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Summary Report

National Forum on the FASD Diagnostic Guidelines

Hosted by: the Canadian Centre on Substance Abuse Ottawa,
March 8 and 9, 2005



Canada

The opinions expressed in this paper are those of the authors and do not necessarily represent those of their affiliations or the Public Health Agency of Canada.

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Public Health Agency of Canada

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Executive Summary

The purpose of the National Forum on the FASD (fetal alcohol spectrum disorder) Diagnostic Guidelines was to identify next steps for the Guidelines, especially in the area of training supports required and ideas for a national data collection system. Participants strongly supported the process of Guidelines development, for the potential that the Guidelines hold for standardized diagnosis across Canada and for the development of a national data collection system that will eventually describe the incidence and prevalence of FASD in Canada.

Participants encouraged national leadership and coordination on the Guidelines as the dissemination plan is formulated and implemented across Canada. They also noted that many issues need to be addressed for the Guidelines to be fully accepted and used.

Participants raised several key issues in the large group discussions, distinct from the main themes of the Forum. Several expressed the need to ensure quality of life for those who have FASD and those who support them. They indicated that quality of life can be compromised for those with FASD and that sometimes this reality is overlooked or forgotten in discussions. Participants alluded to the lack of diagnostic capacity, especially in smaller areas, the dilemma of obtaining a diagnosis and then not having supports available, and the ongoing difficulty of not receiving supports in general, particularly for families that are overwhelmed with caring for persons with FASD.

Other participants noted the lack of diagnostic capacity for adults and the great need for ensuring that diagnosis efforts are not limited to the young. In addition, they noted that if diagnosis is not made early on, secondary disabilities that emerge during early adulthood can cause major difficulties.

With regard to acceptance of the Guidelines within different disciplines, participants stated that particular attention needs to be paid to how the Guidelines are disseminated to the addiction treatment/intervention workforce. It is critical that this group of professionals/paraprofessionals receive training that addresses their role vis-à-vis diagnosis. Next steps must include training supports designed to ensure that those using the Guidelines have all the knowledge and skills necessary to use them most effectively.

Participants also identified the need to validate the Guidelines with various cultural groups.

Several participants urged that the Guidelines be viewed as a living document: that a process be put in place to ensure they remain current, and that they reflect the best practices and knowledge available as the field matures and learns from its experience. It is important that the responsibility for ensuring this be vested in a specific organization, or else it will not occur.

There is a need to ensure ongoing validation of the Guidelines, including a process to collect data/evidence to demonstrate that the Guidelines are being used for their intended purposes and expected results.

Although the Forum did not address in any detail the needs and concerns of affected individuals and families, several participants recognized that it is vitally important to remember these constituents in any dissemination activity. They urged the Canadian Centre on Substance Abuse and the Public Health Agency of Canada to keep families and community support “top-of-mind” in considering next steps.

Finally, the issue of leadership for next steps arose many times during the Forum, at times solicited through discussion and at other times through spontaneous comments.

Participants agreed that national leadership for dissemination is critical. Many concurred that the CCSA mandate is compatible with leading dissemination and bringing partners to the table that have complementary roles to support various aspects of dissemination. The goal of dissemination is to ensure the greatest likelihood of uptake across the country, along with training and data collection.

The top five priorities that emerged from the Forum were:

1. Disseminate the Guidelines and progress to professional and non-professional groups.
2. Develop, establish, implement, evaluate and maintain standardized training.
3. Create and obtain funding.
4. Establish universal access to improve/maintain/sustain expertise in all provinces/territories/First Nations/Inuit/Métis.
5. Establish data collection concurrent with the dissemination of the Guidelines.

Participants confirmed that the event was a good use of time, that the process was productive and that what remained was to turn ideas into action as quickly as possible.



1 Introduction

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This report provides a summary of the presentations and group discussion during the National Forum on the FASD (fetal alcohol spectrum disorder) Diagnostic Guidelines in Ottawa on March 8 and 9, 2005. The Canadian Centre on Substance Abuse (CCSA) hosted this workshop in partnership with the Public Health Agency of Canada (PHAC). It occurred in conjunction with the release of the Diagnostic Guidelines in the *Canadian Medical Association Journal* (CMAJ) on March 1, 2005.

The release of the Guidelines was preceded by an extensive series of consultations, meetings and deliberations that occurred under the leadership and funding of Health Canada and PHAC. The consultation process was led by the National Advisory Committee's Sub-Committee on Screening, Diagnosis and Surveillance.

The Forum represented the culmination of several years' work to develop the Guidelines and make them available on a national basis. PHAC facilitated the initial dissemination of the Guidelines, which were sent out to more than 60,000 partners and stakeholders, including through the CMAJ and its own distribution network.

1.1 Context and Purpose

The purpose of the Forum was to identify critical next steps in relation to the Guidelines, including:

- appropriate supports required through identified training needs and channels
- a system for national data collection

The Forum included a mix of formal presentations and structured small group discussions, followed by the summation of results in large group with the opportunity for comment and reaction. The agenda can be found in Appendix A.

This event was planned and implemented within a very short time frame so it could coincide with the release of the Guidelines in the CMAJ. There is a strong interest and motivation to support the next steps of dissemination. The 11 diagnostic clinics that exist across Canada, which assisted in the development of the Guidelines, are a key part of the next steps.

It is important to note that the Guidelines are intended as a roadmap for diagnosis, as opposed to a strict standard for diagnostic teams to follow. A certain degree of flexibility in interpretation and use is encouraged.

1.2 In Attendance

Seventy-eight participants were invited to the workshop; 52 attended. They included physicians, psychologists, pediatricians, psychiatrists, federal and provincial government officials or representatives, and non-governmental organization and First Nations representatives. The list of participants can be found in Appendix B.

1.3 About This Report

The purpose of this report is to describe the proceedings by reflecting the substance of the program, including small group discussions and presentations, and summarizing the key points. It is not intended to provide editorial comment, and considerable effort has been made to stay as close as possible to wording used by participants.



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2.1 Opening Remarks

Opening Remarks were provided by Michel Perron, who gave an overview of the CCSA and highlighted its commitment to being an active partner in making the Guidelines available to practitioners across Canada.

2.2 Background on the Development of the Guidelines

Health Canada and PHAC jointly sponsored the activities of the National Advisory Committee (NAC) on FASD. On NAC's recommendation, a Sub-Committee on Screening, Diagnosis and Surveillance was established; one of its main tasks was to develop the Guidelines. The Sub-Committee set up an extensive process of consultation with experts, individuals, agencies and organizations across the country to ensure broad input into the Guidelines development. This occurred over a two-year period.

The entire process is a major accomplishment for practitioners, professionals and every partner who contributed to the process.

Dr. Albert Chudley, member of the NAC on FASD's Sub-Committee on Screening, Diagnosis and Surveillance (see Appendix C for a list of Sub-Committee members), described the historical background on the development of the Guidelines. Dr. Chudley noted that the work on the Guidelines began in 2002 and involved a significant amount of input from constituents across Canada.

The Sub-Committee's first task was to review the diagnostic approaches currently being used in the United States and Canada. Members also reviewed the literature and consulted with clinics and clinicians who were currently providing diagnoses across Canada to discover how they were being made. The need for broad consultation was identified in the early stages and was followed up with a series of meetings across Canada, involving stakeholders, experts (Canadian and American), professional groups and governmental organizations and agencies.

The consultation process revealed that there was inadequate diagnostic capacity in Canada, which resulted in many individuals being denied access to diagnosis. Limited resources and uni-disciplinary diagnoses characterized this inadequacy. Clinical geneticists were reluctant and unequipped to diagnose the full spectrum of the disorder and it was clear that no single diagnostic approach was being used. The consultation also revealed a disparity in diagnostic capacity across the country.

The most common strategies for making a diagnosis were to use the Institute of Medicine (IOM) or University of Washington DPN 4-digit code. However, there was no consensus on a behavioural phenotype and no consistent approach to assessment of the brain or brain domains. The need to recognize the complexity of a diagnosis and clarify a diagnostic process was identified.

As a result of its consultations, observations and deliberations, the Sub-Committee began to formulate a structure for the Guidelines that addressed seven elements:

1. FASD assessment
2. Screening and referral
3. Physical examination and differential diagnoses
4. Neurobehavioural assessment
5. Maternal alcohol history
6. Diagnostic criteria
7. Harmonization of the IOM and DPN 4-digit code

In continuing its work, based on advice from consultations, input and feedback, the Sub-Committee developed a set of Guiding Principles that ensured that there was a common mindset for working together. Dr. Jocelynn Cook, a member of the Sub-Committee, identified the principles:

- to recognize that the complexity of the condition demands a collaborative approach (multi or interdisciplinary)
- that the best approach(es) for diagnosis would be based upon published information and experience of experts
- that the process of guidelines development would seek to clarify ambiguities and develop consensus on approach and process of a diagnosis
- to acknowledge that a diagnosis was not a label, but a blueprint for intervention and prevention of further harms
- that the Guidelines should be published in a respected peer-reviewed journal with broad dissemination

The Guidelines were submitted to the CMAJ in June 2004, accepted with revisions in fall 2004, and published as a special supplement in CMAJ on March 1, 2005. They were accompanied by a three-page article on recognizing FASD in primary care practice, in the same CMAJ issue. The supplement is available in both official languages and on the Internet where the entire journal is posted.

(http://www.cmaj.ca/content/vol172/5_suppl/index.shtml)

2.3 Overview of the Diagnostic Guidelines

Dr. Julianne Conry, member of the NAC on FASD's Sub-Committee on Screening, Diagnosis and Surveillance, provided an overview of the Guidelines and their use. Dr. Conry emphasized that the Guidelines are a tool and a guide (as opposed to a strict prescription) for assessing FASD. They represent an extensive body of knowledge and experience that can begin to move Canada forward in a systematic way to provide much-needed services and supports to persons with FASD. The Guidelines will require ongoing communication among practitioners and clinicians to ensure they are accomplishing what they are intended to, and that information gathered from them can be used to better understand the nature and extent of FASD in Canada.

2.4 Small Group Discussion

Using the initial presentations to stimulate discussion, participants were divided into small groups to identify what the issues were in relation to the Guidelines. The groups were consistent in terms of the issues that were identified. Most of the comments related to one or more key themes: what is needed to move forward, specific comments or questions to clarify aspects of the Guidelines, training and data collection supports, and the importance of engaging stakeholders in implementation.

Several respondents mentioned the need to identify champions that will be able to provide leadership in encouraging others to understand and use the Guidelines. Each province and territory is at its own stage with respect to FASD. It will be important to recognize the range of progress and be able to bring some cohesion to a national approach to diagnosis. Champions (including the 11 diagnostic clinics) can help that happen.

Several comments were made about specific aspects of the Guidelines, in particular:

- the reality that the differential diagnosis piece is missing and needs to be addressed
- that there must be caution in diagnosing FASD where facial features do not exist and whether there is a “brain scan” instrument to compensate for this
- that growth charts need to be updated/more normative in order to move forward
- that the nomenclature/language that is used to identify FAS be further examined, especially around the term pFAS: there was a sense that it is not very useful to describe FAS as “partial”

Participants indicated that as much as diagnosis is needed across the country, the supports for intervention for individuals and families are equally required and must be planned concurrently.

Finally, participants strongly urged that careful consideration be given to the training that is needed for all people who are interested in performing diagnosis.

2.5 Overview of Current Training Initiatives

Dr. Diane Fast, a psychiatrist with the BC Women's and Children's Hospital, described the training program that is by Smartrisk.

Liz Lawryk of the Organic Brain Dysfunction (OBD) Triage Institute in Bragg Creek, Alberta, described the program currently in operation to retrieve and prescreen medical documentation to determine the possibility of FASD and to recommend interventions and support services that are most appropriate for the affected individual and his or her support system. She provided an overview of the OBD Triage Assessment Model, which uses a tool developed by the Institute to screen for teratogenic effects on embryonic development. The Institute also offers specialized training and certification to health professionals in administering the tool.

The presentations were used as a stimulus for small group discussion on training supports. Participants were asked to answer a series of questions intended to shape a picture of necessary training supports for PHAC to consider as part of the Guidelines' dissemination. The questions included:

- Who needs to be trained?
- What training supports do various stakeholders require?
- What content needs to be covered?
- Where/how should training take place?
- What organization/s should assume leadership for training?

Although some responses from individual groups to some questions were unique, a strong consensus emerged from all groups about training supports, content, leadership, and who should be trained.

On the issue of **who** should be trained, it appears that training is needed for **all stakeholder** groups when it comes to FASD diagnosis and use of the Guidelines. Several specific groups were mentioned, such as psychiatrists, psychologists, pediatricians, speech and occupational therapists, nurses, front-line workers and paraprofessionals. Participants also mentioned the need to train the community to ensure buy-in and trust.

A picture of a potential framework for training emerged when reviewing the responses. There seems to be strong support for the creation of a **training plan** that has a **national**

reach. This national training plan would ensure that there is standardization to the training, with an **accreditation** or **certification** aspect to it. The national focus would include a **common curriculum and core competencies** tied to specific disciplines, with some level of **flexibility** to account for regional and/or provincial nuances as well as the **different levels of training** required. The curriculum would be **evidence-based** and reflect **best practices**.

One of the groups suggested **linking to professional associations** so that **core competencies** for FASD diagnosis could be established. The training should **build upon existing training** (e.g. in British Columbia, Alberta and Ontario) that has been **evaluated** and shown to be effective, and should have an **evaluation component**. Several participants mentioned that the training should be **designed with a team approach** in mind and move away from training that focuses on the needs of one or two specific disciplines. The training should also recognize the **roles of many other professionals and paraprofessionals** who could have a role in diagnosis, such as judges, teachers, lawyers and probation officers.

Training should be **widely available** (across Canada, including small rural areas) and in a **variety of formats** (face-to-face, distance, hands-on) to ensure the most robust learning environment. The actual training methodology should be **interactive** and reflective of effective **adult education** principles and incorporate opportunities for **demonstration, practice** and **mentoring**. The training must also be **cross-culturally sensitive**.

There also needs to be a **federal commitment to fund the training** and work with partners to ensure national coordination. Several suggestions were made about who should lead the training component. Specific mention was made of **PHAC** and **CCSA**, with **professional associations** leading in their disciplines and **provincial ministries** supporting the effort by setting policy. It was also suggested that perhaps **centres of excellence** could be established, even in a virtual environment, for training leadership. The possibility of **regional leadership** was also suggested.

With respect to the **content** that training should cover, participants acknowledged that there is a wide range of existing knowledge and skills sets in the area of diagnosis. It would be important to assess the current training that is available, for whom, and where. With this information, a clearer picture of the training content would be possible as a starting point for curriculum development.

Specific suggestions for content matched to group included:

Training for Physicians:

- Start with the British Columbia model to guide training design.
- Ensure that the training addresses screening, referral, diagnosis and multidisciplinary team approaches.
- Consider post-grad training.
- Target training to physicians working in corrections and related areas (in areas of higher risk for FASD, such as health care providers in rural and remote locations and in correctional institutions).

Training for Psychologists:

- Include neurodevelopmental/functional assessments in their training.

Training for Speech Language/Occupational Therapists/Early Childhood Educators:

- Identify their role in diagnosis and follow-up support.
- Address the importance of coordination among disciplines.

Participants indicated that the levels of training for each discipline would vary from **basic information** about FASD to **advanced skills** development on diagnosis. They also mentioned that the training needs to address **community capacity** around **understanding the FASD diagnosis** and encouraging ways to support it and the diagnostic team.

2.6 Data Collection and Monitoring System

The second day of the Forum began with a review of the accomplishments of the first day (greater understanding of the Guidelines and specific suggestions for training to support the Guidelines). The intent of the morning session on Day Two was to learn about existing data collection activities and to identify challenges and possibilities for a national FASD data collection system. To stimulate participants' thinking, individuals who are currently involved in data collection/surveillance activities delivered two brief presentations. Catherine McCourt described the existing system of data collection within the Health Portfolio and Dr. Soo Hong-Uh described the Health Status Registry (HSR) that is operated by the British Columbia Vital Statistics Agency. Dr. Hong-Uh noted that the HSR has been in existence since 1952 and that it currently operates under section 10 of *the Health Act*. The purpose of the Registry is to record and classify information concerning congenital anomalies, genetic conditions or chronic handicapping conditions of citizens aged 20 or younger.

The information within the HST serves many purposes: to help health care planners in developing appropriate services; to assist in medical and genetic research; to keep the public informed through timely and accurate reporting; and to respond to research requests. The Registry is continually evolving and could be a valuable partner in collecting and analyzing statistics on FASD in Canada. Following an opportunity for questions, participants were divided into groups to identify challenges and issues that relate to data collection for FASD.

Participants identified several challenges surrounding data collection, not because it is so potentially difficult, but because it is a substantial task and many aspects need to be considered. One key challenge that underlies a data collection system relates to the issue of diagnosis: if children are not being diagnosed (because of lack of diagnostic capacity), it will be impossible to collect data. If diagnosis is occurring, it must be standardized, so that the data will have some meaning and value. Therefore, the dissemination of the Guidelines and the implementation of standard diagnostic procedures are vital prerequisites to data collection.

All groups acknowledged and reinforced the need for a national data collection system. Without it, it is impossible to determine the incidence and prevalence of FASD in Canada. Such information is vital for informing policymakers and politicians of the impact of FASD and generating support (funding, policy) for the services and supports for those affected by FASD.

Another challenge related to a data collection system is **how to track all ethnic and cultural groups** (not just Aboriginal/non-Aboriginal, or on-off reserve populations) for incidence and prevalence data. Definitions of groups must be made with the involvement of the groups and steps taken to ensure that they provide input into the development of the information-gathering process.

As in any system that deals with personal information, the challenge of **protecting privacy** and **confidential information** must be addressed. Furthermore, the issues of who should have access to the information and even who should be collecting the information must be defined very clearly.

A technical challenge that was identified was the need to **create user-friendly fields** in the database that could have research potential. The system should be designed and tested to minimize frustration and difficulty in entering and retrieving data.

One of the groups indicated that a challenge may be the **under-representation of maternal alcohol history** in medical records. Physicians do not routinely ask about alcohol history, which may result in under-reporting of maternal alcohol consumption.

An additional challenge mentioned was the importance of **sharing information at the earliest stage** possible on the reasons for data collection, procedures, and what, if anything, would be shared with the community. Strong caution was urged on the last point, since giving feedback to a community would likely break confidentiality, especially in small communities.

Several comments were made about the need to provide comprehensive training on how to collect data and ensure the system is accomplishing what is required.

Partnerships between provincial/territorial and federal levels may be an area of challenge for data collection. One way to address this may be to consider if the data collection system could be used to report conditions in addition to FASD. Appropriate staff at the federal level need to encourage provincial/territorial support for data collection at the senior levels.

Most of the groups felt that the challenges can be addressed and that with clear communication early in the process, followed by support through training and careful monitoring at each phase of data collection, a system can be designed and implemented.

2.7 Afternoon Opening Remarks

Kelly Stone, Director, Division of Childhood and Adolescence, Public Health Agency of Canada, addressed the participants as the afternoon began. She expressed and reinforced the commitment that PHAC has to the issue of FASD in general and to supporting the dissemination of the Guidelines in particular. She acknowledged the work of the Sub-Committee and the many individuals across Canada who contributed to the development of the Guidelines. Ms. Stone noted that, at this time, there is no new funding allocated to the FASD file and that the FASD Team will continue to work with its broad network of partners to accomplish the work that needs to happen to address FASD in Canada.

2.8 Priority-setting Exercise

The last task of the Forum was to identify priorities for next steps relating to the Diagnostic Guidelines. The purpose of this task was to assist PHAC in devising workplans and moving forward with its work, reflecting the Agency's commitment to involving stakeholders in the work that needs to be accomplished. In small groups, participants brainstormed a list of priorities for consideration by the larger group. Close to 30 priorities were initially identified. Through large group discussion, the list was consolidated into a final list of 18 priorities.

Participants then individually ranked each priority (1 = high priority, 18 = low priority). The rank scores were averaged and resulted in a group rank for each item (see Appendix D). The top five priorities that emerged from this activity included:

1. Disseminate the Guidelines and progress to professional and non-professional groups.
2. Develop, establish, implement, evaluate and maintain standardized training.
3. Create and obtain funding.
4. Establish universal access to improve/maintain/sustain expertise in all provinces/territories/First Nations/Inuit/Métis.
5. Establish data collection concurrent with the dissemination of the Guidelines.

Participants delivered a clear message that the Guidelines must move to the next stage – that of dissemination – and that action should begin immediately so as not to lose momentum. The priorities must be acted upon at the earliest possible time and involve stakeholders at every step. The 11 Diagnostic Clinics were mentioned as key players in any dissemination effort because there is substantial experience and leadership to draw upon.

It must be noted that some of the priorities suggested (while valid and necessary) fall outside the current mandate of the federal government and some of its agencies. These priorities would be tied more appropriately to the mandates of other levels of government and other organizations or agencies.

The background features abstract geometric shapes. A light blue semi-circle is on the left. A large, semi-transparent pink arc overlaps the blue shapes. A solid pink horizontal band is in the middle. Below it, a light blue area contains a blue oval and a blue arc. The text '3 Closing Remarks' is centered in the upper half.

3 Closing Remarks

Michel Perron, Chief Executive Officer of the Canadian Centre on Substance Abuse, thanked participants, recognized the openness, respect and genuine interest that characterized the discussions, and noted that the objective of stimulating a meaningful exchange of ideas had been achieved.



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Appendix 1: Agenda

Day One – March 8, 2005

- 9:00** **Welcome and Opening Remarks; Introductions**
- 9:30 Background to the Forum
- 9:45 Development of the Diagnostic Guidelines
- 10:15 Overview of the Guidelines
- 10:45** **Refreshments**
- 11:00 Small Discussion Groups
- 11:45 Insights from Discussion
- 12:00** **Lunch (provided)**
- 1:00 Overview of Current Training Initiatives
- 1:45 Reaction/Comments
- 2:00 Small Discussion Groups – Generating Ideas for a National Training Plan
- 3:30 Group Reports on Training Ideas
- 4:00 Summary of Day One
- 4:30** **Adjourn**

Day Two – March 9, 2005

- 9:00** **Debrief of Day One and Overview of Day Two**
- 9:10 Current Data Collection and Monitoring Systems
- 9:45 Data Collection Discussion
- 10:30** **Refreshments**
- 10:45 Priorities for Data Collection and Monitoring System
- 11:45 Insights from Discussion
- 12:00** **Lunch (provided)**
- 1:00 Public Health Agency of Canada (PHAC) Remarks
- 1:15 Priority-setting Exercise – Small Groups
- 1:30 Present List of Priorities to Large Group
- 2:00 Discussion/Clarification of Priorities
- 2:30 Individual Ranking of Priorities
- 2:45** **Refreshments**
- 3:00 Presentation and Discussion of Group Priorities
- 4:00 Closing Remarks
- 4:15** **Adjourn**

Appendix 2: Invitation and Participant Lists

Invitation List

Name

1. Sally Longstaffe	2. Christine Loock
3. Ted Rosales	4. Albert Chudley
5. Claudine Longboat-White	6. Nicole Leblanc
7. Gina Muckle	8. Ted Rosales
9. Gideotte Koren	10. Valerie Flynn (Ottawa)
11. Claudette Landry	12. Margaret Clarke
13. Leigh Wincott	14. Hasu Rajani
15. Mary Cox Millar	16. Sterling K. Clarren
17. Dan Dubovsky	18. Deborah Pace
19. Denise Stone	20. Linda L. Storoz
21. Julie Conry	22. Liz Lawryk
23. Darren Joslin	24. Heidi Schroter
25. Michelle Dubik	26. Wendy Burgoyne
27. Ginny Lane	28. Dolores Logan
29. Winnie Banfield	30. Lindsay Crowshoe
31. Roxanne Manning	32. Selma Ford
33. Sherri Wilson	34. Mary Ellen Turpel Lafond
35. Andrea Noonan	36. Dawn Bruyere
37. Brad Bell	38. Kent Saylor
39. Marie Adele Davis	40. Sarah Shea
41. Joachim Kapalanga	42. Francine Knoops

Name

43. K.O. Asante	44. Elaine Orrbine
45. Anne Fuller	46. Vyta Senikas
47. Gail Andrew	48. John Service
49. Maureen O'Donnell	50. Arthur Blue
51. Dawn Ridd	52. Nikki Bansil
53. Peter Noonan	54. Naho
55. Soo-Hong Uh	56. Jo Nanson
57. Nicole Chatel	58. Louise Floyd
59. Johannes Botha	60. Carol Woodworth
61. Lori Vitale-Cox	62. Rachelle Best
63. Barb Benton	64. Bryce Larke
65. Stacy Taylor	66. Mercedes Mompel
67. Mary Lynch	68. Catherine Royle
69. Darlene Oakes	70. Colleen Greene
71. Valerie Massey (no fax)	72. Nancy Taylor
73. Lindsay Crowshoe (no fax)	74. Kathy Inkpen
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Dr. Nicole Leblanc (New Brunswick)

Dr. Jocelynn Cook (Health Portfolio)

Appendix 4: List of Ranked Priorities

PRIORITY and RANK

1. Disseminate guidelines and progress to professional and non-professional groups.
2. Develop, establish, implement, evaluate and maintain standardized training.
3. Create and get funding.
4. Establish universal access to improve/maintain/sustain expertise in all provinces/ territories/First Nations/Inuit/Métis.
5. Establish data collection concurrent with dissemination of Guidelines.
6. Link federal government Ministries/national organizations.
7. Establish national leadership to coordinate access, regulation and partnership.
8. Identify federal/national leadership and leaders in training (provincial).
9. Consult with First Nations/Inuit/Métis on guidelines, aftercare and reporting.
10. Ensure universal access to diagnosis.
11. Build on existing resources (clinics, non-FASD, perinatal).
12. Give presentations at appropriate conferences.
13. Obtain Ministry endorsement.
14. Create screening tools.
15. Establish better linking among professional organizations.
16. Develop or formalize a network among clinics.
17. Review and evaluate in one to two years.
18. Evaluate and monitor links to resources.