

Canadian Association of  
Paediatric Health Centres



Association Canadienne des  
Centres de santé pédiatriques

# FASD National Screening Tool Development Project

## WORKSHOP #2 PROCEEDINGS

March 6<sup>th</sup> & 7<sup>th</sup>, 2008



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# 1. Project Overview

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## 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](http://www.cmaj.ca/cgi/reprint/172/5_suppl/S1.pdf). The capacity of diagnostic clinics, however, 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:

- 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; and
- 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 and Proceedings and recommendations were published.
- A one-day Workshop of Frontline Providers was held to review screening tools and methods and to assess the feasibility of implementing these screening methods across the country. Following the Frontline Provider Workshop, a half-day session was held for those participants working in First Nations and Inuit communities. This session was supported and funded by the First Nations and Inuit Health Branch (FNIHB).

These Proceedings describe the outcomes from both the full-day Frontline Provider Workshop and the subsequent half-day session for participants working in First Nations and Inuit communities.

## 1.2 Workshop Goal & Outcomes

On March 6<sup>th</sup> a workshop of Frontline Providers was held at the Sheraton Gateway Hotel, Toronto, Ontario. Participants for this Workshop were frontline providers from a variety of disciplines and sectors, e.g. health, education, social services, youth justice. Please see Appendix: List of Participants.

The Workshop goal was:

- To review screening tools and methods and assess the feasibility of implementing these tools across the country.

These Proceedings summarize the three outcomes designated for the Workshop:

- Outline the advantages & disadvantages of tools and methods discussed
- Assess capacity for screening – gaps and opportunities
- Identify next steps

On March 7<sup>th</sup> by request from First Nations and Inuit organizations, a half-day session was held for those participants working in First Nations and Inuit communities. The purpose was to further explore implementation of screening methods in these communities and to review the Medicine Wheel tools presented by Dr. Lori Vitale Cox. Section 7 provides results of this session.

## 1.3 Method

In preparation for the Workshop, participants were pre-assigned to small discussion groups to review screening tools identified at the October workshop. Participants were assigned to groups based on background and likelihood of using the tool in their work. Groups were assigned as follows:

- Meconium/FAEE
- Youth Justice Screening Tools
- Child Behaviour Checklist (modified)
- Facial Dysmorphology
- Maternal History of Substance Abuse
- The Clinic for Alcohol & Drug Exposed Children – Intake Process

Tools reviewed can be viewed in full on the CAPHC website [www.caphc.org](http://www.caphc.org).

A template was developed to assist participants to rate and evaluate the practical application of screening tools in the following areas:

Component	Rating Scale 1–5
ease of use	very difficult – very easy
accessibility	inaccessible – very accessible
cost	very expensive – inexpensive
expertise	high level of expertise – minimal expertise
cultural appropriateness	very inappropriate – very appropriate
factors to facilitate implementation	
barriers to implementation	

Small groups were led by Steering Committee members. Participants were asked to rate and evaluate the tools from their own perspectives, e.g. as a community physician, as a child and youth worker. Average rating scores in this document are used to provide a very general indication of the practical applicability of these tools. Both positive and negative components of the screening tools are presented from group report-back sessions and in notes from individual participants using the evaluation template. The objective was to describe a wide range of opinions and perspectives, rather than to reach consensus.

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

## 2. Review of Screening Tools and Methods

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### 2.1 Meconium/FAEE

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) are a unique biological marker for fetal exposure to ethanol.

#### General Comments/Consideration

- The test is non-invasive and objective.
- Screening identifies both the mother and child and, therefore, there should be systems in place for care of both.
- Screening should be universal not just for targeted populations.
- Consent for collection must be considered, especially when there are language or cultural barriers.

#### 2.1.1 Ease of Use ..... average rating ‘collector’: 5

- Collection of meconium by primary caregivers (physician, nurse, midwife) is easy — as demonstrated at the workshop; samples are much easier to collect than cord blood, screening questionnaires or venipuncture.
- Lab equipment required is standard, no specialized equipment needed, and analysis is available in any lab with a gas chromatograph.
- Photo and temperature sensitivity necessitates protected collection techniques; this is a larger issue for remote communities requiring multiple transitions and delays.

#### 2.1.2 Accessibility ..... average rating: 2

- Only one lab in Canada is currently processing samples.
- Early hospital discharge should not limit accessibility because infants are not sent home before they pass their first stool.
- Issues were identified with follow-up of mothers, e.g. turnaround time of two weeks for results.
- Sensitivity and care must be considered when providers give follow-up information.
- If the test is anonymous there is no opportunity for follow-up, the results are useful for prevalence data only.

**2.1.3 Cost . . . . . average rating: 4**

- Cost of testing is considered affordable.
- Related costs for shipping and training of staff, e.g. to counsel on results, are not included.

**2.1.4 Expertise . . . . . average rating: 3**

- Expertise required includes:
- Experience/sensitivity to substance abuse issues.
- Consent and disclosure require appropriate training and expertise for providers and interpreters.
- Lab technicians will require training for the testing.
- Understanding and ability to communicate the difference between screening and diagnosis.

**2.1.5 Cultural Appropriateness . . . . . average rating: 5**

- It is an objective test.
- There is a risk of stigmatization of cultural/ethnic groups or communities; screening should be universal.
- Although the test is straightforward, issues of language and culture must be taken into consideration both in describing the test and communicating the results.

**2.1.6 Factors to Facilitate Implementation**

- Learning that there is greater alcohol exposure than self-reported may help providers, society and government recognize the scope of this issue.
- Screening identifies two patients; if alcohol use is found, there is an opportunity to help mother and child.

**2.1.7 Barriers to Implementation**

- Healthcare providers are often overworked and organizations often understaffed; increasing workload may be a challenge.
- Universal screening will require support from provinces/territories.
- The test is limited to detecting alcohol exposure after the first trimester; there may be a false sense of security if a person tests negative.
- Capacity to provide supports to the child and mother identified as at risk is an issue.
- The question of who ‘owns’ the results, especially in custody situations must be addressed.

## 2.2 Youth Justice Screening Tools

Due to time considerations, this work group focused on **The Asante Centre for Fetal Alcohol Syndrome Probation Officer Screening & Referral Form**. *This form is completed for all youth on adjudicated probation orders who reside in the Vancouver Coastal and Fraser Regions who are suspected of having fetal alcohol spectrum disorder.* The tool is a pre-coded questionnaire which collects information on social and neuro-developmental history of the youth as well as the probation officer’s knowledge of the youth and FASD.

### General Comments/Considerations

- The Asante Centre tool holds promise as a quick, easy to administer tool when proper training is provided to youth workers.
- Validation of the tool, e.g. sensitivity and specificity are in progress and results are necessary for its wider implementation.

#### 2.2.1 Ease of Use ..... average rating: 5

- The tool is easy to administer within two to three minutes by trained frontline personnel.

#### 2.2.2 Accessibility ..... average rating: 4

- Ascertaining pre-natal alcohol exposure is difficult for this age group.
- To date, the tool has only been used for pre-sentence referrals.
- The language needs to be simplified.

#### 2.2.3 Cost ..... average rating: 4

- Further testing of the tool in other centres is required to determine validity.
- Time/cost for training frontline providers, must be considered as an integral part of proper administration of the screening tool.

#### 2.2.4 Expertise ..... average rating: 4

- The tool was considered user-friendly, with only initial training required.

#### 2.2.5 Cultural Appropriateness ..... average rating: 4

- It was considered appropriate across many cultures.
- Currently only available in English, it will require translation.
- It may be difficult to translate certain concepts to other languages.

#### 2.2.6 Factors to Facilitate Implementation

- The SAMHSA FASD Center of Excellence (U.S.) has developed and validated a tool and training manual for this population which may be able to assist in the validation of this tool.
- Working with the Saskatchewan Youth Justice Screening Project, FASD Functional Screening Tool, tools can be improved, e.g. the rating scale used in the Saskatchewan Project offers more flexibility to the scorer.

- The results of the recent National Round Table on Youth Justice can be linked to this work to inform the development of tools appropriate to this population.
- The development of a tool for this population can address gaps and inconsistencies across the country.

### 2.2.7 Barriers to Implementation

- Staff may be reluctant to ask about maternal alcohol consumption; and validation of mother’s alcohol consumption may be difficult.
- Securing on-going funding to provide supports particularly in isolated communities is a chronic problem.
- Acquiring necessary training in isolated areas may be a barrier to implementation.

## 2.3 Child Behaviour Checklist (modified)

The Child Behaviour Checklist (CBCL), is a well-established standardized tool for evaluating children’s behavioural problems. Research at the Hospital for Sick Children in Toronto was conducted using the CBCL to determine if a characteristic behavioural phenotype distinguishes children with FASD from control group children. Seven items were identified reflecting hyperactivity, inattention, lying and cheating, lack of guilt, and disobedience which significantly differentiated children with FASD from controls. This information was used to create a screening tool for referral for FASD diagnosis. Workshop participants reviewed and evaluated this modified CBCL for screening purposes.

#### General Comments/Considerations

- The modified CBCL is short, easy to use and ‘portable’; a user’s manual would be beneficial.
- The tool is not inclusive of other brain domains, e.g. executive functioning, memory, abstract thinking.
- Objectivity of criteria for different cultures, values, and settings, presents problems.

#### 2.3.1 Ease of Use ..... average rating: 4

- The tool is short, has specific questions and is portable
- The tool appears easy to use, but requires a interviewer guide to clarify language; many things are open to interpretation; there may be different responses from a teacher and from a parent.

#### 2.3.2 Accessibility ..... average rating: 4

- Requires an informed consent process specific to FASD particularly when information is provided by someone other than the legal guardian.
- Educators would be a source of information and a first step in the process.
- The tool is straightforward to translate.
- Administering the tool face-to-face overcomes literacy issues or problems with understanding.



**2.3.3 Cost . . . . . average rating 5**

- It is inexpensive to administer — low material costs and short time to complete.

**2.3.4 Expertise . . . . . average rating: 3**

- The screening tool can be administered by trained frontline providers.

**2.3.5 Cultural Appropriateness . . . . . average rating: 3**

- Different/modified tools may be required for various age groups and populations.
- Acceptance of certain behaviours varies by culture; expectations of children will also vary depending on the environment — school vs. home; users of the tool will need guidance/direction on these issues.

**2.3.6 Factors to Facilitate Implementation**

- The tool integrates well into other aspects of the diagnostic process.
- This is an excellent tool that would be enhanced by a procedural manual, professional development for those referring children for screening and role clarity regarding the role of the referrer and the role of the screener, as well as the screener’s relationship with the diagnostic clinic.

**2.3.7 Barriers to Implementation**

- It is not clear how this tool will take into account the effects of social stressors and their influence on behaviour, e.g. attachment, multiple placements, environment.

**2.4 Facial Dysmorphology**

The three facial dysmorphic characteristics of children affected with fetal alcohol syndrome (FAS) are philtrum length, 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. Measurement methods included guidelines for manual measurement using a ruler and, alternately, digital photography coupled with measurement software developed by Dr. Susan Astley, Professor of Epidemiology, Director, WA State FAS Diagnostic & Prevention Network, University of Washington.\*

General Comments:

- Suitable only for target populations.
- Measurement can be challenging and influenced by norms used and age.
- Only captures those with full FAS, which is a small percentage of the FASD population.
- Not feasible as a general screening tool, most appropriate as part of the diagnostic process.

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\* <http://depts.washington.edu/fasdpn/htmls/photo-face.htm>

**2.4.1 Ease of Use . . . . . average rating: 3**

Learning to take a proper photograph was considered relatively easy for most professionals; accurately taking manual facial measurements was seen as considerably more difficult:

- Photos can be easily done with training.
- Measurement can be a challenge for eye-hand coordination

**2.4.2 Accessibility . . . . . average rating: 3**

- The tool is objective and digital photos can be transmitted for distance assessment.
- Requires equipment and training which may be difficult to organize outside of a specialized FASD clinical setting.
- It has limited usefulness/accessibility due to a lack of ethnic-specific norms.

**2.4.3 Cost . . . . . average rating: 4**

- Opinion varied on cost.
- Both plastic measuring instrument and software are inexpensive to use.
- Tool is fairly costly because of equipment and time commitment.
- The effort required for measurement will not result in sufficient identification to provide pay-off – cost-benefit.
- The work needed to develop norms for multiple ethnic groups would require considerable effort/resources.

**2.4.4 Expertise . . . . . average rating: 2**

- Considerable expertise/training and good eye/hand coordination is required to measure accurately.
- Requires an expert to read/interpret results and/or specific training to acquire this expertise.
- Interpreter of results must also have training in how to communicate results to patients, families and caregivers.

**2.4.5 Cultural Appropriateness . . . . . average rating: 2**

- It is difficult to assess genetic influences and cultural differences which may affect interpretation of results.
- Currently measurement is based on Caucasian norms.
- Age differences can effect results.

**2.4.6 Factors to Facilitate Implementation**

- The tool could be very useful in a targeted population for identification and screening.
- If the child/youth has the facial features, maternal alcohol use does not have to be confirmed.

**2.4.7 Barriers to Implementation**

- Most individuals affected with FASD are not captured; if health care professionals do not see facial dysmorphic characteristics they may not evaluate further.
- In a country with so many cultures and so many cross-cultural liaisons it may be too difficult to develop norms and/or norms may be less useful.
- This tool cannot be used on its own — perhaps as part of a screening package.
- Judgment on facial features could be used to label individuals.
- Features begin to fade as youth become adults.
- Typically a method used for diagnosis is not considered appropriate for a screening process.

**2.5 Maternal History of Substance Abuse**

This work group evaluated the feasibility of using maternal history of substance abuse (alcohol and other drugs) as a screening criterion, based on the following assumptions:

- If mother has had other substance abuse problems, then mostly likely she also has abused alcohol.
- If mother has an alcohol abuse problem, then most likely she consumed alcohol while pregnant.

General Comments/Considerations

- Consensus was reached on the definition of substance abuse, i.e. problem substance abuse as defined by misuse or abuse.
- In addition to identifying children through the screening process, there are implications for mothers — these can be positive, with the proper supports/environment, or negative resulting in stigmatization and isolation.
- Although the benefits of screening are clear, families must be ready to take in and use this information.

**2.5.1 Ease of Use: ..... average rating: 3**

Ease of use is dependent on a number of factors:

- How and from whom knowledge is received, e.g. friend, family member, neighbour.
- People differ in their judgement of what constitutes alcohol and drug abuse.
- Discomfort/ethical issues may arise for some service providers to ask history question.

**2.5.2 Accessibility ..... average rating: 3**

- It may be easier in smaller communities to get information on maternal drinking; but there may be more likelihood of stigmatization in small communities.
- Multiple sources of information can help validate information received.
- Fear of repercussions for the mother and child may influence responses; the question must come from supportive counsellor prepared to assist and involve mother in planning.
- Who will collect the information and the legalities of collection must be considered.

### 2.5.3 Cost ..... average rating: 4

- It is relatively cost-effective to ask the mother; a question can be added to existing intake and other questionnaires used by professionals.
- Training for professionals on how to ask the question and interpret the results could have considerable additional cost.
- Once substance abuse issues are identified there are costs connected with providing services to the mother.

### 2.5.4 Expertise ..... average rating: 2

Some participants felt that a high level of expertise is required to obtain reliable information from mothers, e.g.:

- Specialty/expertise in addictions, and/or
- Health, social services professionals with additional training on substance abuse.
- Ability to make clinical judgements and interpret responses.

While others indicated that

- With training, frontline providers could ask the question, e.g. community workers, physicians.
- A compassionate and understanding community member — e.g. elder, could pose the question in some circumstances.

### 2.5.5 Cultural Appropriateness ..... average rating 3

- Community readiness is an issue, e.g.:
  - Some physicians still promoting one drink per day.
  - Making this issue more public, may create rift in the community and avoidance of community services.
- Question can be adapted to many languages and cultures; care must be taken in translating concepts to other cultures.
- Cultural bias can be problematic, e.g. routinely asking aboriginal women and not others.
- Extreme care must be taken re: cultural needs in training and cultural stereotyping avoided.
- Variation in understanding of alcohol use, e.g. beer or wine vs. ‘hard liquor’ should be addressed.

### 2.5.6 Factors to Facilitate Implementation

- A reporting body is needed to record and keep track of the numbers who have been screened and who are awaiting diagnosis.
- Identification provides an opportunity to assist the mother in a supportive environment, e.g. Motherisk, First Steps.

### 2.5.7 Barriers to Implementation

- Custody of the child may be in question, which may prevent disclosure.
- Maintaining confidentiality in smaller communities may be challenging.



# 3. Diagnostic Clinic – Intake Procedure

The interface between community providers and diagnostic clinics is essential for implementation of screening processes. The Clinic for Alcohol & Drug Exposed Children Intake Procedure was selected as an example to illustrate the strengths and challenges which are encountered by both referring providers and clinics in identifying, referring and assessing children at risk for FASD.

**3.1 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. Like many diagnostic clinics across the country, CADEC receives referrals from a wide range of providers and sources in the community and has an intake process for responding to referrals. This process is based on best known practices; pre-natal exposure to alcohol and neuro-developmental problems are the primary conditions for referral for assessment. Workshop participants discussed this intake process from their perspectives as frontline providers making referrals. The Intake Coordinator for CADEC led the discussion group and provided the Clinic perspective.

### General Comments/Consideration

- Capacity is challenged by wait lists and access in remote areas.
- Referring providers require expertise and sensitivity to family conditions and readiness.
- Identification of at risk children requires case management and community supports to assist families immediately and avoid stigmatization.
- Collection of information from multiple sources and ownership of information present challenges.

**3.1.1 Ease of Use . . . . . average rating: 3**

- The referral/intake process is straightforward, but requires an experienced and knowledgeable individual; further screening is required before assessment.
- Supports need to be in place while a child is wait-listed.
- The process to gather information from multiple sources is time consuming.

**3.1.2 Accessibility . . . . . average rating: 2**

- The process requires culturally competent individuals and interpreters.
- Health care providers need both electronic and paper access to the intake process.
- Long wait times between referral and intake can have negative effects on child and family, e.g. stigmatization particularly for those in remote areas/small communities.
- It may be difficult to acquire information on mother’s alcohol use during pregnancy for children in care.
- For children in care this information may impact on re-unification of the family.

**3.1.3 Costs . . . . . average rating: 2**

- Increased identification is associated with increased need for follow up resources.
- Resources are already rationed and wait lists too long.
- Society must recognize that the cost of early identification and treatment will result in long-term cost savings.

**3.1.4 Expertise . . . . . average rating: 2**

- Those making referrals to CADEC for intake:
- A high level of knowledge and expertise in growth and development, women’s issues, family functioning, etc. is required.
- Family readiness to accept and deal with potential issues and fall-out must be addressed.
- The intake process must include sensitivity to issues of domestic violence, individual circumstances, trauma etc. to ensure that it is in the best interest of the child to proceed with the assessment.

**3.1.5 Cultural Appropriateness . . . . . average rating: 3**

- Requires culturally competent individuals and interpreters who know the family and can help them through the entire process.

**3.1.6 Factors to Facilitate Implementation**

- There should be clarity around who ‘owns’ the screening and diagnostic results.
- Support and follow-up issues are paramount; a case management approach where all services are coordinated with the family by a designated provider will work well.

**3.1.7 Barriers to Implementation**

- Everyone in the system is overworked.
- Multiple tools for multiple issues may be overwhelming.
- Identification leads to need for more resources and access to the system of supports and services.
- Family readiness for diagnosis and intervention must be considered; despite benefits of early diagnosis and treatment, families may not be ready to accept/deal with identification.

## 4. Opportunities

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Participants discussed and identified opportunities for promoting and implementing screening strategies across the country. These ranged from infrastructure improvements to raising awareness and knowledge of FASD. The importance of promoting FASD screening within the cultural context of the community was stressed.

### 4.1 Infrastructure Improvements

- Establish one secretariat at a national level.
- Improve internal structures to support primary prevention strategies (not enough to say ‘don’t drink’).
- Screening will require greater capacity for diagnosis — increase the number of centres
- Add FASD and/or alcohol-exposed code to ICD-10.
- Produce objective data — much data exists, but staff are too overworked to evaluate and publish.
- Collect all data from across Canada and make it available through vital statistics.

### 4.2 Buy-in/Awareness

- Develop a community strategy and identify community leaders.
- Identify champions in each sector.
- Target trial lawyer associations — they need to make petitions on behalf of the individual.
- Elicit political buy-in for research, e.g. Asante Centre and BC government support for Probation Officer snapshot survey.

### 4.3 Capacity

- Evaluate what is needed to support families including cultural aspect and mandatory staff training.
- Screening will bring awareness of prevalence which will support advocacy efforts for diagnostic and other services.

### 4.4 Targeting

- Ensure all women are targeted from all economic backgrounds; show that this is not just an aboriginal issue.
- Develop wait list criteria for screening and assessment; objective tools are available in other areas.
- Do outreach to sexually active students.
- Educate men — identify FASD as a society-wide issue.

## 5. Gaps

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Gaps identified focused on two major areas: readiness to accept FASD screening and issues with time-limited, unsecured funding to address FASD consistently and effectively. These issues are echoed in the First Nations and Inuit session described in section 7.

### 5.1 Readiness

There are regional differences in level of readiness to accept FASD screening for both families and communities.

### 5.2 Funding and Capacity

- Intermittent, project-funding which is time-limited allows initiatives to begin but not continue.
- Interim supports between screening and diagnosis are essential for individuals who have been screened.
- With limited diagnostic capacity and long waiting lists, screening runs the risk of becoming a diagnostic tool; frontline workers must be educated on why to screen, how to use and interpret screening information.

## 6. Next Steps

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Participants considered what their next steps will be after this workshop. They were energized by the ideas discussed and identified definitive steps to raise awareness and promote FASD screening including: research efforts, advocacy, collaborative efforts and education, and national planning.

### 6.1 Research

- Inform other medical researchers about the link between alcohol and brain damage.
- Initiate a snapshot survey of probation officers similar to BC.
- Develop a care map to better understand the complexity of issues associated with screening tools.
- Hold another meeting in another year around diagnosis and standardization.

### 6.2 Comprehensive Care

- Maintain a cradle (and before) to grave approach and look at breaking the cycle for FASD children; screening is a snapshot along the way.

## 6.3 Collaboration

- Make contact with the diagnostic clinic and other agencies dealing with FASD families and find ways to advocate for services together.
- Screening must involve all sectors including health, social services, recreation; will begin with bringing the message to midwives.
- Those at risk for FASD are at risk for other problems as well; it is necessary to work collaboratively to identify why women drink while they're pregnant.
- With others in the field, look into the possibility for a national advocacy process; work within territorial governments and provinces to make changes.

## 6.4 Education and Awareness

- Through existing connections [to providers and services] stress the importance of the context for screening — who, why and how.
- Bring back knowledge and skills learned to the community.
- Demonstrate to the community that what appear to be competing issues, e.g. AIDS, diabetes, have the same goals.
- Nunavut is government by consensus — so will speak to MLA, Ministers of Health and Justice, the media.

## 6.5 Building on What Exists

- Examine what can be built into the Public Health strategic plan to support longer term initiatives that are coordinated with existing initiatives.
- Acknowledge the work to date and have a broader perspective; find ways to build on, enhance and share successes.
- Keep the momentum going, look at sexual health education guidelines and how to integrate FASD.

# 7. First Nations and Inuit Session

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## 7.1 Goals for the Day

Participants were asked to identify their goals for the Workshop session which included networking and listening, further discussion and refinement of screening methods discussed the previous day, discussion of the Medicine Wheel approach, and raising awareness of FASD. The group wished to focus on specific populations while also examining broader opportunities and implications for screening.

Based on this input and time limitations, priorities for the session were agreed upon:

- Review of Medicine Wheel approach and tools
- Explore raising awareness in the population
  - working within limits
  - getting funding support

## 7.2 Medicine Wheel Tools

The Medicine Wheel tools present a holistic approach to screening based on an understanding and respect for the relationship between all things. This set of tools was developed by Dr. Lori Vitale Cox, the Eastern Door Centre and Elsipogtog First Nation<sup>‡</sup>. Dr. Vitale Cox showed a video of the use of the Medicine Wheel tools in a Mi'gmaq community school.

- The Medicine Wheel is a whole system, community approach. When major behaviour and school performance issues were identified in the school, the first step was to institute a hot lunch program which received funding through Feed the Children.
- This was followed by a number of interventions to increase school performance and address behaviour issues. The decision was made to track children's progress pre and post interventions, e.g. reading levels, to provide evidence for funding.
- As part of this process, a comprehensive screening program was initiated in the school — all children were screened using the Medicine Wheel tools.
- If the screen identified multiple problems, additional help was provided to the student using a para-professional model. The school did not wait for a diagnosis to act.
- The next stage involves parents as partners and collaborators in identification of the child's problem and finding solutions to address these. A professional external to the school staff interviews and gathers information from the parent and explores alcohol use during pregnancy. Supports are provided to the parent to help her realize her personal goals.

### 7.2.1 Ease of use ..... average rating 4

- The tools appear easy to use and are relevant to Inuit and other First Nations cultures.
- Tools are adaptable, it is possible to select components and choose what is suitable for the individual or community.

### 7.2.2 Accessibility ..... average rating 4

- The tools are accessible, but require translation.
- They are completed by teachers who know the child well.
- Tools are not available for high school students or young adults.
- Tailoring tools and making them accessible to different communities will be a challenge.

### 7.2.3 Cost ..... average rating 4

- The cost of ignoring the child is greater than the cost delivering services.
- Teachers will require training; in northern communities where school attendance may be low and teacher turnover high, training costs could be considerable.
- Measures need to be taken to make staff retention a priority; including training community members.

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<sup>‡</sup> Dr. Lori Vitale Cox, Elsipogtog First Nation – Permission to use as needed granted to all except for profit – for more information [www.nogemag.ca](http://www.nogemag.ca)



- The cost of living, in general, is very high in the North, making any initiative/program more expensive to achieve.
- Roll-out on a national level would be extremely complicated and expensive.
- Materials are inexpensive, but implementation would require time for resource teachers and clinicians to administer the tools, and a shift from traditional testing to a wider collection of information, goal setting and direct service provision for the children.

#### **7.2.4 Expertise ..... average rating 2**

- In the North access to professional expertise is limited; it will be important to build on and encourage the expertise within communities, e.g. teachers, community health workers, parents, guardians, special education consultants, elders, and children and youth.
- Considerable professional expertise is required as well as convincing these professionals to embrace the holistic ‘two-eyed’ approach to assessment.
- The tools provide an opportunity for parents to contribute to the assessment of their children; however it also requires a psychologist/social worker with the skills to assess and work with the parent.
- Expertise/leadership is necessary to coordinate and sustain the program.
- Implementation and effectiveness is dependent upon skills and fundamental beliefs/philosophy of many individuals being in sync.

#### **7.2.5 Cultural Appropriateness ..... average rating 4**

- The cultural context of the Medicine Wheel tools is relevant for an Inuit population. The tools require translation and it may be difficult to translate the Medicine Wheel concept into a single symbol.
- The Medicine Wheel concept will be accepted in many communities both First Nations and non-First Nations, but some communities may resist this approach and bias/prejudice may be encountered.
- Although much of the Medicine Wheel materials will be useable immediately, it may be a challenge to involve the community and value their input, if the program/tools are already developed, i.e. the process of developing the tools is as important as the tools themselves.

#### **7.2.6 Factors to Facilitate Implementation**

- A strength of the tools is the evaluation process which provides outcome data (before and after measures) of the child’s progress.
- The tools can be applied universally in any school setting; an opportunity for a process developed for a First Nations population to be generalized to the Canadian population as a whole.
- There is an opportunity through FNIHB to establish an Inuit focus group to adapt the tools; Dr. Vitale Cox volunteered to assist with this process and stressed that the focus group should include community workers and parents.
- Inuit communities have strong support systems and it should not be difficult to get all parties involved in this process.

- The tools have many positive attributes which would facilitate their implementation as screening tools in First Nations communities, e.g.:
  - can be administered by teachers
  - broad and holistic, and based in historical approaches working within a framework of aboriginal teaching
  - both child and family focused; with an emphasis on a child's gifts
  - explore all areas of need from a determinants of health prospective
  - embody a transformative approach bringing together a number of systems and funding sources
  - provide a mechanism to view the community as an integrated whole — a systems approach rather than an individualistic approach.

### 7.2.7 Barriers to Implementation

- Curricula across the country vary; adaptation of tools to reflect different academic standards may be a challenge.
- Social norms are different in Inuit communities – going to school may not be as important culturally as staying home or learning traditional skills; grades may hold little importance.
- Diagnostic capacity is virtually non-existent in most northern Inuit communities.
- Some territorial governments may not wish to address FASD and related issues.
- It may be difficult to achieve buy-in from different levels of government and different sectors.
- The socio-cultural specific needs of Inuit must be recognized. Frequently programs developed for wide implementation are difficult to adapt to Inuit culture with little or no resources/capacity to make these adaptations.
- In First Nations communities as well access to assessment and diagnostic services is very limited; it may be difficult to assess all children.
- Mainstream systems are not working for First Nations populations; ways must be found to bring together the health and education sectors.
- Within First Nations communities there is a legacy of psychological inferiority; highly skilled personnel from First Nations communities often 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.

## 7.3 Raising Awareness

Participants were asked to consider strategies to raise awareness of FASD. Raising awareness was considered within the context of families, communities, government and the general public.

### 7.3.1 Working within Limits and Constraints

Participants described the limits and challenges they face in initiated and maintaining strategies and programs to address FASD.

In both northern Inuit communities and First Nations communities, those involved in prevention, treatment and support services for individuals with FASD and their families work within a number of limits/constraints. These include:

- Lack of and/or time limited government support for FASD awareness and programming.
- A virtual absence of screening and diagnosis services and limited support services.
- The negative impact on communities and providers when programs and/or awareness initiatives are briefly funded and suspended.
- Lack of FASD coordinators in certain regions.
- In eastern Canada, lack of consistent buy-in from the medical establishment for FASD awareness and prevention; as well in the general public the ‘shame and blame’ attitude persists and readiness to address issues is lagging behind other regions.

Despite these limitations, communities have accomplished a great deal. In the West, particularly British Columbia and Manitoba, there are more training and educational opportunities for professionals working in the FASD field. In these provinces, FASD education is part of the high school curricula.

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. Awareness strategies identified were targeted to either the community or individuals, some were primary prevention approaches and others related to identification, care and support for those with FASD and/or mothers consuming alcohol during pregnancy. Lastly, approaches to elicit support from government funders were outlined.

### **7.3.2 Community Awareness Strategies**

- Address the issues of alcohol consumption during pregnancy with vendors and servers of alcohol beverages; advocate for warning labels on beverages.
- Make presentations at conferences, e.g. provincial justice conference that engaged educators and correctional officers.
- Engage those affected by FASD to communicate messages to the public, e.g. a play developed and performed by girls with FASD.
- Use local radio and other media to engage the public in dialogue around FASD.
- Set up a focus group to develop Inuit-specific strategies to raise awareness.
- Have a workshop twice a year for those involved in FASD prevention and intervention to brainstorm community awareness strategies.
- Distribute the Medicine Wheel video widely to as many people as possible; have a process to follow-up and gauge uptake.

### 7.3.3 Individual Awareness Strategies

- Focus on the strengths of children and youth and what needs to be done to enrich their environment, e.g. sex education in school to ensure they know the risks; a survey conducted in Nunavut showed that awareness of the risks of alcohol consumption during pregnancy increased after a campaign aimed at children.
- Train frontline providers in how to approach women who may be drinking during pregnancy or are at risk of drinking while pregnant; provide education and training for a harm reduction approach and avoidance of ‘shame and blame’.
- When delivering pre-natal services to families take the opportunity to address FASD.
- Improve doctors’ understanding and ability to address FASD through their medical training.
- Educate lawyers and judges using a screening checklist to raise awareness.

### 7.3.4 Strategies for Funding Support

- Engage community ‘movers and shakers’ to raise awareness and advocate for funding
- Engage a high profile national champion, preferably someone with FASD to advocate and raise awareness.
- Develop a strategy to reach chairs of medical organizations — departments of paediatrics, schools of medicine and paediatric hospitals to elicit support and buy-in.
- Raise awareness within governments on the lifelong costs for those affected by FASD in such a way that they have a clear directive to act.
- Use the Medicine Wheel tools to identify children with special needs and seek funding with Lori Vitale Cox to develop a workplan for all regions.
- In connection with universities in the East, promote opportunities for continuing professional education, similar to British Columbia.
- To provide the evidence needed for government funding, work with universities to explore ways to engage graduate students in analyzing the wealth of data on children and adults affected by FASD, modelling the initiative at University of British Columbia.

## 7.4 Next Steps

Participants described some of the first steps they will take as a result of knowledge and contacts acquired at the workshop.

### 7.4.1 Linkages and Opportunities

Participants will go on to explore linkages and opportunities to promote FASD awareness both in their own communities and across the country:

- Compare the results of the recent Youth Justice Round Table in B.C. with this workshop and re-examine the PHAC strategic plan.
- Approach FASD as a large ‘elephant’ and look for ways for each of us to ‘take a piece’ — CAPHC.
- Elicit funding support through FNIHB for Inuit focus groups as requested.
- Find ways to support the development of awareness raising strategies through PHAC.

- Learn more about what's going on in other Inuit communities and identify opportunities.
- Offer the support to providers and organizations in the East, based on progress made in the West.
- Incorporate what's been learned into own workplan and build more links with other nationally funded programs at the individual and political levels.

#### **7.4.2 Screening Tool Development and Implementation**

- Some participants will proceed and/or continue with developing tools or implementing the Medicine Wheel tools in their own work:
- Meet with a small group within David Livingston Community School, Winnipeg, to look at how to use the Medicine Wheel tools to improve students' achievement levels.
- Incorporate own psychological assessment process into the Medicine Wheel tools for use with the File Hills Qu'Appelle First Nations community.
- Validate the Medicine Wheel tools and develop tools for each of the developmental stages.
- Continue to develop population-specific norms for facial dysmorphology.

#### **7.4.3 Advocacy, Awareness and Education**

Others will continue with advocacy and awareness activities to educate various populations and groups in the prevalence of the problem and the need for screening and related services.

- Develop a wider community strategy [beyond Medicine Wheel tools] which will enable us to look at incidence and prevalence and further develop screening guidelines.
- Provide education sessions for physicians in New Brunswick.
- Conduct a workshop in Nunavut in Inuktitut.
- Continue to promote meconium screening as a tool to estimate the size of the problem and elicit buy-in and reach more paediatricians.

## 8. Summary

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Every effort was made to capture the breadth and depth of the Workshop discussions. The following is a summary of key points which should be viewed within the context of the rich conversations that transpired at the both sessions of the workshop.

### 8.1 Screening Tools and Methods

With the exception of facial dysmorphology as a screening method, the tools reviewed were considered to hold promise for further development and wider-scale implementation.

**8.1.1 Meconium/FAEE Screening** was considered an objective, non-invasive tool suitable for universal application. In addition to identifying both mother and child, if widely implemented, it can provide hard evidence of the prevalence of alcohol exposed children.

Consent, cultural understanding and follow-up of the identified child and mother were seen as challenges.

**Further work required:**

- cost and lab set-up nationally require further consideration
- buy-in for wide-scale implementation: provincial funders, hospitals, professionals, the public

### 8.1.2 Youth Justice Screening Tools

**Asante Centre Probation Officer Screening Form** was highly rated for ease of use, accessibility, cost, expertise needed and cultural appropriateness for use with the youth justice population.

**Further work required:**

- tool requires validation (in progress)
- language and cultural adaptations may be necessary
- buy-in to implement and train providers

Subsequent to the Workshop, Steering Committee members reviewed the Saskatchewan Fetal Alcohol Spectrum Disorders Functional Screening Tool<sup>§</sup>. This comprehensive functional screening tool, which is still in development, was not considered appropriate for inclusion as a recommended tool at this time.

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<sup>§</sup> © Perry, Prediger, Blakley & Pringle-Nelson, 2008. For more information please contact the writers at (306) 655-7804 or [garry.perry@saskatoonhealthregion.ca](mailto:garry.perry@saskatoonhealthregion.ca). It is important to remember that the Functional Screening Tool is still under development (in research phase) and should only be used as part of an assessment process in conjunction with other assessment information. The tool must not be used to make a FASD diagnosis.

**8.1.3 Child Behaviour Checklist (modified)** was rated highly for ease of use, cost and accessibility. A trained frontline provider can easily administer this short questionnaire; a user's manual would be beneficial.

Concerns were raised re: cultural appropriateness, environmental stressors, and age-related developmental factors which could influence a child's score.

**Further work required:**

- validation of tool for different cultural groups and ages/stages of development
- development of a user's manual/guide

**8.1.4 Facial Dysmophology**, at this point, was not recommended as a general population screening tool due to perceived difficulty in measurement and lack of ethnic-specific norms. As well this method does not capture the majority of those at risk for FASD.

**Further work required:**

- development of ethnic-specific norms as part of the diagnostic process and possibly for screening with select target populations

**8.1.5 Maternal History of Substance Abuse** as a screening criterion was considered appropriate as part of the screening process with these considerations:

- Information from family/community member may be biased and may stigmatize communities or individuals, and therefore must be handled with utmost sensitivity and respect.
- Considerable expertise (professional or personal) is required to ask the question with sensitivity.
- Responses may affect custody issues and reporting requirements.
- Readiness and capacity of communities to provide supports to identified mothers and their children must be considered.

**Further work required:**

- research question(s) which can be added to existing questionnaires used by frontline providers

**8.1.6 Medicine Wheel Tools**

The Medicine Wheel approach and tools were considered highly appropriate and adaptable for implementation in other First Nations communities as well as Inuit communities. Some concerns were raised re: teacher training and retention, and different cultural norms, e.g. academic achievement vs. other measures of learning.

**Further work required:**

- validation of the tools
- adaptation/translation of tools
- buy-in from communities and government support for wide implementation

### 8.1.7 Diagnostic Clinics Intake and Screening Tools and Methods

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.

### 8.1.8 Screening Tool Ratings and Recommendations

The following table provides a summary of the average rating scores for the screening tools reviewed and recommendations for inclusion a tool kit of screening tools and methods.

SCREENING TOOL RATINGS FOR APPLICABILITY						
Tool/Method	Ease of Use	Accessi- bility	Cost	Expertise	Culturally Appropriate	Recommended for Screening Tool Kit
<b>Meconium/FAEE</b>	5	2	4	3	5	YES
<b>Asante Centre PO Form</b>	5	4	4	4	4	YES
<b>CBCL modified</b>	4	4	5	3	3	YES
<b>Facial Dysmorphology</b>	3	3	4	2	2	NO
<b>Maternal History criterion</b>	3	3	4	2	3	YES
<b>Medicine Wheel Tool</b>	4	4	4	2	4	YES

#### Component

ease of use

accessibility

cost

expertise

cultural appropriateness

#### Rating Scale 1–5

very difficult – very easy

inaccessible – very accessible

very expensive – inexpensive

high level of expertise – minimal expertise

very inappropriate – very appropriate

## 8.2 Awareness and Implementation Strategies – A blueprint for action

Participants provided many innovative and creative ways to raise awareness of FASD and lay the groundwork for implementation of screening tools and methods across the country. Together these ideas provide a 'blueprint for action' summarized as follows:

### **At the national/provincial/territorial level:**

- Develop a secretariat for the coordination of FASD-related activities.
- Collect data across Canada and make it available in Vital Statistics.
- Coordinate all initiatives on the national level and include in PHAC strategic plan.
- Identify a national champion to advocate and raise awareness.
- Advocate for FASD screening within the context of other child health initiatives and for sustainable long-term funding.
- Address screening and diagnostic capacity and supports within a continuum of care framework.
- Provide data on prevalence and life-long costs in a way that leads to direct action.

### **At the community level:**

- Raise awareness among community leaders and elicit support.
- Engage those affected by FASD in awareness-raising.
- Focus on prevention and education re: effects of alcohol consumption and pregnancy.
- Assess community readiness to address FASD issues.
- Use local media to initiate a public dialogue.
- Support community-wide approaches to screening to ensure they do not single-out or stigmatize individuals or groups.
- Develop forums with community-wide representation to review and adapt screening tools and methods.

### **At the professional level:**

- Target and raise awareness among lawyers and other youth justice professionals.
- Model other projects, e.g. BC Probation Officer snapshot survey; University of British Columbia professional development support.
- Inform medical researchers re: the links between alcohol and brain damage.
- Employ a cross-sectoral approach to bring message to providers in many sectors: health, social services, education, recreation.
- Assess compatibility of screening approaches with para-professional models used in some communities.
- Train frontline providers on how to approach women who may be drinking and in harm reduction strategies.
- Improve physician understanding and ability to address FASD as part of their medical training.

- Develop a strategy to reach chairs of medical organizations — dept’s of paediatrics, schools of medicine and paediatric hospitals to garner support and buy-in.
- Further develop University of British Columbia initiative to engage graduate students in FASD data aggregation and analysis.
- Convene forums for professionals working in FASD and share knowledge and lessons learned; bridge the gap between mainstream and First Nations and Inuit professionals.

## 9. Recommendations

The Steering Committee has carefully reviewed and evaluated the information gathered from the two workshops of researchers in FASD and frontline providers involved in the care and treatment of children and youth with FASD, the review of the literature, and the survey of diagnostic clinics. Based on this wealth of information, the Committee has compiled the following recommendations.

### 9.1 Tool Kit

The Tool Kit which is being recommended was developed using a set of criteria to evaluate the identified tools in terms of sensitivity, specificity, positive and negative predictive values, and for their practical applicability in terms of ease of use, accessibility, cost, expertise required, and cultural appropriateness. A common theme in both workshops was ‘one size does not fit all’. Different ages, stages and settings influence which tool is most appropriate. The Tool Kit provides a number of options to ensure that there are multiple opportunities to screen children and youth for FASD.

RECOMMENDED SCREENING TOOL KIT			
TOOL	TARGET GROUP	SETTING	SECTOR
Meconium FAEE	Newborn	Hospital/home	Health
Child Behaviour Checklist (modified)	6 – 18 yrs.	Multiple	Health, Social Services, Education
Medicine Wheel Tools	4 – 14 yrs.	School	Education
Asante Centre Probation Officer Tool	Youth	Youth Justice System	Justice
Maternal History Criterion	At-risk mothers	Multiple	Health, Social Services

## 9.2 Future Directions – Implementation

The Proceedings from this workshop outline the challenges and opportunities for implementation of screening tools. Buy-in at the provincial, professional and community level will be key to effective implementation of screening processes. The Committee is therefore recommending a staged process to successful implementation of the tools across the country.

**Manual Development:** With the exception of the Medicine Wheel tools, the recommended tools will require detailed procedures manuals to ensure proper use and interpretation of results. Researchers who have developed these tools will need to develop the manuals, and their resource requirements will have to be assessed.

**Introduction & Uptake of the Tool Kit:** A two-stage approach is recommended for introduction and uptake of screening tools and methods.

- **Policy-maker Workshops:** Piloting of the Tool Kit, as a whole, with policy makers and other key stakeholders is recommended to garner support for the screening methods proposed. Workshops will focus on knowledge transfer and elicit buy-in through hands-on ‘testing scenarios’ to illustrate the Kit’s potential for effective screening.
- **Uptake of Specific Tools:** Depending on readiness in different jurisdiction, individual tools will be piloted. Workshops will be held with stakeholders involved in uptake of specific tools, e.g. professionals, local and regional government, children’s health organizations, diagnostic clinics and parents. Again, a hands-on, problem-based approach will be adopted. Results from these pilots, will be used to launch implementation on a larger scale.

**Evaluation:** An evaluative process will be developed to accompany both sets of workshops that will measure the effectiveness of knowledge transfer. This information will be critical for assessing readiness to implement screening tools and methods, and for developing strategies that are appropriate for various settings, sectors, providers and communities.

## Appendix – List of Participants

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### Workshop Day 1:

**Gail Andrew**, MDCM, FRCP(C), Medical Site Lead – Paediatric Rehabilitation, Medical Director FASD Clinical Services, Glenrose Rehabilitation Hospital

**Diane Boswall**, Coordinator, PEI Reproductive Care Program

**Brian Broskie**, Custodial Youth Worker, Kilburn Hall Youth Center, Saskatoon

**Teresa Brown**, Project Coordinator, FASD Youth Justice Program, Manitoba Department of Justice

**Ashley Chafe**, BSW, RSW Social Worker, Child, Youth and Family Services, Corner Brook, Newfoundland Western Health

**Laura Elliott**, FASD Outreach Worker, McMan Youth, Family and Community Services Association Alberta

**Ray Hartley**, Program Manager, PLEA Community Services of BC

**Betty Wiebe Hosein**, Program Counsellor, Interagency FASD Program, Winnipeg, MB

**Mary Hutchings**, Assistant Director, Child and Youth Services, Children's Aid Society of Toronto

**Claudette Landry**, MN RN, Senior Program Advisor, Office of the Chief Medical, Officer of Health, NB Department of Health

**Carolyn A. Lane**, MD, CCFP, FCFP, Assistant Clinical Professor, Department of Family Medicine, University of Calgary

**David Martin**, Consultant, Dept. of Education, Government of Newfoundland and Labrador

**Dave St Amour**, Neuroscientist, CHU Sainte-Justine, QC, Université de Montréal, QC

**Hazel Russell**, MSW, RSW, Social worker, Child, Youth and Family Services, Western Health, Newfoundland Labrador

**Dorothy Schwab**, O.T.Reg.(MB), Occupational Therapist, Clinic for Alcohol and Drug Exposed Children, Community Liaison and Follow-up Worker

**Nancy Taylor**, Early Learning Co-ordinator, English Program Services, Department of Education, Nova Scotia

**Janet Thompson**, Support Teacher, The Winnipeg School Division Special Education Department

**Sharon Wazney-Prendergast**, Social Worker, Clinic for Alcohol and Drug Exposed Children

**Richard Willier**, Aboriginal Youth Probation Specialist for Vancouver, BC Government — Ministry of Children and Family Development

## Workshop Day 1 and 2:

**Geri Bailey**, Interim Manager, Maternal Child Health, Pauktuutit Inuit Women of Canada

**Winnie Banfield**, FASD/ECD Coordinator Health and Social Services, Government of Nunavut

**Sarah Carriere**, Project Coordinator, Inuit Tapiriit Kanatami

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

**Lori Vitale Cox**, Educational Psychology Coordinator, Eastern Door Centre

**Elizabeth Dawson**, Nurse Specialist Early Childhood Development, Labrador Health Secretariat, First Nations & Inuit Health, Health Canada

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

**Marilyn Gosselin**, Registered Psychologist

**Phat Ha**, Policy Analyst, Public Health, Health and Social Secretariat Assembly of First Nations

**Bessie Hagen**, FASD Mentor Trainee for Tuktoyaktuk

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

**Gideon Koren**, Professor of Paediatrics, Pharmacology, Pharmacy, Medicine and Medical Genetics, University of Toronto

**Elena Labranche**, Assistant Director of Public Health Department Nunavik Regional Board of Health and Social Services

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

**Jenelle McMillan**, FASD Consultant/Educator/Counsellor “FASD Consulting and Training” affiliated with Hey Way Noqu Healing Circle for Addictions Society

**Doug Maynard**, Associate Director, Canadian Association of Paediatric Health Centres

**Sharon O'Brien**, M'ikmaq Family Resource Centre, PEI

**Elaine Orrbine**, President and CEO, Canadian Association of Paediatric Health Centres

**Carla Pamak**, Mental Health Worker, Nunatsiavut Government, Dept. of Health and Social Development.

# Appendix – List of Participants

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## Workshop Day 1 and 2: (continued)

**Wayne Podmoroff**, PhD, Psychologist, Baffin Correctional Centre Department of Justice Government of Nunavut

**Lois Roberts**, Director, Aboriginal Family Centre, Happy Valley-Goose Bay, Newfoundland and Labrador

**Ted Rosales**, Pediatrician/Geneticist Clinical Professor of Pediatrics MUN, FASD Consultant-NLFASDRC

**Charlotte Rosenbaum**, Charlotte Rosenbaum Consulting Services, FASD Screening Tool Development Project Coordinator

**Gillian Saunders**, FASD Coordinator, Nunatsiavut Dept. of Health & Social Development

**Renata Sharkey**, Health Policy Analyst, FASD Strategic Programming Unit First Nations and Inuit Health Branch, Health Canada

**Bev Wahl**, Principal, David Livingston Community School, Winnipeg