

**Alberta Clinical FASD Stakeholders
Working Group**

**In response to the
Fetal Alcohol Spectrum Disorder (FASD):
Canadian Guidelines for Diagnosis**

November 10, 2005

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Preamble

On March 1, 2005 the Canadian Medical Association Journal (CMAJ) published the document “**Fetal alcohol spectrum disorder: Canadian guidelines for diagnosis**” by Chudley, Conry, Cook, Loock, Rosales, and LeBlanc. This publication was the culmination of a review by a subcommittee of the Public Health Agency of Canada’s National Advisory Committee on Fetal Alcohol Spectrum Disorder. It was presented as “the first Canadian guidelines for the diagnosis of FAS and its related disabilities”.

When any new guideline is developed a host of questions arise. Experts ponder whether the new information is correct. Clinicians ask themselves if their practice needs to change. Health system decision makers ask themselves if their resources and priorities need to change. Other stakeholders such as those involved in guideline development and continuing professional education look to see what impact these guidelines have on their offerings. All are asking what needs to be done next.

This effect is particularly pronounced when, as with FASD in Alberta, a national guideline arrives in an environment with an established provincial guideline, well-developed clinical practices and on-going policy work. The diagnosis of FASD is a complex question and involves systemic challenges beyond the scope of any single clinician. It was quickly recognized that it was critical for Alberta clinicians to react and, if necessary, change in a coordinated fashion.

To that end, a group of key Alberta clinical stakeholders assembled to help shape a common response (membership attached in Appendix 1). These were clinicians and organizations with a special expertise and interest in FASD. At a meeting on May 9, 2005, that group determined that a response was desirable and appointed a subgroup to draft their collective response. The response was developed by successive iterations. First a sample of individuals was interviewed and a tentative draft response developed. That response was revised in a facilitated subgroup meeting on September 16, 2005 and then further refined by email review. Finally, it was submitted to the larger committee for approval.

This document is that response. It contains the collective response of key Alberta clinicians, developed by consensus, to inform both clinicians and policy makers concerning the impact of the Canadian guidelines and how best to proceed in Alberta. It is structured as responses to the key questions raised by and for each “audience.”

We trust that you will find this information useful.

Feedback to Alberta clinicians
Re: Canadian guidelines for diagnosis of FASD

How do the Canadian guidelines for diagnosis of Fetal Alcohol Spectrum Disorder (FASD) affect my practice?

The Alberta Clinical FASD Working Group recommends the following:

- **Use the Canadian guidelines for awareness and screening** - Fetal Alcohol Spectrum Disorder (FASD) continues to be a challenging and complex medical condition. The Canadian guidelines expand on the current Alberta Guidelines (based on the Institute of Medicine 1999 criteria) in that it provides some additional details and references to the current literature. The Canadian guidelines are recommended as an education resource for interested clinicians to raise awareness and improve screening for FASD.
- **Refer for diagnosis** - As reiterated by the Canadian guidelines, patients should be referred for diagnosis to clinicians with specific training and multidisciplinary resources. The working group continues to support the use of the Diagnostic Prevention Network (DPN) tool as the method of choice for these specialized teams in Alberta.
- **Refer for functional assessment** – If possible, patients should also be referred for a multidisciplinary functional assessment either as part of the diagnostic assessment or upon receiving a diagnosis of FASD. This assessment serves to determine the specific services needed by that patient.
- **Be aware of changing presentation** - Clinicians are reminded that presentation and function related to FASD changes over the lifespan of the patient. A negative diagnosis at an early age does not preclude a diagnosis at a later age. Likewise, improved functioning at a later age does not negate a previous, properly-informed diagnosis.
- **Be cautious if investigating maternal alcohol consumption** - Clinicians are also reminded that there are significant risks related to asking birth mothers about maternal ingestion of alcohol. These questions may trigger depression, relapse in addiction and even suicide. Clinicians are directed to the Alberta guidelines for information on how to investigate and how to follow up with mothers at risk. Clinicians are also reminded of the importance of screening for alcohol use in the prevention of FASD.
- **Be cautious in use of physical markers** - The Canadian guidelines provide a thorough and lengthy review of FASD's physical characteristics. However, clinicians are reminded that the guideline maintains that brain function is the key to an accurate diagnosis of FASD. Presence or absence of physical characteristics, while potentially indicative, is not determinative of a diagnosis.

**Feedback to the Alberta Policy Makers
Re: Canadian guidelines for diagnosis of FASD**

How does the arrival of Canadian guidelines for diagnosis of FASD affect the functioning of the Alberta health system in diagnosis of FASD?

The Canadian guidelines reinforce Alberta's excellent standard of practice and the need for further resources. The Alberta Clinical FASD working group makes the following observations:

- **Alberta is on track** - Although the Canadian guidelines provide some clarification and expansion they reiterate and reinforce the basic points established by the Alberta guidelines based on 1999 Institute of Medicine criteria.
 - Practice in Alberta has since improved beyond both its own guidelines and the new Canadian guidelines. The clinical expertise generated in Alberta since the development of the original Alberta guidelines can and should be tapped to further enhance the Alberta guidelines.
- **Continued need for specialized, multidisciplinary teams for diagnosis** - The Canadian guidelines reinforce the Alberta approach of specialized and multidisciplinary diagnosis.
 - As per the Canadian guidelines, the Alberta Clinical FASD working group continues to support the importance of a multidisciplinary approach to diagnosis and assessment and continues to stand behind the strong recommendations for capacity improvements.
 - As per the Canadian guidelines, the Alberta Clinical FASD working group continues to support the importance of a rigorous diagnosis made by specialized, trained clinicians with supporting resources. Clinicians without enhanced training and non-clinicians should refrain from diagnosis and refer to advanced practitioners.
 - Although not specifically addressed by the Canadian guidelines, the Alberta Clinical FASD working group recommends that these advanced practitioners continue to use the Diagnostic Prevention Network (DPN) tool as the method to develop the information required for a diagnosis of FASD.
- **Common language** - Consistent with the Canadian guidelines, the Alberta Clinical FASD working group continues to use and support the term "Fetal Alcohol Spectrum Disorder (FASD)" as the umbrella term for this related set of diagnoses.
- **A lifetime risk** - Although this area was not addressed by the Canadian guidelines, the Alberta Clinical FASD working group reminds decision makers that presentation and function related to FASD differ over the lifespan of the patient. A negative diagnosis at an early age does not preclude a diagnosis at a later age. Likewise, improved functioning at a later age does not negate a previous, properly-informed diagnosis.

Next Steps for Alberta Re: Diagnosis of FASD

What should Alberta stakeholders do next to improve the diagnosis of FASD?

In the view of the Alberta Clinical FASD working group the arrival of the Canadian guidelines represents an opportunity to re-examine Alberta's clinical experience and make further improvements. The working group recommends the following:

1. **Maintain the gains** - All stakeholders should continue to support the fundamental principles originally expressed by the Alberta CPG and now reinforced by the Canadian guidelines.
2. **Review and update** - With Alberta's wealth of experience it is possible to go beyond the existing guidelines (both provincial and national) and establish new and better tools. Relevant organizations responsible for Alberta's guidelines (such as the Toward Optimized Practice (TOP) program) should update the Alberta guidelines. In doing so, the working group recommends the following:
 - Guidelines should look to a broader group of professionals beyond the traditional focus on physicians
 - As much as possible, guideline development should be conducted in communication with, or in the context of, provincial government cross-ministry initiatives and initiatives with other provinces
 - The guidelines should address the challenges of investigating maternal ingestion of alcohol and other substances
 - The guidelines should address the specifics of the special training and multidisciplinary resources required for diagnosis of FASD
 - The resulting changes to the Alberta Guidelines should be disseminated to Alberta clinicians.
3. **Encourage clinical education** - Organizations and groups involved in continuing medical education and continuing professional education should address the need for further information about the appropriate approach to diagnosis of FASD.
4. **Address non-clinician investigation/diagnosis** – The Alberta Clinical FASD working group acknowledges the importance of identifying FASD in education, justice, social services and other agencies in order to provide affected individuals with appropriate support. However, the working group respectfully raises significant concerns about the trend for non-clinical “diagnosis” and maternal ingestion investigation. Clinical experience has shown three significant risks:
 - Misdiagnosis (both over and under diagnosis) resulting in either missed supports or pejorative and damaging labeling
 - Harm to mothers as a result of the investigation, up to and including suicide
 - Initial maternal denial motivated by fear of consequences impairing later clinical investigation and diagnosis.

The working group recognizes the practical challenges of access to the right clinical resources, but urges all stakeholders and especially the Alberta FASD Cross-Ministry Committee to do everything in its power to minimize non-clinical investigation / diagnosis and the associated risks.

Noted Policy Issues for the Cross-Ministry Committee on FASD

The Alberta Clinical FASD working group acknowledges that the development of FASD policy is outside of their mandate. It is further noted that the Alberta FASD Cross-Ministry Committee is working in this area. However, the review of the Canadian FASD diagnostic guidelines, like any discussion of FASD care, illuminated a number of policy issues. In the interest of supporting policy development, the working group recorded issues that arose and provides them here for the consideration of policy makers. However, it should be noted that this list is not exhaustive.

Policy issues identified are as follows:

Resources

- In general, examine the need to provide more and sustainable funding for diagnosis, support and analysis of the needs of FASD patients and families.

FASD Diagnosis

- Examine the need to train and implement more specialized teams across the province
- Examine how to intervene early with FASD patients to prevent or reduce secondary dysfunction
- Examine and support recommendations forthcoming from this working group regarding avoidance of over-diagnosis and using the correct resources for diagnosis and information gathering
- Examine the different challenges for access to diagnosis and follow-up based on rural vs. urban and children vs. adults

FASD Support

- Recognize the need for ongoing support as a requirement for individuals with FASD including the importance of links to community services
- Increase community capacity to support FASD patients and caregivers
- Summarize and communicate learnings from parents/caregivers on how to address the needs of individuals with FASD

FASD Analysis

- Determine how individuals diagnosed with FASD are doing, what works in terms of treatment and supports, and what we can learn about how they progress
- Examine the need for targeted funds to address FASD prevention, diagnosis, treatment and support
- Determine the most critical areas of need and then examine the current provincial focus for FASD to determine if it is addressing these areas (e.g. high-risk mothers; transition to adulthood, cultural sensitivity)
- Determine how the information on individuals with FASD is used, communicated and shared to ensure privacy issues are addressed

**Recommendations to the Public Health Agency of Canada
Re: Canadian guidelines for diagnosis of FASD**

How can Alberta's experience and expertise further assist the development of a national response to the challenges of FASD?

In the experience of the Alberta Clinical FASD working group, guidelines are a necessary and valuable step but just a first step in the development of an effective system for the diagnosis of FASD. Alberta's successes to date come as a result of a program of education and training based on the Alberta Clinical Practice guidelines and the application of resources to deliver the needed services. For this reason, the working group urges the Public Health Agency of Canada to:

- Foster the development and delivery of education and training in the diagnosis of FASD using the Canadian guidelines.
- Develop a mechanism to maintain the Canadian guidelines. Specifically a review and update should occur within five years time.