated a national initiative entitled: "Developing a National Screening Tool Kit for Those Identified and Potentially Affected by FASD". This project brought together many FASD experts and organizations to critically evaluate and recommend FASD screening tools for a national screening toolkit. The objectives of this initiative were three-fold:

- a) to survey and critically evaluate FASD screening tools and methods in the published literature and used by clinics in Canada for referral to or acceptance into diagnostic clinics:
- b) to evaluate epidemiological characteristics (sensitivity, specificity, and predictive values) of these tools; and
- c) to develop practical guidelines (toolkit), based on the identified and evaluated tools.

## 1.2 Method

from diverse backgrounds, **Professionals** including FASD experts were asked to critically review the literature related to the screening and identification of FASD and to present their own research and findings. Nine panels were created and focused on the following areas: impact of screening, population variability, growth retardation, facial dysmorphology. neurobehavioural characteristics (two panels), biomarkers meconium, clinic tools and youth justice population (A full listing of articles reviewed and workshop presentations can be found on the website www.caphc.org/documents\_programs/fasd/).

## 2. Essential Components of Screening

The UK National Screening Committee definition of screening was adopted for the purposes of this task. It defines screening as: "A public health service in which members of a defined population, who do not necessarily perceive they are at risk of, or are already affected by a disease or its complications, are asked a question or offered a test, to identify those individuals who are more likely to be helped than harmed by further tests or

treatment to reduce the risk of a disease or its complications".<sup>2</sup>

Although screening has the potential to save or improve the quality of life through early diagnosis of serious conditions, it is not a foolproof process. Screening can reduce the risk of developing a condition or its complications, but it cannot offer a guarantee of protection because there is always an irreducible minimum of false positive cases (wrongly reported as having the condition) and false negative cases (wrongly reported as not having the condition). An effective screening tool is cost-effective and quickly administered. Successful screening will identify a greater number of individuals than the true number who are affected by the condition. In most cases, these individuals are referred for further assessment and diagnosis for confirmation of the condition.

A good screening test must demonstrate both high sensitivity and high specificity. Sensitivity is the ability to correctly identify persons with the condition in the population who screen positive. Specificity is the ability to correctly identify persons without the condition in the population who screen negative. The higher the sensitivity and specificity reported, the greater the accuracy of the test. The positive predictive value (PPV) is the probability of the condition among individuals with a positive test. The negative predictive value is the probability of no condition among those with a negative test. A reference standard (an alternative method to determine the condition independent of the screening test) is required. At present, such a standard is not available for FASD other than a full diagnostic work-up.

# 2.1 Screening Criteria in the Context of FASD

According to the World Health Organization, to successfully implement a screening program the following conditions should be met.<sup>3</sup>

- i. A suitable test should exist;
- ii. The disease or condition that is being screened for should be important medically, socially, or economically;
- iii. The natural history of the disease should be understood and the population at risk should be identifiable;
- iv. The test should be acceptable to the population;

- v. The condition should be recognizable at an early stage;
- vi. There must be an accepted and effective treatment for the condition;
- vii. There should be facilities for assessment, diagnosis and rehabilitation;
- viii. Interventions should be acceptable to the population;
- ix. The cost of screening should not be disproportionate to the cost of caring for the affected individuals; and
- x. Screening programs should be a continuing process.

The rationale for FASD screening meets most, but not all of the above screening criteria. Universal screening for FASD using these criteria can result in beneficial outcomes. FASD results from prenatal alcohol exposure. prevalence of FASD is estimated at 9.1 per 1000 live births, with an estimated lifetime cost for one individual exceeding \$1 million. 4,5,6,7,8 The screening options for FASD are non-invasive and can result in earlier interventions such as early diagnosis, special education, increased resources and environmental modifications that have been shown to reduce the effects of developmental disabilities in children with FASD. As a result there would be a reduction of secondary disabilities, leading to societal savings that can offset screening costs.

A drawback to universal FASD screening is that there is currently no widely validated, generally accepted screening test. In addition the acceptability of various test methods has not been fully explored. Although the tests are non-invasive, there may be ethical and stigma issues for children and their family as well as time and cost issues for providers. In some areas of the country, FASD is not universally recognized or is believed to occur only in aboriginal populations only. Although facilities for diagnosis and assessment exist in Canada, they are overwhelmed; current average wait times in diagnostic clinics are six months to two years.

# **2.2** Comparisons with Other Universal Screening Programs for Children

Despite affecting an estimated 1/100 or over 330,000 Canadians, there is currently no accepted standardized screening test for FASD in

Canada. 4,6,7,8 In contrast, rarer conditions such as phenylketouria and congenital hypothyroidism are universally screened for at birth.9 conditions, however, have specific and effective biomedical treatments. HIV, cord blood testing, and testing for other rare genetic disorders have also become routine in maternal and perinatal care. 10,11 Not only can a positively screened child closely monitored for developmental disabilities and receive earlier interventions that can decrease or mitigate against FASD related secondary disabilities, but the mother can also receive necessary interventions to reduce or prevent ethanol consumption. Animal studies have demonstrated that ethanol exposed pups receiving earlier intervention had better outcomes because of brain plasticity.<sup>1</sup>

A diagnosis of FASD would enable increased access to services and supports and more appropriate sentencing or conditions of probation after sentencing of affected youth in the youth justice system. Detecting a FASD affected child also identifies the addicted mother and possibly other children who may be at risk. Helping mothers could potentially result in reduced alcohol exposure in subsequent pregnancies.<sup>13</sup>

# 2.3 Impact of Screening

While FASD screening may facilitate early diagnosis and intervention, the potential negative impact of screening on children's and families' lives must be carefully considered. Families and communities may suffer from stigmatization and screening may cause additional burden to already stressed families. The overall system capacity to consistently provide interventions, supports and resources throughout the life stages for these children must be assessed and will require political will and commitment for the long term.

Screening on a national level should be evaluated by careful cost-benefit analysis, and compared with the benefits of screening for identified high risk groups. The ability to reach the highest risk populations and the likelihood of compliance with treatment must also be addressed.

## 2.4 Population Variability

The epidemiology of FASD is quite variable. Overall, the prevalence of full -blown fetal alcohol syndrome (FAS) is estimated to be somewhere between 1-3/1000 live births. 4,6,7,14 Rates can vary ethnically, culturally, and regionally dependent. Published Canadian prevalence studies tend to focus on aboriginal populations, with prevalence rates varying from 1.5 to 9.1 per 1,000 for FASD. 4,6,14,7 Approximately 12.5% of women of childbearing age are at-risk drinkers (>7 drinks/week – 4 or more drinks per occasion), suggesting the importance of prevention efforts. 15

# 2.5 Population Variability and Key Screening Domains

Variability amongst the population may result in varied FASD effect and may limit the ability to screen. Research has shown that ethnic group/genetic factors, cultural/environment factors and age-related factors varied to such a significant degree that population-specific norms need to be developed. Alcohol damage is affected by genetic factors, maternal drinking history and pattern of drinking, mother's nutrition and weight, and other risk factors, e.g. smoking and drug use.

The most important risk factor is high blood alcohol concentration, and associated variables such as: timing of exposure during fetal development, the pattern of consumption, i.e. binge drinking and the frequency of use. <sup>17,18</sup> The Canadian Diagnostic Guidelines emphasize the importance of confirmed alcohol exposure, rather than hearsay, lifestyle, other drug use or a history of alcohol exposure used solely to indicate maternal alcohol consumption for a specific pregnancy.

Psychometric screening norms: functional norms on standardized assessments vary across cultures. In addition behavioural expression of disability can be affected by environment. A child's genetic make-up may vary from standardized screening norms, e.g. birth weight and growth; head circumference; and facial features, e.g. palpebral fissure measurements. In addition, facial features modify with age; some key psychometric assessments are difficult before age five or six; and risks factors may vary depending on child's stage of development, e.g. behaviours such as lying, cheating, and stealing.

# PHASE 1: SCIENTIFIC EVALUATION OF SCREENING METHODS

# 3. Evaluation of Screening Tools and Methods

Panelists presented and critically reviewed research related to tools and methods for FASD screening. Information was provided from critical review of the literature as well as unpublished research findings and practical application of clinic tools and methods in Canada. Benefits and limitations of tools and methods were discussed in detail and are summarized in this section.

## 3.1 Neurobehavioural Methods

The neurobehavioural profile for FASD is Neurobehavioural deficits/problems must be closely examined to distinguish between those caused by FASD brain damage and those attributable to other causes or conditions. The literature was critically reviewed to determine which neurobehavioural specific deficit(s) constitute effective screening methods. practice, screening for FASD occurs frequently in children exhibiting problem behaviour. It is typically initiated by non-clinicians e.g. teachers, foster parents, and vouth court workers. The checklists presently used are not scientifically validated and clinic intake procedures may screen for a variety of neurobehavioural deficits. Confirmed alcohol exposure is required for referral for FASD assessment. Clinic data has shown that First Nations children are more likely to be screened for FASD while non-aboriginal children are more likely to be considered ADHD. A concise, validated neurobehavioural checklist would be a valuable tool.

At present there is no single, consistent neurobehavioural profile of FASD in children. The literature search identified a number of cognitive, academic and behavioural factors that are associated with FASD. Broad-based indicators for screening from multiple sources are required, for example:

- Alcohol exposure, without which a diagnosis cannot be made
- Attention deficit disorder
- Academic school performance problems

- Behavioural school performance problems
- Screening of specific high risk groups which may have built-in markers (e.g. youth justice, Neonatal Abstinence Syndrome in infants)

In an attempt to develop a screening tool, Streissguth et al. proposed the Fetal Alcohol Behaviour Scale (FABS).<sup>19</sup> This tool was not able to discriminate between FASD and other clinical groups. The Personality Inventory for Children (PIC) has also been considered as screening tools, but it can only be administered by psychologists.<sup>20</sup> The Child Behaviour Checklist (CBCL), a wellestablished tool for evaluating children's problems is behavioural administered psychologists. Research from the Hospital for Sick Children in Toronto has demonstrated the utility of items from the CBCL as a possible screening tool for FASD behavioural phenotype which can be administered by non-clinicians.<sup>21</sup> Children with FASD were found to exhibit seven specific behavioural characteristics that were highly sensitive and specific for distinguishing them from children with ADHD:

- Acts too young for his/her age
- Can't concentrate/poor attention
- Can't sit still/restless/hyperactive
- Disobedient at home
- No guilt after misbehaving
- Impulsive/acts without thinking
- Lying or cheating

This information was used to create a screening tool for referral for FASD diagnosis. The modified CBCL test was further validated for children (6-16 years of age) with or without hyperactivity and poor attention. A systems approach to FASD screening has been proposed. This is based on the premise that FASD is not a behavioural disorder, but a neurological deficit (brain damage) resulting from prenatal alcohol exposure. The damage can manifest differently depending on age and environmental factors. Screening for FASD is strongly influenced by social system and the professionals working within these systems. A systems approach includes a staged screening process that examines problems in multiple profile domains that interfere

with development, investigate developmental history-risk factors, e.g. prenatal alcohol and drug history, screening in communities with high prevalence, and collaboration of professionals from various systems.

The benefits of screening using the modified CBCL include its quick and straightforward administration; it can be administered by trained non-clinicians or a parent/caregiver who knows the child; it can be administered to all children; it uses scientifically objective measures; standardized tools exist for assessing cognitive and academic functioning; this tool may be able to differentiate between non-FASD ADHD children and FASD affected children.

The limitations of screening using the modified CBCL include that although the findings have been replicated in another cohort, the research has not been replicated in a large population. It is currently being repeated in a larger sample and also investigating persons with opposition defiant disorder and conduct disorder and examining potential confounders such as age, gender, socioeconomic status, home situation and IQ effects. There may be rater bias by the users. Users of the tool must have a background in normal child development to assess age appropriate behaviour. There are many overlaps with other neurobehavioural deficits e.g. ADHD. The behaviours being screened can also arise due to prenatal/genetic factors or environmental factors or experience. Although a statistical significant difference was observed, this does not mean that there are clinically significant differences.

Finally, there is a circularity of diagnosis - an individual has FASD and therefore has neurobehavioural deficits.

## 3.2 Facial Dysmorphology

Children affected with FAS are characterized by three dysmorphic facial features: a poorly formed philtrum, thin vermillion border of the upper lip and a short palpebral fissure length. The majority of children affected with FASD do not exhibit these facial characteristics. Assessment of facial dysmorphology, using a tool for diagnostic purposes, was considered for its applicability as a screening method. Measurements could be obtained manually by using a ruler. Alternatively digital photography coupled with measurement

software could be used to obtain measurements. A study in Seattle screened 2,000 children in foster care, demonstrating a prevalence of 1/100.<sup>22</sup>

The benefits of facial screening are it is a safe, non-invasive methodology that is relatively low cost. Screening for facial dysmorphology has been demonstrated to have very high sensitivity, specificity, and positive predictive value.<sup>23</sup> Digital cameras and software allow non-clinicians to interpret results with high interobserver reliability. Screening using this tool will decrease duties of diagnostic clinics.

The limitations of screening for facial dysmorphology include that a vast majority of children with FASD do not present with facial dysmorphology. In addition, the face changes with age. Facial features can be affected by genetics and ethnicity and there are no specific ethnic norms available. Thus it is hard to screen in ethnically diverse and mixed populations. Accurate measurements are dependent on well-taken photograph. There is a need to distinguish between "statistically significant" and "clinically relevant".

# 3.3 Meconium Testing for Ethanol Conjugates

Prenatal exposures to chemicals can be quantified in meconium. Studies of fatty acid ethyl esters (FAEE) in meconium have been conducted in Canada, the United States, Europe and South Africa. <sup>24,25,26,27</sup> FAEE are unique biological markers of fetal exposures to excessive maternal drinking. Meconium levels of FAEEs above 2nmol/g identify heavy fetal alcohol exposure from light exposure at very high specificity and sensitivity. <sup>26,27,28</sup>

Meconium begins to form at approximately the 12<sup>th</sup> -14<sup>th</sup> week of pregnancy. As the fetus swallows amniotic fluid, prenatal exposure to chemicals can be quantified in meconium. Meconium measurement of fatty acid esters (FAEEs) (fatty acids synthesized with ethanol) is an unique biological marker for fetal exposure to ethanol. The benefit of screening meconium is that it is an objective, non-invasive, sensitive and specific method that collects a natural waste product.<sup>27,28</sup> Meconium screening identifies both mother and child. Positive FAEE results have been associated with lower Apgar scores, low birth weight and lower executive functioning.<sup>29,30</sup>

Animal studies have also demonstrated a relationship between FAEE levels and growth retardation as well as brain weight.<sup>31</sup> Screening meconium can demonstrate prenatal exposure when maternal self-report is not reliable. Meconium screening has been demonstrated to be cost-effective.<sup>32</sup> A limitation of meconium screening is that it must be collected in the first 72 hours after delivery. Also, exposure during the first trimester of pregnancy is not captured in this screen. There are ethical concerns regarding informed consent of the mothers and reporting positive screens to child protective services.

## 3.4 Growth Retardation

Intrauterine growth can be influenced by a number of factors including genetics, ethnicity, and diabetes. Growth retardation is considered as part of the diagnosis process because alcohol is associated with impaired fetal growth. Growth retardation as a screening mechanism may have merit in combination with other biomarkers such as meconium screening.

The limitations of growth restrictions included that growth standards differ for various populations. Only a small percentage of infants who are small for gestational age are associated with prenatal alcohol exposure of more than two drinks per day. The consequences of small for gestation age are significant e.g. high fetal and higher infant mortality, short-term metabolic problems, and deficits in growth and neurocognitive delays. However the sensitivity is 10-30%, therefore a majority of cases are missed. It was generally agreed that growth retardation on its own is not useful as a screening method, but may have merit in combination with other perinatal screens, such as meconium screening.

## 3.5 Youth Justice Population

The youth justice population poses unique challenges for screening of FASD. There is evidence in the literature that individuals affected with FASD represent a disproportionately large number of youth and adults in the criminal justice system.<sup>33</sup> In youth corrections, behavioural characteristics may drive interventions. Failure to feel remorse or understand consequences of actions has been described as neurobehavioural characteristics of some of those affected by FASD.

This presents a challenge to the youth justice system to find appropriate deterrents/incentives for this population.

The FASD Youth Justice Project Manitoba screens youth 12-18 years of age with no prior FASD diagnosis and confirmed prenatal alcohol exposure who are undergoing pre-sentencing in Winnipeg. Items included on the screening questionnaire include:

- Repeated failure to comply
- Lacking empathy
- Poor school experiences
- Difficulties within institutions: compliance, peers, academics
- Unable to connect actions with consequences
- Not affected by past punishment
- Followers, rather than leaders, in crime
- Crimes involving risky behaviour for little gain

Screening was effective in this selective population and resulted in 50/178 individuals receiving diagnostic assessment which resulted in 30 being diagnosed with FASD, 29 with ARND. The screener had a 60% positive predictive value (personal communication, Manitoba FASD Youth Justice Program).

In the Youth Justice system in Saskatchewan, judges are instructed to screen based on the criteria used in the FASD Youth Justice Project in Manitoba. the judge observes characteristics, the youth court worker collects alcohol history through interview with the mother or a reliable source. The FASD Screening Tool Project in Saskatchewan has reviewed a number of screening tools and conducted a research study to validate a screening tool for use with offenders. In a collaborative research approach, agreement was reached on 28 risk factor items. The screening tool had a high inter-rater reliability 0.82, with a high validity 76% (personal communication, FASD Screening Tool Project).

A study conducted at Stony Mountain Institution near Winnipeg, Manitoba screened all offenders undergoing preliminary assessment. A Brief Screen Checklist (BSC) that included behavioural and historical indicators and maternal alcohol consumption was used to identify

individuals for further assessment. Information was collected from the offender, parole officers and collateral sources. The study concluded that the incidence of FASD was ten times greater in the study sample compared to the North American population. The BSC items were highly correlated with a diagnosis of FASD. In addition, there was a high rate of neuropsychological impairments found in the study sample (personal communication, Stony Mountain Institution).

The Asante Centre for Fetal Alcohol Syndrome Probation Officer Screening & Referral Form is completed for all youth adjudicated on probation orders who reside in the Vancouver Coastal and Fraser Regions who are suspected of having fetal alcohol spectrum disorder. The tool is questionnaire which pre-coded collects information on social and neuro-developmental history of the youth as well as the probation officer's knowledge of the youth and FASD. The survey tool was designed to screen youth for referral based on environmental factors and personal (neurobehavioural) factors. Referrals were made based on the combination of either one social/environmental factor plus two personal factors or no environmental/social factors but at least three personal factors. 26.5% of youth met the FASD criteria for further assessment (personal communication. Asante Centre for Fetal Alcohol Syndrome).

Subsequent to the Workshop, the Steering Committee members reviewed the Saskatchewan Fetal Alcohol Spectrum Disorders Functional Screening Tool. This comprehensive functional screening tool, which is still in development, was not considered appropriate for inclusion as a recommended tool at this time. The benefits for screening within the youth justice system is that by investing in the youth justice system by screening for FASD individuals it will enable the correct services of the needs and services for individuals to reduce the risk of re-offending, thereby resulting in long-term cost- and time-savings. A further benefit is that the tool can also be administered by frontline workers.

The limitations of screening within the youth justice system include that there is no validated screening tool for young offenders. It may also be difficult to collect information regarding maternal alcohol exposure. Frontline workers may be resistant to use screening techniques and there are

issues regarding obtaining consent and maintaining the confidentiality of the information. On the other hand, the family and/or youth may not agree to the assessment.

## 3.6 Clinic Tools

Screening tool currently used in diagnostic clinics across Canada show promise for broader application for different populations. However, all the tools require further validation. The Complex Developmental Behavioural Conditions (CDBC) Referral Form is used by the CDBC Network in British Columbia which provides screening and referral for provincial and regional developmental paediatric services. The Program diagnostic assessment services are intended for children and youth who have significant difficulties in multiple areas of function including those with known or suspected history of exposure to substances with neurodevelopmental effects. The referral form has been developed with guidelines that reflect the diagnostic assessment process, i.e. development and learning, mental health/behaviour, adaptive and social skills and biomarkers. Within the CDBC Network, referrals are taken from paediatricians or child psychiatrists with exceptions in remote areas where a family physician or nurse practitioner can make a referral. This tool has the potential to be developed and used as a screening tool by a wider range of providers, e.g. teachers, day care workers.

The Clinic for Alcohol & Drug Exposed Children (CADEC) in Manitoba does not use a screening checklist per se but provides the following criteria for referral:

- Consent
- Age 9 months to 12 years
- Confirmation of prenatal alcohol exposure
- Readiness for the assessment-child and parents' stability
- Behavioural and developmental concerns realistic expectations of assessment

In addition, background information on the child's birth history, medical history, family history, school records, psychological assessment, and social history is obtained. The diagnostic rate using these intake criteria was approximately 50%. The specificity of this tool was 24.5%. The

sensitivity was 100% but there are an unknown number of false negatives. These criteria have not validated (personal communication, CADEC). The Labrador Alcohol Research Group (LARGE) is a primary health care approach in Labrador to address FASD in the population (personal communication, LARGE). Referral information includes family/household information, history, foster home involvement, neurobehavioural indicators, school support, public health reports and medical information.

The benefits for these clinic screening tools are they screen for all complex developmental behavioural conditions. They also reflect the diagnostic criteria/domain used in the assessment process. These tools are limited because they must be completed by a specialist physician. These tools also require further validation.

## **3.7 Community Tools**

The Medicine Wheel Tools were developed for the Elsipogtog Mi'gmag First Nations community in New Brunswick (personal communication Elsipogtog Mi'gmag First Nations). The tools employ the Medicine Wheel framework which draws from traditional medicine in combination with scientific measures and indicators. A set of tools has been designed for a staged approach to screening and assessment in the school environment.

The first stage of screening involves the Medicine Wheel Student Index which is administered by the child's teacher. It explores mental, emotional, physical and social indicators along with spheres of learning and special services received. The tool takes approximately 15 minutes to administer. Significant problems in cognitive sub-domains or problems in one cognitive area coupled with problems in one or more of the conduct, social sub-domains or physical domain suggest the need for the second stage of screening involving the Medicine Wheel Developmental History. This is a semi-structured parent interview-administered by a professional (other than teacher) in collaboration with the parent. Children who have screened positive proceed to diagnosis and assessment. A study screening 237 results in 29 referrals to diagnostic clinics where 67% were diagnosed with FASD.

The benefit of this screening tool includes that it is quick to administer. It can be

administered by properly trained teachers and relies on their judgment. The tools incorporate a First Nation's worldview and framework providing cultural context and relevance. Parents are engaged in the second step of the process as such there is a feeling of contribution. Limitations include that the tool has not been validated and assessed in other populations.

# 4. Promising Approaches

It was recognized that there is not one screening tool or method that would be suitable for all ages, cultures and environments. Several tools show promise for universal and/or targeted screening and may be included in the toolkit. Universal screening methods include meconium screening, and the modified CBCL. The targeted screening methods include the Medicine Wheel screening tools, screening for facial dysmorphology, and all presented youth justice screening tools.

While challenged by attempts to identify effective screening methods, the Steering Committee strongly felt that one should not disregard that maternal history of drug or alcohol abuse has been shown to correlate strongly with problem drinking in the index pregnancy. Hence it is important to consider children of these mothers as being an at-risk group that needs careful follow-up. These children can be considered for diagnostic assessment if concerns regarding their appearance, growth, behaviour or development become evident.

# 5. Key Considerations

National screening initiatives must be considered within the context of providers' and health and educational/social services' capacity to diagnosis, treat and support families, children and youth with FASD throughout life stages. Screening tools should be assessed for cultural appropriateness, age/stage of development, and environment or genetic factors which may influence their outcomes. Effective screening by non-clinicians will require training, as well as their support and commitment. The screening tools will need to be given consideration in terms of cost-effectiveness, public acceptance, and potential stigmatization. The screening tools will need further validation. In addition to screening, primary prevention plans

should be developed. Screening for FASD may be a challenging task as most screening methods employ clinical and laboratory markers which are not part of the sought condition itself, but rather strongly correlate with it. In the context of FASD, most proposed screening methods constitute one or more signs of the syndrome itself. Second, many of the proposed FASD screening methods have not been validated for their epidemiological properties of sensitivity, specificity and predictive values. Third, due to the limited diagnostic capacity there is a fear that screening may result in a "positive screen" becoming a false "de facto diagnosis". There was a consensus in the Steering Committee that "screening" is not "diagnosis" and should never be used as such. The Steering Committee felt strongly that wide screening will empower a change in climate toward more support for diagnosis and management of children and adults affected by FASD, as governments and other decision makers will realize the scope of this epidemic in their jurisdictions. Fourth given the paucity of validated screening methods, it is apparent that different approaches and methods are required for screening depending upon the life stage of the child — from infant to young adult.

# PHASE 2: FEASIBILITY OF IMPLEMENTATION OF SCREENING METHODS

A workshop with frontline providers of various disciplines and sectors (e.g. health, education, social services, and youth justice) was hosted to assess the feasibility of implementing select screening tools across the country. In addition, a half-day session was held with First Nations and Inuit organizations to assess the Medicine Wheel tool and identify issues affecting the implementation of screening methods in their respective communities.

# **METHODS**

Workshop participants were pre-assigned to small discussion groups to review selected screening tools. Participants were assigned to groups based on their professional background and likelihood of using the tool in their work. Each group evaluated one of the six screening tools: FAEE screening in meconium, Youth Justice screening tools,

modified CBCL, facial dysmorphology, maternal history of substance abuse, and the Clinic for Alcohol & Drug Exposed Children intake process.

Each group was led by a Steering Committee member. Participants first received a review of the screening tool, following which, they were asked to comment on the practical application of the screening tool and rate the screening tool on a scale of 1-5. Tools were assessed on ease of use (1=very difficult, 5=very easy); accessibility (1=inaccessible, 5=very accessible); cost (1=very expensive; 5=inexpensive); expertise (1=high level of expertise, 5=minimal expertise); cultural appropriateness (1=very inappropriate, 5=very appropriate). They were also asked to comment on factors to facilitate implementation and barriers to implementation.

Subsequent to review of the screening tools, participants discussed gaps and opportunities for screening and made recommendations on how to build capacity.

# 6. Screening Tools

# **6.1 Screening FAEE in Meconium**

Screening for biomarkers in meconium is an objective non-invasive method of universal screening. This screening method identifies both the mother and child; therefore, systems should be in place for the management of both persons prior to the implementation of screening. This method could provide prevalence data. Obtaining consent for the collection must be carefully considered amongst different languages and cultures.

## 6.1.1 Ease of Use

Participants were given a hands-on demonstration of meconium collection. Meconium collection was given an average rating of very easy (average=5). Collection was deemed much easier than collecting cord blood, asking screening questionnaires or venipuncture. Due to light and temperature sensitivities, there needs to be protective collection techniques. There may also be an issue for specimens coming from remote communities requiring multiple transitions or are delayed during transport. The analysis can be conducted in a laboratory with a gas chromatograph.

## **6.1.2** Accessibility

Meconium collection was deemed slight inaccessible (average=2). Currently, only one lab in Canada processes meconium samples. Early hospital discharge should not limit the accessibility of the test because infants are not sent home before they pass their first stool. Issues were also identified regarding follow-up, turnaround time to receive results, and sensitivity of the providers review screening results with mothers. When conducted anonymously, there is no opportunity to follow up with the mothers and the data can only be used to assess the prevalence.

## 6.1.3 Cost

Testing meconium was considered affordable (average=4). Costs related to shipping and training staff were not included in this consideration.

## 6.1.4 Expertise

Meconium testing received an average rating for expertise required to perform the test (average=3). Persons obtaining the sample would have to receive training regarding obtaining consent for the screening test. Lab technicians would also require training on conducting the analysis. Persons disclosing screening results would have to be able to communicate the difference between screening and diagnosis. They would also need training on substance abuse issues.

# **6.1.5** Cultural Appropriateness

Meconium testing was deemed very culturally appropriate (average=5). It is an objective test and with universal implementation there is little risk of stigmatization of cultural/ethnic groups or communities. Although the test itself is straight forward, language and cultural issues should be considered when describing the screening test and communicating the test results.

## **6.1.6 Factors to Facilitate Implementation**

Identifying a larger amount of prenatal alcohol exposure than self-reported may increase awareness of this issue. This screen identifies two patients (i.e. the mother and the child) who can potentially be helped.

# **6.1.7 Barriers to Implementation**

Barriers to implementation of meconium screening as a universal screener include that it requires the support from provinces and territories. In addition, healthcare providers and organizations are already overworked and understaffed, thus this may increase their workload. There needs to be a method of support for both the child and mother who are identified as at risk. The test is limited to detecting alcohol exposure after the first trimester; therefore there may be a false sense of security when the meconium screens negative. In addition there is a question as to who 'owns' the results. This may be more relevant in custody cases. Setting up a national laboratory requires further consideration. There needs to be additional support from the public, healthcare professionals, hospitals, and government for wide-scale implementation.

#### **6.2 Youth Justice Screening Tools**

The youth justice screening tools focused on the Asante Centre for Fetal Alcohol Syndrome Probation Officer Screening & Referral Form. This is a quick and easily administered tool in trained workers. The validity of the tool needs to be established prior to wider implementation.

## 6.2.1 Ease of Use

The form was deemed very easy to use (average=5). The tool can be administered within two to three minutes by trained frontline personnel.

## 6.2.2 Accessibility

The form was deemed accessible (average=4). To date, the tool has only been used for pre-sentence referrals. The language of the form needs to be simplified. Confirmation of prenatal alcohol exposure may be difficult to obtain in this age group.

## 6.2.3 Cost

Screening using this form is slightly inexpensive (average=4). Although there is little cost associated with the form, there is a cost for training providers regarding the administration of the form. Testing of the form in other organizations will be able to confirm its validity.

## **6.2.4 Expertise**

The form was considered user-friendly and required minimal expertise (average=4).

## **6.2.5** Cultural Appropriateness

The form was considered appropriate across many cultures (average=4). Currently, the form is only available in English. It will require translation into other languages; however, it may be difficult to translate certain concepts into other languages.

# **6.2.6** Factors to Facilitate Implementation

The SAMHSA FASD Center of Excellence (U.S.) has developed and validated a tool and produced training manual for this population which may be able to assist in the validation of this tool. The tool may be improved when combined with the Saskatchewan Youth Justice Screening Project and FASD Functional Screening Tool. This tool has contributed to the results of the recent National Round Table on Youth Justice.

# **6.2.7 Barriers to Implementation**

Staff may be reluctant to ask about maternal alcohol consumption; and validation of mother's alcohol consumption may be difficult. The tool is currently undergoing validation test. Securing ongoing funding to provide training and support, particularly in isolated communities, is a chronic problem. The tool may need to be adapted for different languages and cultures. Providers would need to be trained on the administration of this tool.

## 6.3 Modified Child Behaviour Checklist

The tool is not inclusive of other brain domains such as executive functioning, memory, abstract thinking. The objectivity of the assessor may be influenced by differences in cultures, values and settings.

# 6.3.1 Ease of Use

The modified CBCL is a short and easy to use questionnaire (average=4). An interviewer's manual would be beneficial for administrators to clarify the language. Some of the questions are open to interpretation and may elicit different responses from the respondent.

#### **6.3.2** Accessibility

The modified CBCL was deemed accessible (average=4). It requires a consent process when the information is being provided by someone other than the legal guardian. Educators are most likely to be the first people to be a source of information. Administering the tool in person would overcome literacy issues or problems with interpretation of questions. The tool is straightforward to translate.

#### 6.3.3 Cost

The modified CBCL was deemed inexpensive to administer (average=5). There are low material costs and it takes a short time to complete.

## **6.3.4** Expertise

Moderate level of expertise would be required to administer the modified CBCL (average=3). The tool could be administered by trained frontline providers

## **6.3.5** Cultural Appropriateness

The modified CBCL was deemed culturally appropriate (average=3). Different/modified tools may be required for various age groups and populations as there is an acceptance of certain behaviours varies by culture and environment.

# **6.3.6 Factors to Facilitate Implementation**

The modified CBCL integrates well with the diagnostic process. It can be improved with a procedural manual to clarify the role of the referrer and the role of the screener.

## **6.3.7 Barriers to Implementation**

It is not clear how the modified CBCL will account for social and environmental influences on behaviour. The tool needs to undergo validation testing in different cultural groups and ages/stages of development.

# **6.4 Facial Dysmorphology**

Screening for facial dysmorphology is only suitable for target populations. It only screens for individuals with FAS, which is a small percentage of the FASD population. Measurements can be challenging to obtain. Dysmophology is not feasible to use as a screening tool and would be more appropriately used in the diagnostic process.

#### **6.4.1** Ease of Use

The facial screening tool was deemed neither difficult nor easy to use. Most professionals considered learning to take accurate photographs relatively easy. Manual facial measurement, on the other hand, was seen as considerably more difficult. Obtaining measurements require good hand and eye coordination.

## **6.4.2** Accessibility

Facial measurement is objective; however it is limited by its lack of ethnic norms. This is an accessible screen (average=3) and digital photographs can be transmitted over distances. Interpretation of the results requires training.

#### 6.4.3 Cost

Opinions varied on the cost associated with facial screening. On average it was deemed slightly inexpensive (average=4). The measurement software and ruler were inexpensive; however the equipment and time commitment was considered expensive.

## **6.4.4 Expertise**

Facial measurements would require a fair amount of expertise to administer (average=2). Considerable training and hand and eye coordination would be required to accurately measure, interpret, and deliver results

## **6.4.5** Cultural Appropriateness

Facial screening was considered culturally inappropriate (average=2). The measures are based on Caucasian norms and it is difficult to assess the effects of genetic influences and cultural differences which may affect interpretation of results.

## **6.4.6** Factors to Facilitate Implementation

Facial screening could be useful in a targeted population. If the child has these dysmorphic features, maternal alcohol use does not have to be confirmed.

# **6.4.7 Barriers to Implementation**

Facial screening does not identify the majority of persons affected with FASD. Establishing facial norms for all cultures and persons of mixed heritage would be difficult (require considerable resources). Facial features also fade with age. Judgment on facial features could be used to label individuals. It is difficult to accurately measure facial features. This tool does not screen for the majority of individuals affected by FASD. This tool cannot be used on its own and is typically used during the diagnostic process. As such the tool is not considered to be appropriate as a general population screening tool.

# **6.5 Maternal History of Substance Abuse**

Screening for maternal history of substance (alcohol and drug) abuse assumes that if the mother has a substance abuse problem, she is likely to have abused alcohol. If she has an alcohol abuse problem then it is likely there was prenatal alcohol exposure. Substance abuse is defined as misuse or abuse. A positive screen can result in children receiving necessary supports but may result in stigmatization and isolation. Families have to be prepared to receive a positive result.

#### 6.5.1 Ease of Use

Screening mothers was deemed neither difficult nor easy (average=3). It would depend on who provided the information (e.g. friend, family member, neighbour) as different people have varying judgment of what constitutes alcohol and drug abuse. Service providers may be uncomfortable screening women.

## **6.5.2** Accessibility

Screening for maternal history of alcohol use was deemed neither accessible nor inaccessible (average=3). Although it would be easier to obtain information from smaller community, there may an increased risk of stigmatization. However fear of repercussions for the mother and child may influence the response. Confirmation from multiple sources can assist in the validation of information. The legalities of the collection of the information must be considered.

# **6.5.3 Cost**

Screening for maternal alcohol consumption is a slightly inexpensive method (average=4) where the question can be added to existing questionnaires. Professionals need to be trained on how to ask the question without alienating the

mother. There are costs associated with the treatment services provided to the mother.

# 6.5.4 Expertise

Maternal screening requires expertise to obtain reliable information (average=2). This may include training on substance abuse and training on how to approach the subject. With appropriate training any frontline worker or compassionate community member could be able to screen mothers.

## **6.5.5** Cultural Appropriateness

Screening mothers was deemed culturally appropriate (average=3). Community readiness to address prenatal alcohol exposure is essential. Some physicians still promote alcohol consumption during pregnancy. The question can be adapted into many languages and cultures. However care must be taken to avoid stereotyping within cultures.

# **6.5.6** Factors to Facilitate Implementation

A reporting body needs to track all screened individuals who are waiting for diagnosis. In addition, screening provides an opportunity to assist the mother in a supportive environment.

## **6.5.7 Barriers to Implementation**

Information received may be biased. Maintaining confidentiality in smaller communities may be a challenge. In cases where there is a question of custody, disclosure may be required. There must be capacity to support identified mothers and children.

# 6.6 Diagnostic Clinic – Intake Procedure

The Clinic for Alcohol & Drug Exposed Children (CADEC) Intake Procedure was selected to illustrate the strengths and challenges which are encountered by both referring providers and diagnostic clinics in identifying, referring and assessing children at risk for FASD. CADEC is a FASD diagnostic clinic in Manitoba that receives referrals from a range of sources. The persons making the referrals for CADEC are experts who are sensitive to family conditions. There currently exists extensive wait lists for diagnosis. The identification of children necessitates immediate case management and family support. Since

information is collected from multiple sources, ownership of information is challenging.

## 6.6.1 Ease of Use

The CADEC intake procedure was deemed straightforward and neither difficult nor easy to use (average=3). The overall process of collecting information from multiple sources was considered time consuming and requires an experienced and knowledgeable individual. Supports need to be available to children waiting assessment.

## 6.6.2 Accessibility

The CADEC intake procedure was deemed slightly inaccessible as it requires culturally competent individuals and interpreters (average=2). Healthcare providers need access to both electronic and paper documents. In addition, it may be difficult to acquire information on prenatal alcohol exposure. This information could impact the reunification of a child with their family. Moreover, long wait times could have negative effects on the child and their family.

## **6.6.3 Costs**

The CADEC intake procedure was deemed slightly inexpensive (average=2). However with increased screening follows an increased need for diagnostic capabilities and resources for follow up. Society must recognize that the cost of early identification and treatment will result in long-term cost-savings.

# 6.6.4 Expertise

The CADEC intake procedure requires a fairly high level of expertise in child growth and development, women's health, and family counseling (average=2). The family must be prepared to accept the potential consequences of a positive screen.

# **6.6.5** Cultural Appropriateness

The CADEC screening form was deemed neither culturally appropriate not inappropriate (average=3). This process requires screeners who are culturally competent and interpreters who can assist the family through the process.

## **6.6.6 Factors to Facilitate Implementation**

There should be clarity around who 'owns' the screening and diagnostic results. In addition,

support and follow-up are best offered by a case management approach where all services are coordinated with the family by a designated provider.

## **6.6.7 Barriers to Implementation**

The interface between community referral agents and diagnostic clinics is crucial as part of a comprehensive and seamless approach for children and families with FASD. Before implementing screening tools, capacity of diagnostic clinics, as well as 'fit' and compatibility of screening tools with clinic intake procedures should be assessed. The screening process adds to an already overworked system. In addition diagnosis will result in the need for increased resources of supports and services. Despite the benefits of early screening and diagnosis, family readiness must also be considered.

#### **6.7 Medicine Wheel Tools**

The Medicine Wheel tools present a holistic approach to screening involving a community approach. A video demonstrating the use of the Medicine Wheel tools in a Mi'gmag community school was shown. A number of interventions were provided to increase school performance and address behaviour issues. As part of this process, a comprehensive screening program was initiated in the school — all children were screened using the Medicine Wheel tools. The school did not wait for a diagnosis to act. Supports were provided to the parents to help them realize their personal goals.

## 6.7.1 Ease of use

The Medicine Wheel screening tools appear easy to use and are relevant to First Nations and Inuit cultures (average=4). The tools are adaptable therefore it is possible to use components that are suitable for individuals or communities.

## 6.7.2 Accessibility

The Medicine Wheel screening too was deemed accessible but would require translation (average=4). The tool is completed by teachers who knows the child well. Unfortunately the tool is not applicable to high school students (young adults). The tool could be tailored to individual communities but this will require additional work.

#### **6.7.3 Cost**

The cost of the Medicine Wheel screening tool was deemed slightly inexpensive (average=4). The cost of ignoring the child who may have FASD is greater than the cost delivering services. The materials are inexpensive, however the training required to administer the tool and the high teacher turnover may result in high costs. Thus measures should be taken to retain teaching staff and also train community members. The implementation of this tool on a national level would be complicated and potentially expensive.

# **6.7.4** Expertise

The Medicine Wheel screening tool was deemed to require a fair amount of expertise (average=2). There is limited professional expertise available to First Nation and Inuit communities thus it is important to develop experts within the community. Experts or leaders would be required to coordinate or sustain the program. The tool provides an opportunity for the parents to contribute to the screening but requires a psychologist/social worker. The implementation of the tool is dependent on the philosophy of individuals. For examples some professionals may not embrace the holistic approach.

## **6.7.5** Cultural Appropriateness

The Medicine Wheel screening tools was deemed culturally appropriate for First Nations and Inuit communities (average=4). The tools would require translation, which may be difficult. Since these tools are predeveloped, some communities may feel they have a lack of input. Some communities may resist this screening approach because of the bias/prejudice that may be associated.

## **6.7.6 Factors to Facilitate Implementation**

The Medicine Wheel tools are holistic and based on the framework of aboriginal teaching. The tool can be administered by teachers and is a systems approach to screening that includes the family. It also evaluates various determinants of health. The tool is able to evaluate the child's progress while emphasizing the child's positive attributes. There are opportunities to adapt the tool to different First Nations and Inuit communities. This should be done with the input of community workers and parents. The Medicine Wheel is able to be applied

in any school setting therefore it can be generalized to the Canadian population.

# **6.7.7 Barriers to Implementation**

Barriers to implementation of this screening include that First Nations communities have limited access to assessment and diagnostic services. In fact diagnostic capacity is not existent in some Inuit communities. The tools may have to be adapted. The academic curriculum varies across the country. In addition, social and cultural norms also vary across communities therefore receiving a formal education at school may not be as important as learning traditional skills.

It may be difficult to achieve support from different levels of governments as some governments may not wish to address FASD and related issues. There also must be a method of establishing collaborations between health and education sectors. Within First Nations communities there is a legacy of psychological inferiority. Some highly skilled personnel from First Nations communities feel a lack of respect from mainstream counterparts and are reluctant to engage with mainstream organizations and providers. This can be a barrier to information sharing, referrals and program development and participation. The tool needs adapted/translated and validated before its use.

## 7. Opportunities

## 7.1 Infrastructure Improvements

The establishment of a secretariat at an international level would centralize efforts. Standardized national screening would enable the collection of data and statistics. The data would demonstrate that there is a greater need for diagnostic centres. Personnel in the field are too overworked to evaluate their efforts and publish their data. There needs to be an ICD-10 code for FASD and/or alcohol-exposure.

## 7.2 Working within Limits and Constraints

In northern First nations and Inuit communities there is lack of and time-limited funding available for FASD awareness and programming. There is a negative impact on communities when programs and initiatives are suspended due to the lack of funding. There are a lack of FASD coordinators and an absence of screening and diagnostic

services within the region and limited support services.

There is a lack of consistent messaging from the medical establishments in Eastern Canada regarding FASD awareness and prevention. Conversely in Western Canada there are more education and training opportunities for professionals and FASD education is included in the school curriculum. FASD awareness must be addressed within the context of overall quality of life improvements and efforts to address the root causes of substance abuse. Raising awareness requires different strategies and approaches depending on who is being targeted.

# 7.3 Raising Awareness and Knowledge

A community strategy for prevention should be developed and there should be improved primary prevention strategies. Community leaders and champions in each sector should be identified. There should be political support for research within different sectors. Local media outlets should be used to engage public dialogue around FASD. Persons affected by FASD should also communicate with the public.

Education of professionals within different sectors would result in better support for affected individuals. Delivering presentations at conferences will increase awareness of professionals e.g. doctors, lawyers, and justice workers. Promoting the importance of screening across the community is also important. Educating and providing professionals with screening checklists will also heighten their awareness. Training frontline providers on how to approach women who may be drinking during pregnancy and harm reduction would decrease the "shame and blame" mentality. Education of children and youth would also improve awareness. Awareness should increased amongst vendors and servers of alcoholic beverages. Perhaps placing warning labels on beverages would be effective. Hosting a workshop or focus group twice a year for persons involved in FASD prevention and intervention provide opportunities brainstorm to community awareness strategies.

## 7.4 Capacity

Screening will result in an estimate of the prevalence FASD, which would advocate for the establishment of more diagnostic clinics and

associated services. In addition, there needs to be an evaluation of what is needed to support families as well as criteria for a waiting list for screening and assessment should be developed.

# 7.5 Targeting

As FASD is a society-wide issue, education should target both women and men from all cultures and economic backgrounds. Conducting outreach to sexually active youths is also important.

# 8. Gaps

# 8.1 Readiness to Accept FASD Screening

There currently exists a regional difference in the level of readiness to accept FASD screening.

# 8.2 Funding and Capacity

Current funding for FASD diagnostic efforts is limited. Intermittent, time-limited funding allows initiatives to begin while sustainability remains an ongoing challenge. Due to the limited diagnostic capacity and long waiting lists, screening may run the risk of being a diagnostic tool. Thus frontline workers must be educated on how to interpret the screening information. Interim supports for individuals between screening and diagnosis must be established.

# 8.2.1 Strategies for Obtaining Funding Support

Engage community leaders and a national champion to raise awareness and advocate for resources and sustained funding. Raise awareness within governments by providing evidence with regard to lifelong costs for those affected with FASD. Develop partnerships with medical organizations such as hospitals and universities to elicit support. Promote opportunities to continue professional education. Analyze existing data from clinics to provide further evidence.

## **8.3** Awareness and Implementation Strategies

The participants of the workshop proposed many methods of increasing FASD awareness and the implementation of the screening toolkit across the country. It was proposed that a secretariat be developed to coordinate FASD-related activities at the national/provincial/territorial level. A national champion should be identified to advocate and raise awareness of FASD.

FASD screening should be advocated within the context of other child health initiatives for sustainable long-term funding. By using standardized screening tools across the country, screening initiatives could be coordinated on a national level and included in PHAC's strategic plan. Screening and diagnostic capacity and supports could be fostered with a continuum of care framework. The use of a standardized screening method would also result in the collection of vital statistics, providing prevalence data and estimates of life time costs.

As a first step, it would be necessary to assess the readiness of the community to address FASD. Increased awareness of FASD amongst the community and its leaders could be used to elicit support. Awareness could focus on prevention and education regarding the effects of alcohol consumption during pregnancy. Public dialogue could be initiated through local media. Efforts should be directed to the entire community to avoid singling out or stigmatizing specific groups within the community. Community forums could be assembled to review and adapt the screening tools and methods.

It was recognized that a cross-sectoral approach must be employed to engage professionals in health, social services, education, and recreation. Frontline providers would need training on approaching women who may be drinking in order to implement harm reduction strategies. Physicians would need to improve their understanding and ability to understand FASD. Medical training and awareness could be by partnerships with organizations, hospitals and medical schools. Medical researchers should be informed of the links between alcohol and brain damage and initiatives should be undertaken to engage graduate students in FASD data aggregation and analysis. Awareness should be raised amongst lawyers and other youth justice professionals. Perhaps this could be modeled after other existing projects e.g. British Columbia Probation Officer snapshot survey and professional development support. Professionals should convene in forums to share knowledge and lessons learned. In addition the gaps between mainstream and First Nations and Inuit professionals need to be addressed.

#### RECOMMENDATIONS

After reviewing and evaluating information collected from the literature review, diagnostic clinic surveys, and the workshops that were held with the scientific experts and frontline provider, the Steering Committee recommended that screening tools be included in the toolkit based on criterion including sensitivity, specificity, positive and negative predictive values, and practical applicability (ease of use, accessibility, cost, expertise required, and cultural appropriateness). Since it was recognized that there is no "one size fits all" screening tool, multiple tools were recommended to screen for FASD amongst children and youth of different ages, stages, and within diverse settings. Universal screening of all mothers for prenatal alcohol exposure was also recommended. Universal screening of FAEE in meconium could be conducted in newborns. Screening using the modified CBCL could be conducted in children 6-18 years of age. Screening using the Medicine Wheel tool could be conducted in children 4-14 years of age. Screening using the Asante Centre Probation Officer Tool could be conducted in the youth population. Facial dysmorphology was eliminated by consensus as a screening tool.

# **Future Directions** — **Implementation**

workshop identified challenges opportunities for implementation of FASD screening. In order to effectively implement screening, community, provincial, and professional participation and cooperation will be required. A staged process of screening is appropriate and most effective across various settings, sectors, providers, and communities. A toolkit will now be assembled containing manuals and tools required for screening and the interpretation of results. Focus groups and workshops will be conducted with policy makers and stakeholders to garner support, assess readiness and identify methods of improving knowledge transfer and the adoption of the toolkit into practice. In addition, assessment of resource requirements will occur prior to the implementation of this screening program.

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# REFERENCES

- Chudley AE, Conry J, Cook JL, Loock C, Rosales T, LeBlanc N. Fetal Alcohol Spectrum Disorder: Canadian Guidelines for Diagnosis. CMAJ 2005;172:S1-S21.
- 2. UK National Screening Committee. What is Screening?

  <a href="http://www.nsc.nhs.uk/whatscreening/whatscreening/whatscreening.htm">http://www.nsc.nhs.uk/whatscreening/whatscreening.http://www.nsc.nhs.uk/whatscreening/whatscreening.http://www.nsc.nhs.uk/whatscreening/whatscreening.htm</a> (March 3, 2008).
- 3. Wilson, JMG and Jungner, G. Principles and practice of screening for disease. Geneva: WHO (1968).http://www.who.int/bulletin/volumes/86/4/07-050112BP.pdf (January 1, 2008).
- 4. Chavez GF, Cordero JF, Becerra JE. Leading Major Congenital Malformations Among Minority Groups in the United States, 1981-1986. MMWR CDC Surveill Summ 1988;37:17-24.
- Stade B, Ungar WJ, Stevens B, Beyen J, Koren G. Cost of Fetal Alcohol Spectrum Disorder in Canada. Can Fam Physician 2007;53:1303-1304
- 6. Sokol RJ, Clarren SK. Guidelines for Use of Terminology Describing the Impact of Prenatal Alcohol on the Offspring. Alcohol Clin Exp Res 1989;13:597-598.
- 7. Sampson PD, Bookstein FL, Barr HM, Streissguth AP. Prenatal Alcohol Exposure, Birthweight, and Measures of Child Size From Birth to Age 14 Years. Am J Public Health 1994;84:1421-1428.
- 8. Sampson PD, Streissguth AP, Bookstein FL, et al. Incidence of Fetal Alcohol Syndrome and Prevalence of Alcohol-Related Neurodevelopmental Disorder. Teratology 1997;56:317-326.
- 9. Hanley WB, Demshar H, Preston MA, et al. Newborn Phenylketonuria (PKU) Guthrie (BIA) Screening and Early Hospital Discharge. Early Hum Dev 1997;47:87-96.
- Walfish PG, Ginsberg J, Rosenberg RA, Howard NJ. Results of a Regional Cord Blood Screening Programme for Detecting Neonatal Hypothyroidism. Arch Dis Child 1979;54:171-177.
- Dorval V, Ritchie K, Gruslin A. Screening HIV in Pregnancy: a Survey of Prenatal Care Patients. Can J Public Health 2007;98:379-382.
- Sussman R, Koren G. Attenuating the Effect of Prenatal Alcohol Exposure With Postnatal Interventions: Critical Review of Animal Studies and Applications to Clinical Research. J FAS Int 2006;4:e13.
- 13. Kvigne VL, Leonardson GR, Borzelleca J, Brock E, Neff-Smith M, Welty TK. Alcohol

- Use, Injuries, and Prenatal Visits During Three Successive Pregnancies Among American Indian Women on the Northern Plains Who Have Children With Fetal Alcohol Syndrome or Incomplete Fetal Alcohol Syndrome. Matern Child Health J 2008.
- Streissguth AP, Sampson PD, Olson HC, et al. Maternal Drinking During Pregnancy: Attention and Short-Term Memory in 14-Year-Old Offspring--a Longitudinal Prospective Study. Alcohol Clin Exp Res 1994;18:202-218.
- 15. Ingersoll K, Floyd L, Sobell M, Velasquez MM. Reducing the Risk of Alcohol-Exposed Pregnancies: a Study of a Motivational Intervention in Community Settings. Pediatrics 2003;111:1131-1135.
- 16. Moore ES, Ward RE, Wetherill LF, et al. Unique Facial Features Distinguish Fetal Alcohol Syndrome Patients and Controls in Diverse Ethnic Populations. Alcohol Clin Exp Res 2007;31:1707-1713.
- 17. May PA, Gossage JP, Marais AS, et al. Maternal Risk Factors for Fetal Alcohol Syndrome and Partial Fetal Alcohol Syndrome in South Africa: a Third Study. Alcohol Clin Exp Res 2008;32:738-753.
- Centres for Disease Control and Prevention (CDC). Alcohol Consumption Among Women Who Are Pregnant or Who Might Become Pregnant--United States, 2002. MMWR Morb Mortal Wkly Rep 2004;53:1178-1181.
- Streissguth AP, Bookstein FL, Barr HM, Press S, Sampson PD. A Fetal Alcohol Behavior Scale. Alcohol Clin Exp Res 1998;22:325-333.
- Roebuck TM, Mattson SN, Riley EP. Behavioral and Psychosocial Profiles of Alcohol-Exposed Children. Alcohol Clin Exp Res 1999;23:1070-1076.
- Nash K, Rovet J, Greenbaum R, Fantus E, Nulman I, Koren G. Identifying the Behavioural Phenotype in Fetal Alcohol Spectrum Disorder: Sensitivity, Specificity and Screening Potential. Arch Womens Ment Health 2006;9:181-186.
- Astley SJ, Stachowiak J, Clarren SK, Clausen C. Application of the Fetal Alcohol Syndrome Facial Photographic Screening Tool in a Foster Care Population. J Pediatr 2002;141:712-717.
- Astley SJ, Clarren SK. Diagnosing the Full Spectrum of Fetal Alcohol-Exposed Individuals: Introducing the 4-Digit Diagnostic Code. Alcohol Alcohol 2000;35:400-410.
- 24. Bearer CF, Lee S, Salvator AE, et al. Ethyl Linoleate in Meconium: a Biomarker for Prenatal Ethanol Exposure. Alcohol Clin Exp Res 1999;23:487-493.

- Moore CM, Lewis D. Fatty Acid Ethyl Esters in Meconium: Biomarkers for the Detection of Alcohol Exposure in Neonates. Clin Chim Acta 2001;312:235-237.
- 26. Chan D, Bar-Oz B, Pellerin B, et al. Population Baseline of Meconium Fatty Acid Ethyl Esters Among Infants of Nondrinking Women in Jerusalem and Toronto. Ther Drug Monit 2003;25:271-278.
- Bearer CF, Jacobson JL, Jacobson SW, et al. Validation of a New Biomarker of Fetal Exposure to Alcohol. J Pediatr 2003;143:463-469.
- 28. Chan D, Klein J, Koren G. Validation of Meconium Fatty Acid Ethyl Esters As Biomarkers for Prenatal Alcohol Exposure. J Pediatr 2004;144:692.
- Peterson J, Kirchner HL, Xue W, Minnes S, Singer LT, Bearer CF. Fatty Acid Ethyl Esters in Meconium Are Associated With Poorer Neurodevelopmental Outcomes to Two Years of Age. J Pediatr 2008;152:788-792.
- Hutson JR, Magri R, Suarez H, Miguez H, Koren G. Fatty Acid Ethyl Esters and Cotinine in Meconium Are Predictors of Birth Weight in a Uruguay Cohort. Can J Clin Pharm 2007;14:e169.
- 31. Brien JF, Chan D, Green CR, et al. Chronic Prenatal Ethanol Exposure and Increased Concentration of Fatty Acid Ethyl Esters in Meconium of Term Fetal Guinea Pig. Ther Drug Monit 2006;28:345-350.
- Hopkins RB, Paradis J, Roshankar T, et al. Universal or Targeted Screening for Fetal Alcohol Exposure: a Cost-Effectiveness Analysis. J Stud Alcohol Drugs 2008;69:510-510
- 33. Conry J, Fast DK. Fetal alcohol syndrome and the criminal justice system. Vancouver: Fetal Alcohol Syndrome Resource Society, 2000.