



FASD Screening Tool Development Project WORKSHOP PROCEEDINGS

October 29 & 30, 2007



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1. Project Overview

1.1 Project Rationale

On March 1, 2005 the Public Health Agency of Canada endorsed the Canadian Guidelines for the diagnosis of Fetal Alcohol Spectrum Disorder (FASD) www.cmaj.ca/cgi/reprint/172/5_suppl/S1.pdf. The capacity, however, of diagnostic clinics is low compared to the prevalence of FASD. The validity and reliability of available screening tools has not yet been verified, limiting the ability of health care and allied professionals across Canada to consistently screen for FASD and refer for further assessment and diagnosis.

In partnership with many FASD experts and organizations, the Canadian Association of Paediatric Health Centres (CAPHC) is currently facilitating a national initiative, funded by the Public Health Agency of Canada, entitled: “*Developing a National Screening Tool Kit for Those Identified and Potentially Affected by FASD*”. Drs. Albert Chudley, Sterling Clarren, Gideon Koren, and Ted Rosales are the content experts leading the Project’s Steering Committee.

The primary objectives of this initiative are to:

- To survey and critically evaluate FASD screening tools and methods in use in Canada for referral to or acceptance into diagnostic clinics;
- Evaluate practical values (sensitivity, specificity, and predictive values) of these tools;
- Develop practical guidelines (Tool Kit), based on the identified and evaluated tools.

Accomplishments to date include:

- A survey of FASD Diagnostic Clinics in Canada has been conducted to assess what screening tools and methods are currently being used;
- A critical review of the North American literature on FASD screening tools and methods has been conducted;
- A National Advisory Group has been established of recognized content experts from Canada and the United States;
- A National Advisory Group Workshop was held. These Proceedings describe the results of the Workshop.

1.2 Workshop Goal & Outcomes

On October 29th and 30th a workshop of the National Advisory Group (see Appendix A) was held at the Sheraton Gateway Hotel, Toronto, Ontario. The Workshop goal was:

To critically review screening tools and methods and offer suggestions as to the level of appropriateness of the tools and methods discussed

These Proceedings summarize the three outcomes designated for the Workshop:

- Describe essential components of screening
- Evaluate specific screening tools and methods
- Draft recommendations & next steps

1.3 Method

In preparation for the Workshop, content experts from the Advisory Group were asked to critically review the literature related to the screening and identification of FASD and to present their own research and findings. The Workshop consisted of presentations by experts in nine panels each followed by in-depth discussion. The nine panels focused on the following areas:

- Growth Retardation
- Facial Dysmorphology
- Neurobehavioural Characteristics (two panels)
- Meconium FAEE
- Clinic Tools
- Youth Justice Population
- Population Variability
- Impact of Screening

A full listing of articles reviewed and workshop presentations can be found at www.caphc.org. A table mapping the screening tools presented can be found in Appendix B.

2. Essential Components of Screening

The UK National Screening Committee 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.”

This definition of screening was adopted for the purposes of this workshop.

Although screening has the potential to save or improve quality of life through early diagnosis of serious conditions, it is not a fool-proof process. Screening can reduce the risk of developing a condition or its complications, but it cannot offer a guarantee of protection. In any screening program, there is an irreducible minimum of false positive results (wrongly reported as having the condition) and false negative results (wrongly reported as *not* having the condition).

An effective screen is cost-effective and quickly administered. Successful screening will identify more than the possibly affected persons who have 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, i.e. 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 Screening

According to the World Health Organization, to successfully implement a screening program the following conditions should be met:

- 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;*
- x. Screening programs should be a continuing process.*

The rationale for FASD screening meets most, but not all of these criteria. Universal screening for FASD should be carefully considered in the context of these criteria. For example arguments for screening include:

Benefits

- FASD prevalence in Canada is estimated at 9.1 per 1,000[§] live births; estimated lifetime cost for one individual with FASD is one million dollars;
- The natural history of FASD is fairly well understood;
- Possible screening tests for FASD are non-invasive;
- Interventions such as early diagnosis, special education, resources & environment have been shown to reduce the effects of developmental disabilities in children with FASD;
- Reduction in these disabilities can lead to societal savings which can offset screening costs.

Challenges to FASD screening include:

- The major drawback to universal screening is, at present, no general screening test has been widely validated;
- Although facilities for diagnosis and assessment exist in Canada, they are overloaded; current average wait times in diagnostic clinics are six months to two years;
- The acceptability of various test methods has not been fully explored; although tests are non-invasive there may be ethical and stigma issues for mothers and children and time/cost issues for providers;
- In some parts of the country the problem is not universally recognized or is believed to occur only in aboriginal populations.

[§] Estimates on FASD incidence and prevalence are based on those presented in the Canadian FASD Diagnostic Guidelines

Comparisons with Other Universal Screening Programs for Children

Despite affecting an estimated 1/100 that is over 330,000 Canadians, there is currently no accepted standardized screening test for FASD in Canada. In contrast, rarer conditions such as phenylketouria and congenital hypothyroidism are universally screened for at birth. However, these conditions have specific and effective biomedical treatments. HIV cord blood testing, and testing for other rare genetic disorders have become routine in maternal and perinatal care.

FASD is a disorder that can be completely prevented by eliminating alcohol exposure during pregnancy. By screening for FASD, children can be closely monitored for developmental disabilities, and receive the necessary interventions at an earlier period. This has been shown to be associated with decreased disabilities that are commonly associated with FASD. Animal studies have demonstrated that ethanol exposed pups receiving earlier intervention had better outcomes, i.e. brain plasticity is apparent.

A diagnosis of FASD would enable increased access to services and supports and more appropriate sentences in the youth justice system. Detecting a case of FASD also identifies the addicted mother and possibly other children at risk, and may potentially help mothers change their alcohol use in subsequent pregnancies.

2.2 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 overstressed families. Overall system capacity to consistently provide interventions, supports and resources throughout the life stages for these children must be assessed and requires 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 to treatment must also be addressed.

2.3 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 0.1/1000 and 3/1000 live births. Rates can be ethnically, culturally, and regionally dependent. The prevalence of FASD is considerably higher, but there are no good estimates given the wide range of outcomes. Canadian incidence/prevalence studies tend to focus on aboriginal populations with prevalence rates varying from 1.5 to 9.1 per 1,000 for FASD. Approximately 12.5% of women of childbearing age are at-risk drinkers (>7drinks/week – 4 or more drinks per occasion), suggesting the importance of prevention efforts.

Population Variability and Key Screening Domains

Population variability was examined in terms of key screening/diagnostic domains.

- growth
- facial dysmorphology
- neurobehavioural factors
- alcohol consumption
- maternal risk factors

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. For example:

- **Alcohol use:** how much damage a specific amount of alcohol causes is affected by genetic factors, maternal drinking history and pattern of drinking, mother's nutrition and weight, and other risk factors, e.g. smoking, drug use;

According to the Canadian Diagnostic Guidelines 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. The 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; behavioural expression of disability can be affected by environment;
- **Genetics:** a child's genetic make-up may vary from standardized screening norms, e.g. birth weight and growth, head circumference, facial features, e.g. palpebral fissure measurements;
- **Age cohort:** Facial features modify with age; some key psychometric assessments are difficult before age five or six; risks factors may vary depending on child's stage of development, e.g. behaviours such as lying, cheating, stealing.

3. Evaluation of Screening Tools and Methods

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

3.1 Neurobehavioural Methods

The development of a neurobehavioural profile for FASD is complex and requires the examination of neurobehavioural deficits/problems and the ability 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 specific neurobehavioural deficits or their combination can constitute effective screening methods. In practice, screening for FASD takes place frequently. This screening is typically initiated by problem behaviour and may be carried out by non-clinicians, e.g. teachers, foster parents, youth court workers. Checklists presently used are not scientifically validated and intake procedures may screen for a variety of neurobehavioural deficits. Confirmed alcohol exposure is required for referral for further FASD assessment. Clinic data reviewed 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.

Potential Benefits

- Quick and straightforward to administer;
- Ideally could be applied to all children or at least to all children at-risk;
- Use of objective measures based on scientific knowledge;
- Could be used by trained non-clinicians;
- Standardized tools exist for assessing cognitive and academic functioning;
- Multiple indicators can be used and collected from multiple sources.

There were a number of challenges identified in using findings in the literature to identify FASD markers:

Challenges

- Circularity of diagnosis – an individual has FASD and therefore has neurobehavioural deficits;
- Rating scales used by non-clinicians introduce rater bias; tool users must have background in normal child development to assess age appropriate behaviour;
- There is a great deal of overlap with other neurobehavioural deficits, e.g. ADHD;
- Statistically significant differences may not equate with “clinically significant” differences;
- Behaviours often associated with FASD, e.g. immaturity, stealing, lack of remorse can be attributable to other prenatal/genetic factors or environmental factors or experience.

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

- alcohol exposure, without which a diagnosis cannot be made
- facial features
- 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 infants)

Specific Tools

In an attempt to develop a screening tool, the **Fetal Alcohol Behaviour Scale** (FABS) was proposed. 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.

A **systems approach to FASD screening** has been proposed (see also Section 3.6. The Medicine Wheel Tools). This approach starts from the premise that FASD is not a behavioural disorder, but a neurological deficit (brain damage) as a result of prenatal alcohol exposure. This brain damage expresses itself in different ways depending on age and environmental factors. Secondly, screening for FASD is strongly influenced by social system and perceived through the lens of the professionals working within these systems. A systems approach includes:

- A staged screening process is proposed that examines severe problems in multiple profile domains that interfere with development; and investigation of developmental history-risk factors, e.g. prenatal alcohol and drug history;
- Screening in communities of possible high prevalence using system specific screening tools with high sensitivity;
- Development of validated system screening tools requires researchers and practitioners in various systems to work in collaboration.

The Child Behavioural Checklist (CBCL) Presently, this tool can only be administered by a psychologist. Research from the Hospital for Sick Children in Toronto has demonstrated the utility of items from CBCL as a possible screening tool for FASD behavioural phenotype which can be administered by non-clinicians. Children with FASD were found to exhibit specific behavioural characteristics.

Comparing children with FASD to children with ADHD, seven items on the CBCL associated with conduct disorders were highly sensitive and specific observed in children with FASD:

- 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

The test was further validated for children with or without hyperactivity and poor attention.

Benefits

- A potentially concise screening tool which can identify children who may have FASD, and differentiate between ADHD and FASD affected children;
- Simple checklist which can be completed by parent or any caregiver who knows the child.

Limitations

- The research has not been replicated in a large population, although it has been replicated with similar results in another cohort by the same group;
- Potential confounders such as age, gender, socioeconomic status, home situation and IQ effects were not examined.
- Further research is underway using a larger sample, examining the effect of confounders, and including a comparison group with opposition defiant disorder and conduct disorder.

3.2 Facial Dysmorphology

The three facial dysmorphic characteristics of children affected with FAS are the appearance of the philtrum, upper lip thinness and palpebral fissure length. The majority of children affected with FASD do not exhibit facial dysmorphic characteristics. Facial dysmorphology, a tool used for diagnostic purposes, was considered for its applicability as a screening method. Benefits and challenges to using this method for screening included:

Benefits

- Digital cameras and software exists which allow non-clinicians to accurately interpret results; inter-observer reliability is high;
- Relatively low cost;
- Safe, non-invasive method for evaluating children.

Limitations

- Vast majority of FASD children do not present with facial dysmorphology;
- Age differences can affect results, i.e. facial dysmorphology most distinctive between the ages of eight months and eight years;
- Parental genetics/ethnicity can affect facial features; there are no ethnically specific norms available;
- Studies have warn against generalizability with ethnically diverse and mixed populations;
- There is a need to distinguish between differences which may be statistically significant and those which are clinically relevant.

Specific Tools

A targeted FAS screening project for children in foster care in the Seattle area was implemented over a nine-year period. Starting in 1999 all children who entered foster care were screened for full rank-4 facial features. Trained case workers took digital photographs that were interpreted by clinicians using software based on measurements for the Caucasian and African American populations. Over 2000 children were screened, demonstrating a prevalence of 1/100.

Benefits

- The screening method has been shown to have very high sensitivity, specificity and PPV;
- Using a single tool for screening does not overwhelm clinics and clinicians;
- Once these children have been identified they can receive placement in special needs foster care;
- The ability to identify the high prevalence in this population helps to document the extent of the problem and advocate for funds;
- Non-invasive, fast and inexpensive test.

Limitations

- May not be feasible as a universal screen; more appropriate to known high risk populations where prevalence of FAS is expected to be high;
- Does not capture those with FASD who do not exhibit facial dysmorphology;
- Accurate measurement is dependent on well-taken photograph.

3.3 Meconium Testing for Ethanol Metabolites

Meconium is formed at approximately the 12th–14th week of pregnancy. As the fetus swallows amniotic fluid, prenatal exposures to chemicals can be traced in meconium. Studies in meconium have been conducted in Canada, the United States, Europe and South Africa. Meconium measurement of fatty acid esters (FAEEs) (fatty acids synthesized with ethanol) are a unique biological marker for fetal exposure to excessive maternal drinking. Meconium levels of FAEEs above 2nM/g of meconium separate heavy fetal alcohol exposure from light exposure at very high specificity and sensitivity.

Benefits

- The sensitivity and specificity of meconium has been tested repeatedly;
- Results for fatty acid ethyl esters (FAEEs) have been found to be both highly sensitive and specific;
- Collecting meconium is a non-invasive process as it is a natural waste product;
- Universal screening using meconium may be considered at birth as collection of other human products are collected for diagnosing even rarer conditions such as PKU;
- Meconium screening identifies two potential patients/clients mother and child.
- Little chance of misjudging mother's alcohol use;
- Significant correlations have been found between FAEE and lower APGAR scores, low birth weight and lower executive functioning;
- Animal studies have shown a relationship between FAEE levels and growth retardation as well as brain weight;
- Meconium analysis is the only chance to show excessive fetal exposure to alcohol which is a fundamental prerequisite for diagnosis of FASD;
- Inexpensive test, with the possibility of dropping cost to \$10-15/sample.

Limitations

- Meconium must be collected in the first 72 hours after delivery;
- Meconium formation only begins at 12 weeks; any exposure that terminated by 12 weeks of gestation would not be captured;
- As yet, there is only partial correlation between positive FAEE in meconium and the amount of alcohol exposure that the mother has had in pregnancy;
- There are ethical concerns regarding reporting of mothers to children's services agencies, although there is no legal requirement to report maternal drinking.

Screening Study

A recent study in the Grey Bruce area of 800 births in one year examined anonymous meconium samples. Out of 700 births, 2.6% tested positive for alcohol exposure. High risk births from this area were transferred to St Josephs Health Care (SJHC), London, Ontario. When meconium samples were collected from babies in NICU at SJHC from this area, the rate of alcohol exposure jumped to 26%.

3.4 Growth Retardation

Data were presented on the feasibility of using intrauterine growth retardation as a screening indicator for FASD. Intrauterine growth can be influenced by a number of factors. Increased growth can be affected by genetics, diabetes and ethnic/racial norms. Growth retardation is considered as part of the diagnosis process because alcohol is a known teratogen which can impair fetal growth and growth retardation is associated with other FASD diagnostic indicators: facial dysmorphology, brain development and alcohol history.

Benefits

- Growth retardation as a screening mechanism may have merit in combination with other biomarkers, e.g. meconium screening; an animal study found an inverse relationship between FAEE concentrations and body/brain weight.

Limitations

- Research examining maternal alcohol use and infants deemed small for gestational age (SGA) indicated that only a very small percentage of SGA was attributable to drinking more than 2 or more drinks a day;
- Although consequences of SGA are significant, e.g.
 - high fetal mortality and higher infant mortality
 - short-term metabolic problems
 - deficits in growth and neuro-cognitive delaysusing SGA for screening has a sensitivity rate of 10–30%, therefore missing the majority of cases;
- Different growth standards may be required for various populations.

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 testing.

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. This population of teenagers and young adults may not have been diagnosed with FASD, yet the involvement with the youth justice system may be related to some of the neurobehavioural characteristics described for those with FASD. In youth corrections, reasons for behaviour drive interventions. Failure to feel remorse or understand consequences of actions has been described as neurobehavioural characteristics of those affected by FASD. This presents a challenge to the youth justice system to find appropriate deterrents/incentives for this population. There were a number of limitations and benefits described for screening with this population.

Benefits

- Savings in cost and time through better use and prioritizing of needs and services;
- Youth involved with the justice system tend to be heavy users of other systems;
- More effective programming appropriate to neurobehavioural deficits associated with FASD and ultimately a reduced risk of re-offending.

Limitations

- Difficulties in ascertaining maternal alcohol exposure many years after the fact;
- Issues of consent and privacy of information;
- No validated screening tool for young offenders;
- Frontline workers may be resistant to using potential screening techniques, e.g. photographing for facial dysmorphology indicators.

Specific Tools

FASD Youth Justice Project Manitoba started as a pilot project and now has on-going funding. Its goal was to build capacity and design multi-dimensional interventions. Youth 12–18 years with no previous FASD diagnosis and confirmed pre-natal alcohol exposure were selected pre-sentencing in Winnipeg. A multi-disciplinary assessment was conducted. “Red flags” included:

- 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

One hundred seventy-eight met the screening criteria; 50 received diagnostic assessment, 30 were diagnosed with FASD, 29 ARND (PPV 60%). Although this was a highly selective population, screening was fairly effective.

In the Youth Justice system in Saskatchewan, judges are made aware of a number of ‘red flags’ to trigger referral for assessment. Judges are instructed to screen based on criteria similar to the indicators used in the FASD Youth Justice Project in Manitoba. If the judge observes these 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. Two custody workers were trained as raters and screened 100 files comparing custody and community files with a matched clinical sample. Inter-rater reliability was high, 0.82; validity was also high with 76% higher score for those with FASD than for controls. The tool has been refined with the 28 items interconnected in three sections:

- A concise screen specifically aimed at screening for FASD;
- A focused functional assessment designed to identify strengths and limitations of the individual;
- An environmental scan to assess for community supports and resources.

A research study to identify offenders with FASD was conducted at Stony Mountain Institution near Winnipeg, Manitoba. All offenders undergoing preliminary assessment were recruited to the study. 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 produced the following conclusions which have implications for the use of this tool with the youth justice population:

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;
- High rate of overall neuropsychological impairments found in the study sample.

3.6 Clinic Tools

Presentations were made on some of the screening tools which are currently being implemented in clinics across Canada. These tools show promise for broader application for different populations. All 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.

Benefits

- A single referral/screening process for all complex developmental behavioural conditions;
- Reflects the diagnostic criteria/domain used in the assessment process which have been validated.

Limitations

- Referral form must be completed by specialist physician.

Probation Officer Screening Tool. The Asante Centre for Fetal Alcohol Syndrome in British Columbia conducted a 'snapshot survey' with all probation officers in Fraser and Vancouver Coastal regions. Probation Officers completed an FASD survey for youth on adjudicated probation orders. In a subsequent two month period all probations officers were asked to complete an FASD 'new referral' survey for all new youth on their caseload. Research was aimed at determining the number of youth suspected of FASD, probation officer knowledge of FASD, characteristics and behaviours used to identify youth and the probation officers' perceived value of an FASD diagnosis and barriers to diagnosis and assessment.

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. The survey found that Probation Officers identify a number of other behavioural factors which may suggest FASD. They also identified some social, physical skills and compliance indicators that they believe are not indicative of FASD. The principal barriers to FASD assessment which probation officers identified were the unwillingness of the family and/or youth to be assessed.

Benefits

- Potential for use of the tool with other youth populations;
- Tool can be administered by frontline workers;
- Provides insights into frontline workers perception of FASD;
- Identified factors that are red flags for frontline workers;
- Identified barriers to assessment.

Limitations

- Tool has not been validated.

The **Medicine Wheel Tools** were developed for the Elsipogtog Mi'gmaq First Nations community in New Brunswick. 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.

Stage 1

Medicine Wheel Student Index: administered by the child's teacher explores mental, emotional, physical and social indicators along with spheres of learning and special services received. The teacher uses severity scales for items within each domain or sub-domain. Administration time is approximately fifteen minutes. 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, trigger a referral to Stage 2.

Stage 2

Medicine Wheel Developmental History: 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.

In the first two years of using the tools, 237 children, K4 to grade 8 were screened. Twenty-nine percent proceeded to diagnosis; of these 67% were diagnosed with FASD.

Benefits

- Relies on teachers' judgement who know the child; research has shown that teachers' judgement is reliable and essential to assessment of school-aged children;
- Quick to administer;
- Teachers receive training in proper administration of the tool;
- Tools incorporate a First Nation's worldview and framework providing cultural context and relevance;
- Parents are engaged as collaborators in Stage 2 of the process.

Limitations

- Tools have not been validated;
- Tools appropriateness for other populations has not been assessed.

The Clinic for Alcohol & Drug Exposed Children (CADEC) in Manitoba was funded to expand capacity, reduce wait lists, and provide increased training for rural, remote and northern physicians. CADEC does not use a screening checklist per se but provides criteria for referral based on the following:

- 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

The diagnostic rate using these intake criteria was approximately 50%.

Benefits

- Specificity 24.5%; only 89 were normal, 464 were true positives and 277 received another diagnosis.

Limitations

- Sensitivity was 100% but is falsely high as false negatives cannot be determined in those screened;
- Referral criteria not validated

The Labrador Alcohol Research Group (LARGE) is a primary health care approach in Labrador to address FASD in the population. Its goals are to refer, diagnose, and train professionals and other frontline workers, collect data and develop an FASD framework for Labrador. Referral information included family/household information, family history, foster home involvement, neurobehavioural indicators, school support, public health reports and medical information. The project concluded that although the Canadian FASD Guidelines are the 'gold standard', each community must use the guide based on the resources that are available and in recognition of the common goals for those affected and their families.

4. Promising Approaches

A theme throughout the Workshop was "No one size fits all". No one screening tool or method emerged as suitable for all ages, cultures and environments. There are several tools that show promise for universal and/or targeted screening and may become part of a 'tool kit' that will help to standardize and enhance screening practices in Canada.

Table 1 summarizes the screening tools and methods currently in use or being tested for use.

Table 1. Age Grouping by Screening Tools and Methods

Age Cohort	Screening Test	Screening Venue	Professional Required	Universal/targeted	Validated
newborn	FAEE in Meconium – first bowel movement	Hospital Home delivery	Physician, Nurse, Midwife	Universal	Yes
8 mos – 8 yrs	Facial dysmorphology Digital photo & software	Community clinic Home	Social Services Workers Clinicians—interpret results	Targeted	Yes
9 mos – 12 yrs.	CADEC 6-item Referral form child and family characteristics	Physicians’ offices/clinics	Physicians	Universal	Preliminary
6 yrs – 18 yrs	Modified Child Behavioural Checklist – 7 items distinguish between FASD & ADHD	Community clinic School system Children’s mental health agency	Educators, Social Services Workers	Universal	Preliminary
4 yrs – 14 yrs	Medicine Wheel 51 items in 6 domains—severity scales	Schools	Teacher - stage 1	Targeted	No
Children & youth	CDDB referral form— 3 neuro-developmental categories plus biomarkers	Specialized clinics; Physicians’ offices	Paediatricians Child Psychiatrists	Universal	No
Children & youth	Fetal Alcohol Behaviour Scale 36 item questionnaire	Clinics	Psychologist	Universal	Yes
5 yrs – 19 yrs.	Personality Inventory for Children—275 items	Community clinic	Psychologist	Universal	Preliminary
12yrs – 18 yrs	Manitoba Youth Justice Project Screening guide 10 ‘red flag’ items—behavioural/social/ academic	Youth justice system	Justice system personnel Social Service Workers Teachers	Targeted	Preliminary
Youth	Saskatchewan Project 28 item personal/social; school/ employment antisocial/criminal & skills plus environmental scan	Youth justice system	Custody Workers Community Youth & Adult workers	Targeted	Preliminary
Youth	Asante Clinic Probation Officer Screening tool Groups of personal and environmental indicators	Youth justice system	Probation Officers	Targeted	No
Youth/ adults < 30 yrs	Stony Mountain Brief Screen Checklist 28 behavioural indicators & history	Corrections	Community providers	Targeted	Preliminary



Universal Screening Methods

Meconium screening for newborns is a validated tool that can be considered for universal screening. There is a very small window of opportunity for use of this tool. A preliminary study of high risk births yielded a very high incidence of alcohol exposure. Given the costs for this screening it may also be considered for targeted populations.

Most screening tools presented or reviewed in the literature were checklists that covered a range of neurobehavioural, social, family and academic indicators. Of the checklists suitable for children in the general population (CADEC, CBCL, CDBC, FABS, PIC) only the CBCL was being tested as a screening tool which could be administered by a non-clinician. The other checklists required administration by a physician or psychologist. The CDBC Referral Form warrants additional consideration as it screens for a range of 'complex developmental and behavioural conditions'. This information can be used to create a broader picture of the prevalence of these disabilities in the community.

Targeted Screening Methods

The Medicine Wheel tools are currently used with a First Nations community and are not validated. They may hold promise for use with a broader population and have the benefit of being administered in the school setting by teachers (stage 1). The systems approach considers the environment and cultural context as well as engaging parents in the process, factors that are applicable to any successful screening process.

Facial dysmorphology tools were effective screening mechanisms for FAS in a targeted population. As facial dysmorphic features are not apparent for most affected by FASD, it is unlikely to be considered as a universal tool. Genetics influence facial features and more work needs to be done to establish standards for a broader range of ethnic groups.

Four screening tools were presented which were designed for use with youth/young adults in the justice system. All can be administered by justice system or community services personnel with training. Preliminary findings indicate that these may be effective screening tools with this target population. Given the behavioural characteristics of FASD affected individuals, an effective screening tool for the youth justice population is particularly relevant as traditional systems of incentives/disincentives may be ineffectual.

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;
- A screening initiative should be part of a broader prevention plan that addresses primary prevention, i.e. abstention from alcohol during pregnancy; and follow-up and supports to mothers identified as alcohol users during pregnancy;
- Screening tools that are considered for either targeted or universal application must be assessed for cultural appropriateness, age/stage of development, and environment or genetic factors which may significantly influence outcomes;
- First Nations, Inuit and Métis ethno-cultural groups should be considered as distinct populations when assessing the cultural appropriateness of various screening tools and methods;
- Effective screening by non-clinicians requires training, commitment of resources and workers' support and comfort with screening processes;
- Most screening tools considered require further validation which will require resources and time commitment;
- Targeted vs. universal screening must be given careful consideration in light of cost-effectiveness, public acceptance and potential stigmatization.

6. Steering Committee Comments and Next Steps

The identification of appropriate screening methods for FASD is an extremely challenging task for several interrelated reasons:

1. Classically, 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. As examples, measurements of palpebral fissures, or the use of elements of the CBCL, are part of the diagnosis of facial or neurodevelopmental features.
2. Many of the proposed screening methods for FASD have not been validated for their epidemiological properties of sensitivity, specificity and predictive values. The exceptions are the face measurements, the CBCL and meconium FAEE.

3. There has been a healthy dose of scepticism whether screening methods are needed at all in the grim reality of very limited diagnostic capacity at the present time. Related to this scepticism is the fear that, limited diagnostic capacity may turn “positive screening” into 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 horrible scope of this epidemic in their jurisdictions.
4. Acknowledging the paucity of validated screening methods, the Steering Committee sought the advice and direction from experts in the field, the results of which are summarized in these Workshop Proceedings. It is apparent from this exercise that different approaches and methods are required for screening depending upon the life stage of the child — pre-natal to young adult.

For these reasons, the Steering Committee has opted to propose a “Tool Kit” which may offer a menu of different options to different personnel in different settings. For example:

Newborn Screening

Meconium FAEE screening holds promise as a screen for newborns particularly those infants deemed at high risk and/or in NICU. Those who screen positive become part of an at-risk group due to alcohol exposure and can have an automatic referral to early child development and family support services already in existence. Mothers can be offered support and counselling.

There may also be an opportunity to track these children for research which can lead to better understanding of the development of FASD-related disabilities and their amelioration. Issues of confidentiality and stigmatization must be carefully considered, as preliminary research indicated that anonymity and universality were conditions for consent.

This screening tool’s main drawback is that it only identifies second and third trimester alcohol exposure. For infants exposed in the first trimester substantial risks may remain. A negative screen does not necessarily mean a low risk.

Neurobehavioural Checklists

While the meconium FAEE is a powerful tool to identify heavy fetal exposure to alcohol, it will not be able to help screening of older children. There will still be a need for a widely applicable neurobehavioural checklist which can be easily administered by non-clinical personnel in a variety of community settings.

A modified version of the CBCL is currently being validated as a screening checklist for pre-school and school-aged children and youth which can be administered in community settings by non-clinicians. The CBCL method is attractive because this brief questionnaire can be filled by anyone who knows the child. Yet, at present time the test has not addressed some important potential confounders.

It should be tested further taking into account those factors identified in other checklists, e.g. adjustments for age/stage of development, cultural appropriateness and context, training of non-clinicians.

Youth Justice Population

Those youth affected by FASD remain a distinct population within the youth justice system. It is imperative that these young offenders are identified so that appropriate incentives and disincentives can be introduced which will reduce recidivism. The tools developed by the FASD Screening Tool Project in Saskatchewan and the Asante Centre for Fetal Alcohol Syndrome in British Columbia are the most promising for this targeted population. Both have conducted research to assess the capacity of community youth workers and probation officers to effectively screen. Both require further investigation and validation.

Special Populations – Children in Care

In Seattle, a FAS screening project used digital photographs taken by trained case workers to screen children in foster care. Results were interpreted by clinicians using software to assess facial features. This is a validated tool, applicable to populations with a very high likelihood of pre-natal alcohol exposure. Identification of these children can ensure appropriate placement and supports. The test is non-invasive. It should be emphasized that this screening tool identifies only those children with FAS-related facial dysmorphism. The majority of children within the FASD spectrum may screen negative using this methodology.

Next Steps

While challenged by attempts to identify effective screening methods, the Steering Committee strongly felt that one should not disregard the obvious:

History of maternal 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.

The present effort should be regarded as a first attempt of creating a screening platform for FASD. By no means should it be interpreted as a final version, as more research and day-to-day practice with existing methods are needed to verify their utilization and effectiveness.

To this end the following next steps are deemed necessary:

- **A workshop of frontline service providers** from a variety of professional backgrounds. These providers can contribute to the development of the tool kit, by identifying the practical opportunities and barriers to implementation of screening methods in different sectors, geographical areas, and populations. Their expertise will further direct the development of feasible, validated, cultural and age appropriate screening methods;
- Subsequent to this workshop, the **Steering Committee** will evaluate all the information provided to date and **recommend a tool kit of screening methods** and approaches;
- **A third workshop will be convened of policy and decision-makers** who have the capacity to address provincial uptake within the various child and youth health initiatives in each province and territory.

Appendix A: Workshop Participants

Dr. Kwadwo Ohene Asante, Medical Director, Asante Centre for FAS, Vancouver BC

Dr. Susan Astley FAS DPN, Center on Human Development & Disability, University of Washington

Dr. James Brien, Professor of Pharmacology and Toxicology, Director of Research within the Faculty of Health Science at Queen's University

Ms Sarah Carriere, Project Coordinator, Inuit Tapiriit Kanatami

Dr. Jocelynn L. Cook, Manager, Research Coordination Unit, Health Information, Analysis & Research Division, First Nations & Inuit Health Branch, Health Canada

Dr. Albert Chudley, Professor, Dept of Pediatrics & Child Health, and Biochemistry and Medical Genetics, University of Manitoba Health Science Centre

Dr. Julianne Conry, Research Psychologist, Asante Centre for FAS, Vancouver BC

Dr. Lori Vitale Cox, Educational Psychology Coordinator-Education Division, Eastern Door FASD Diagnostic Team

Dr. Ellen Fantus, Psychologist, The Hospital for Sick Children

Ms Valerie Flynn, Manager, FASD Strategic Programming Unit, First Nations and Inuit Health Branch, Health Canada

Ms Y. Ingrid Goh, PhD student, University of Toronto, Hospital for Sick Children

Mr. Phat Ha, Statistical Analyst, Public Health, Health and Social Secretariat, Assembly of First Nations

Ms Mary Johnston, FASD Team Manager, Public Health Agency of Canada

Dr. Michelle Keightley, C.Psych. Assistant Professor Department of Occupational Science and Occupational Therapy & Department of Rehabilitation Science, University of Toronto

Dr. Gideon Koren, Professor of Paediatrics, Pharmacology, Pharmacy, Medicine and Medical Genetics, University of Toronto, Hospital for Sick Children

Dr. Michael Kramer, Scientific Director of the Institute of Human Development, Child and Youth Health (IHDCYH), Dept of Paediatrics, McGill University

Dr. Christine Loock, Developmental Paediatrician, BC Children's Hospital and Associate Professor in the Department of Paediatrics at the University of British Columbia

Ms Holly MacKay, Senior Program Consultant Project Monitor, Public Health Agency of Canada

Dr. Stuart MacLeod, Executive Director, Child & Family Research Institute; Vice President, Academic Liaison & Research Coordination, Provincial Health Services Authority, Professor, Dept. of Pediatrics, Faculty of Medicine, University of British Columbia

Ms Patricia MacPherson, Acting Senior Research Manager, Addictions Research Centre, Correctional Service Canada, Montague, PEI

Dr. Jo Nanson, Psychologist, Adjunct Professor, University of Saskatchewan Saskatoon

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Ms Elaine Orrbine, President and CEO, Canadian Association of Paediatric Health Centres (CAPHC)

Mr. Garry Prediger, Director Saskatoon Provincial Correctional Centre, SK

Dr. Ted Rosales, Pediatrician/Geneticist Clinical Professor of Pediatrics , Memorial University

Ms Charlotte Rosenbaum, Project Coordinator, Charlotte Rosenbaum Consulting Services

Dr. Peter Rosenbaum, Co-Director, CanChild Centre for Childhood Disability Research, McMaster University, Faculty of Health Sciences

Ms Debra Schleyer, Executive Assistant, CAPHC

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Ms Paula Stanghetta, Project Coordinator, Canadian Centre on Substance Abuse

Ms Eva Szczerba, Associate Director CAPHC

Dr. Suzanne Tough, Associate Professor, University of Calgary and Scientific Director, Alberta Centre for Child, Family and Community Research

Ms Su-Ping Walther, Senior Policy Advisor – Aboriginal Health Transition Fund, Métis National Council

Appendix B. Summary of Screening Tools

Summary of Screening Tools					
Tool	Population	Description	Strengths	Weaknesses	Validity/Reliability
Checklists/Referral Forms					
Child Behavioural Checklist-modified	Children & youth 6–18 yrs	7-item parent/caregiver questionnaire	<ul style="list-style-type: none"> - concise - distinguishes between FASD & ADHD 	<ul style="list-style-type: none"> - research not replicated in larger pop. - confounders: age, gender, environment not examined - must have known alc exp. 	86% sensitive 82% specific
Complex Developmental Behavioural Conditions Referral Form	Children & youth	Referral form mirrors diagnostic assessment domains; screen for all CDBC	<ul style="list-style-type: none"> - one referral form range of CDBC - based on validated diagnostic criteria 	<ul style="list-style-type: none"> - referrals only from specialist physician 	
Fetal Alcohol Behaviour Scale	All ages	36 item questionnaire	<ul style="list-style-type: none"> - results are valid regardless of age, race, gender or IQ 	Unable to distinguish between FASD & other clinical groups	
Personality Inventory for Children	Ages 5–19	275 item questionnaire assessing hyperactivity, conduct disorder, and social problems	<ul style="list-style-type: none"> - completed by the rater who knows the child well 	Can only be administered by psychologist	
Medicine Wheel Tools	K4–Gr 8 First Nations	School-based, staged screening approach incorporating traditional Medicine Wheel	<ul style="list-style-type: none"> - stage 1 teacher administered - quick to administer - culturally appropriate - stage 2 parent involvement 	Not validated. Appropriateness for broader pop. unknown	
FASD Youth Justice Project Manitoba	Youth 12–18 in justice system	Multi-disciplinary assessment w/ behavioural red flags items	<ul style="list-style-type: none"> - concise - relatively effect w/this population 	- not validated	Pilot project showed PPV 60%
FASD Screening Tool Project Saskatchewan	Youth in justice system	Trained raters used 28-item screening tool	<ul style="list-style-type: none"> - broad involvement in selection of factors & scoring system - matched study custody & community file w/clinical sample 	- requires further validation	76% greater chance that an FASD youth to have a higher score .82 reliability coefficient

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Tool	Population	Description	Strengths	Weaknesses	Validity/ Reliability
Checklists/Referral Forms					
Stony Mountain Institution Brief Screen Checklist	Offenders 30 and under— new admissions	BSC included 28 behavioural, plus historical & maternal alcohol use indicators	<ul style="list-style-type: none"> - information collected from multiple sources - found incidence of FASD 10x greater than pop. - BSC items highly correlated with a diagnosis of FASD 	<ul style="list-style-type: none"> - Study needs to be replicated — increase sample size, include women 	From Self-report Scale: 78% sensitive 88% specific 41% PPV 97% NPV
Probation Officer Screening Tool Asante FASD Centre	Youth with probation orders	Groups of personal and environmental indicators for use with a youth justice population	<ul style="list-style-type: none"> - can be administered by frontline workers 	<ul style="list-style-type: none"> - not validated 	
Clinic for Alcohol & Drug Exposed Children (CADEC)	9 mos–12 yrs.	Referral form designating child and family criteria for referral.	<ul style="list-style-type: none"> - program provides training and support to physicians in remote & northern communities 	referrals only from physicians	55.9% PPV
Facial Dysmorphism					
Seattle Foster Care	Children in foster care	Trained case workers took digital photos, interpreted by clinicians; screen for Rank 4 FAS facial features.	<ul style="list-style-type: none"> - non-invasive, quick - measurement software available 	<ul style="list-style-type: none"> - vast majority of FASD children do not have FD; age & ethnic differences can affective results 	100% sensitive 99% specific 86% PPV 100% NPV
Biomarkers					
Meconium	newborns	Biomarker found in newborns' 1 st stool; traces pre-natal exposure to alcohol from 12–14 th week of pregnancy by amt. of FAEE	<ul style="list-style-type: none"> - non-invasive - tested validity & reliability - identifies 2 patients - correlates w/other indicators—LBW, APGAR 	<ul style="list-style-type: none"> - narrow window; must be collected w/in 72 hrs. - misses exposure before 12 wks 	84.2% sensitivity 83.3% specificity

