Canadian Association of Paediatric Health Centres

Association Canadienne des Centres de santé pédiatriques

FASD National Screening Tool Development Project

WORKSHOP #2 PROCEEDINGS

March 6th & 7th, 2008

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1. Project Overview

1.1 Project Rationale

On March 1, 2005, the Fetal alcohol spectrum disorder (FASD): Canadian guidelines for diagnosis were published in the *Canadian Medical Association Journal* (CMAJ) **www.cmaj.ca/cgi/reprint/172/5/S1.pdf**. The development of the guidelines were facilitated by the Public Health Agency of Canada and Health Canada.

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 6th 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 7th 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**.

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

2.1 Meconium/FAEE

Meconium begins to form at approximately the 12th–14th week of pregnancy. As the fetus swallows amniotic fluid, prenatal exposure to chemicals can be qunatified 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.