

# **Investigating Fetal Alcohol Spectrum Disorder (FASD) Diagnostic Training Services in the Canadian Context**

**An Environmental Scan**

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## Executive summary

In July 2008, the New Brunswick Department of Health in collaboration with the Public Health Agency of Canada undertook an environmental scan of existing Fetal Alcohol Spectrum Disorder (FASD) diagnostic training services across Canada. The intent was to provide a description of existing FASD diagnostic training service capacity in the Canadian context. This scan included the completion of key informant interviews with:

- service providers and managers involved in the delivery of FASD diagnostic training services; and
- other provincial and territorial stakeholders knowledgeable about FASD related assessment and intervention programs in their respective jurisdictions.

Interviews were completed from February until mid-August 2009. Content analysis was used to identify emergent theme categories from the synthesized interview data.

Participants highlighted 11 specific diagnostic training services in the Canadian context. Diagnostic training programs were described as services oriented for the provision of instruction to interprofessional or multidisciplinary team members. The cited training programs combined delivery of FASD assessment services with their given training programs.

Participants reported that training services were most often delivered in-person at the given training sites involving both group and individual delivery approaches. Training ranged from two-to three days, with some services including opportunities for follow-up contacts or consultations. Follow-up contacts varied from the provision of informal consultations to delivery of full-day post-training sessions of up to two days. The use of telehealth services and similar technology were identified as flexible and cost-effective means for providing full-team and individual mentorship training services for professionals from both local and remote areas.

Participants outlined various key areas of content related to diagnostic training services. These included:

- screening and referral processes;
- diagnostic criteria and differential diagnosis;
- standardized assessment instruments and protocols;
- example cases and diagnostic applications;
- case planning and sources of community support; and
- interprofessional education, and cultural considerations.

The content of post-training sessions focused primarily on the provision of consultation for diagnostic cases being undertaken by individuals who had completed the initial education component.

Specific challenges associated with the provision of training to professionals included the difficulties in scheduling sessions and costs associated with travel and the time required to be away from direct service activities. In contrast, highlighted training accomplishments included:

- improved service accessibility;
- increased awareness about FASD;
- strengthened or extended service provider networks;
- improved research and knowledge exchange; and
- increased government recognition of FASD-related concerns.

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Almost all participants supported the development of such a national diagnostic training program. Suggested key actions to accomplish this goal included:

- the creation of a national planning committee;
- the formation of university and professional association alliances;
- a revision of diagnostic practices; and
- the adoption of effective training approaches.

Many participants asserted the importance of identifying a national-led organization to co-ordinate the planning of such an initiative. Other participants emphasized the importance of obtaining support from senior level provincial and territorial health authorities early in the planning of a national diagnostic training program. Participants stressed the importance, in addition to obtaining leadership support, of carrying out consultations and involving individuals and groups at local, regional and provincial levels.

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## Project overview

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In July 2008, the New Brunswick Department of Health in collaboration with the Public Health Agency of Canada undertook an environmental scan of existing FASD diagnostic training programs across Canada. The intent was to provide a description of FASD diagnostic training service capacity in the Canadian context. In addition, this effort included data collection focused on providing feedback about the potential development of a national training program for FASD diagnostic services. The project encompassed a four phase methodology including:

- the creation of a key informant interview instrument to carry out data collection for the environmental scan;
- the administration of the key informant interviews to FASD stakeholders from territorial and provincial jurisdictions across Canada;
- an analysis of key themes arising from data gleaned from key informant interviews; and
- the completion of a final project report.

Project activities were completed in September 2009 and culminated in the dissemination of the final project report to FASD government and practice stakeholders. This document provides a summary of the intent, methodology, and findings of this initiative. It is hoped that the outcomes of this project will provide useful insights into existing accessible diagnostic training resources in Canada as well as potential direction for expanding future training capacity for FASD diagnosis.



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# Investigating FASD diagnostic training services in the Canadian context

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## INTRODUCTION

The purpose of this data collection was to provide a scan of existing FASD diagnostic training programs or services in Canada as well as to obtain key perspectives from FASD stakeholders about the implications for a national diagnostic training program. This scan included the completion of key informant interviews with:

- service providers and managers involved in the delivery of FASD diagnostic training services; and
- other provincial and territorial stakeholders knowledgeable about FASD-related assessment and intervention programs in their respective jurisdictions.

## METHODOLOGY

A key informant list was finalized in collaboration with the Project Advisory Committee in January 2009. Potential participants were identified in all major national jurisdictions including the North, the West, the Prairies, and Central and Eastern Canada. A preliminary e-mail invitation to be involved with this data collection was forwarded to all possible informants. This correspondence was followed up by a telephone call by the research team. For those individuals successfully contacted, the purpose of the project and the nature of their potential involvement were explained. Upon obtaining participants' consent, individual interview times were arranged. A structured interview was subsequently conducted by telephone in either French or English, given the preference and regional considerations of the interviewee. Interviews were completed from February until mid-August 2009. The average length of the interview was about one hour. A structured recording form was used to gather data at each interview. Key areas of inquiry for investigation included:

- diagnostic training services: general considerations;
- training personnel;
- training format;
- training materials and resources;
- core content areas;
- training evaluation and outcomes; and
- creation of a national training program.

Interviews included open-ended questions and corresponding prompts to encourage sufficient exploration of the various areas of inquiry. At the close of each interview, a session summary was formulated. Summaries were subsequently merged to provide a unified data set. Content analysis was used to identify emergent theme categories for the various areas of inquiry. The major findings for this investigation are presented in the following sections.

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## PARTICIPANTS

Sixty-one participants were initially contacted; among them, 32 were successfully reached and consented to participate in the interview. Tables 1 and 2 respectively provide the location and the professional role of participants.

- **Geographic distribution**

<b>Geographic location (number)</b>	<b>Number of participants</b>
North Yukon - 2 Nunavut - 1	3
West British Columbia - 7	7
Prairies Alberta - 3 Saskatchewan - 2	5
Central Ontario - 8 Quebec - 1	9
East Prince Edward Island - 2 Nova Scotia - 3 New Brunswick - 2 Newfoundland and Labrador - 1	8

- **Professional role**

Professional role	Number of participants * Some participants identified multiple professional roles
FASD-related program co-ordinators/managers	19
Clinical and health service providers	18
Researchers	9
Other service providers or program managers	3

Of the participant group, 22 had knowledge of Canadian-based diagnostic training services or had collaborated with these sites, whereas 10 had direct involvement with organizations or agencies that deliver FASD diagnostic training services.

## **DIAGNOSTIC TRAINING SERVICES: GENERAL CONSIDERATIONS**

- **Identified training services**

Eleven specific diagnostic training services in the Canadian context were highlighted by participants:

- Regina Child and Youth Services: Cognitive Disabilities Diagnostic Support, Regina, Saskatchewan;
- Glenrose Rehabilitation Hospital, Edmonton, Alberta;
- Clinic for Alcohol and Drug Exposed Children, Winnipeg, Manitoba;
- University of Saskatchewan, Saskatoon, Saskatchewan;
- Eastern Door Centre for Diagnoses, Intervention and Prevention of FASD and Related Birth Conditions, Elsipogtog First Nation, New Brunswick
- Fraser Development Clinic, Surrey, British Columbia;
- Asante Centre for Fetal Alcohol Syndrome, Maple Ridge, British Columbia;
- Lakeland Centre for FASD, Cold Lake, Alberta;
- St. Michael's Hospital, Toronto, Ontario;
- Sunny Hill Health Centre for Children, Vancouver, British Columbia and
- Motherisk Program, Toronto, Ontario.

Participants indicated that there were generally no formalized links among the diagnostic training services; a few, however, mentioned specific examples of contacts or knowledge exchanges that had taken place between individual training team members associated with the various sites.

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- **Scope of training services**

Participants cited that most training programs emphasize the delivery of training in diagnostic services for children and youth; a few, however, indicated that when requests for training in adult-focused assessments are made, they are also addressed. In all instances, the highlighted training programs combine delivery of FASD assessment services with their given training programs. Direct assessment and training services for the various identified sites were reported to be provided within their respective local and provincial jurisdictions, and in some instances, extended to other provincial and territorial regions, and in one instance internationally.

*“Participants are usually professionals interested in diagnosis...; however, policy members have also taken advantage of the training to gain a greater understanding of the process.”*

*“We provide training to anyone who requests it...we want to reduce barriers to getting knowledge out.”*

- **Interprofessional team focus**

Diagnostic training programs were described as services oriented for the provision of instruction to interprofessional or multidisciplinary team members. This included delivery of training services to such professionals as:

- physicians;
- psychologists;
- speech language pathologists;
- occupational therapists;
- social workers;
- intake workers;
- team co-ordinators and managers;
- nurses and nurse practitioners; and
- clinical and medical interns.

One participant indicated that government policy analysts in the area of FASD had also attended team-based training programs. With respect to training professionals, it was expected that most would have basic knowledge of FASD as well as general assessment competencies relevant to their respective clinical disciplines. A few participants also spoke of the benefits of providing individuals with a preliminary session on FASD (e.g., FASD 101) if this was their initial introduction to this diagnostic area or if they were interns or new to their given profession. Most participants emphasized that they make a concerted effort to tailor training to the professional needs of their audience taking into account their basic knowledge of FASD and related assessment methods.

With respect to recognition for interprofessional team members, provision of continuing educational credits was not linked to any of the identified training services or programs. Similarly, academic recognition for completion of specific educational sessions or components was not highlighted as a routine or formalized part of available training opportunities. A few participants mentioned that some health professionals who had attended training had applied for continuing education credits from their respective professional associations.

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- **Promotion of training services**

Participants reported that awareness of training programs is often a result of sharing among professionals who have a common interest in FASD. Others indicated that specific training opportunities were promoted through e-mail messages to professional groups, announcements on health or education websites (e.g., Canadian Centre on Substance Abuse – CCSA website), and distribution of brochures. Personalized contacts were identified as the most effective means of reaching specific assessment professionals or teams that would benefit from FASD diagnostic training services.

- **Financial supports**

Participants reported that the cost of training is usually covered by the attendees' respective health or service organizations. Other cited sources of financial support to assist with delivery of programs included funding from provincial governments, grants from universities and resources from federal government departments (e.g., Public Health Agency of Canada, Health Canada, First Nation and Inuit Health Branch). Individuals who attend training often have in-kind support from their given organization through release time or support to meet the costs of travel, meals, and accommodations.

- **Challenges associated with accessing training**

Specific challenges associated with the provision of training to professionals included:

- the difficulties in scheduling sessions in which all members of given teams could be present;
- travel costs; and
- the time required to be away from direct service activities.

*“There is a lack of qualified professionals to deliver training . . . and a lack of training programs available to professionals.”*

Other participants indicated that there were limited opportunities for training in the Canadian context and a lack of qualified individuals available to deliver such services to professionals. In response to these challenges, participants mentioned the potential advantages of delivering training using telehealth services. Given the accessibility of this technology to many clinical and medical professionals, it was identified as a flexible and cost-effective means for providing full-team and individual mentorship training services for professionals from both local and remote areas.

## **TRAINING PERSONNEL**

The number of training personnel for the various cited programs ranged from six to nine personnel. Training staff represented a range of different health, clinical and service specialists including:

- physicians;
- pediatricians;
- occupational therapists;
- social workers;
- speech language pathologists;
- psychologists; and
- counsellors and mentors

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Personnel delivering diagnostic training services were usually involved in providing direct clinical assessments. In this regard, they were identified as having graduate-level assessment training and substantial applied clinical experience related to their respective professions. A few participants emphasized the importance of training faculty having additional expertise in developmental and educational psychology.

Training faculty's background and expertise in FASD diagnostic assessment was obtained through:

- the completion of formalized training programs;
- involvement in supervised clinical work experiences; or
- participation in mentorship learning opportunities with other colleagues on existing diagnostic teams.

Specific training, internship, and mentorship sites attended by faculty members who participated in the interview included:

- the University of Washington, Seattle, Washington;
- Centre for Alcohol and Drug Exposed Children, Winnipeg, Manitoba;
- Lakeland Centre for FASD, Cold Lake, Alberta;
- the Glenrose Rehabilitation Hospital, Edmonton, Alberta;
- Sunny Hill Health Centre for Children, Vancouver, British Columbia and
- the Harvard University Medical School, Boston, Massachusetts.

## TRAINING FORMAT AND DELIVERY

- **Duration and location**

Training services were reported to be most often delivered in-person at the given training sites. A few participants indicated that diagnostic training content is also available through web-based or video-conferencing technology. Initial training ranged from two to three days, with some services including opportunities for follow-up contacts or consultations. Most diagnostic training programs were reported to be delivered in English, with only one site highlighting its capacity to provide services in French.

- **Group and individual instructional formats**

Participants reported that training formats for FASD diagnosis involve the use of both group and individual delivery approaches. Maximum sizes for group formats ranged from 20 to 50 professionals. Group instructional formats may incorporate:

*"The format includes introductory sessions for everyone... followed by smaller group interactions based on professional backgrounds."*

- focused instructional lecture-type presentations;
- professional presentations based on instructors specific areas of expertise;
- preliminary sessions for all attendees, followed by breakout group sessions based on professional designation;
- observation of example case presentations or live taped case demonstrations; and
- discussion sessions focusing on the assessment activities and outcomes of given case examples.

In contrast, individual formats focused on one-on-one mentorship situations involving job shadowing or collaborative work with an existing team member. Individual approaches typically are undertaken among persons from the same disciplines, such as having individual physicians visit existing diagnostic teams and shadowing the diagnosing physician during team-based assessment activities. When new professionals join diagnostic teams, training is often provided as part of the initial employment orientation for that new clinician. In most instances, the clinical team leader or director sets up preliminary meetings between new and existing team members as a means of establishing professional mentorship relationships.

*"Participants are matched with someone from the existing team... this involves use of a mentorship approach."*

- **Client and family members as collaborators in training**

Individuals with FASD or parents of children with FASD were generally not identified as being involved in the delivery of training or presentation of core content. A few participants indicated that video-taped or live demonstration sessions with clients have been used as part of training sessions. There was mixed feedback among participants about the benefits and appropriateness of involving clients as part of specific training components. A few participants highlighted examples of the roles that family members had played in speaking about the importance of screening for FASD and provision of timely support to children and their caregivers. Some participants also indicated that they had personal family experiences related to FASD that had been an important source of information for them in preparing and delivering training for other professionals.

- **Follow-up consultation and training activities**

Following initial training, participants underscored the importance of providing follow-up sessions or contacts. This was viewed as critical for supporting individuals and teams as they apply the knowledge and approaches they have gleaned from the initial training programs. Follow-up contacts varied from the provision of informal consultations to delivery of full-day post-training sessions of up to two days in length. The content of post-training sessions focused primarily on providing consultation for diagnostic cases being undertaken by persons who had completed the initial education component.

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## TRAINING MATERIALS AND RESOURCES

Participants reported that consultation with training programs had contributed to the development of training content and materials in the Canadian context. Several noted that consultations with, as well as material received from research and educational specialists associated with FASD training services at the University of Washington had been particularly beneficial. In addition, a range of specific documents were identified as useful for guiding the selection of training content and development of program materials. These included:

- **The Canadian guidelines for diagnosis**

All participants reported that this document is a central resource for guiding the development and delivery of diagnostic training services. In this regard, the Canadian Guidelines for Diagnosis were identified as critical for ensuring uniformity in diagnostic practices outlined in training sessions from varied services or sites. The most frequently cited examples of potential revisions that might be included in future developments of the guidelines were:

- the addition of written sections outlining areas of cultural sensitivity that should be taken into consideration within diagnostic practices and protocols;
- statements of specific limitations of the guidelines and the role of clinical judgment in application of diagnostic procedures; and
- the refinement of growth measurements in established diagnostic guidelines to reflect new physical norms for specific populations.

*“Use of the Canadian Guidelines is critical for our training...”*

*“It is important that Canada be recognized for having diagnostic guidelines.”*

- **The 4-Digit Diagnostic Code Method**

In their discussion of key reference documents, participants highlighted web-based documents related to the 4-Digit Diagnostic Code Method. This method provides a gestalt approach for diagnosing the full spectrum of outcomes of clients with prenatal alcohol exposure through application of quantitative, objective measurement scales and specific case definitions. The four digits in the code reflect the magnitude expression of four key diagnostic features of FAS:

- (1) growth deficiency;
- (2) the FAS facial features;
- (3) central nervous system (CNS) damage/dysfunction; and
- (4) prenatal alcohol exposure (published online by the University of Washington).

- ***Trying Differently Rather Than Harder***

Participants identified this book publication as providing an effective model for working with children, adolescents and adults with FASD. In this resource case examples are applied to illustrate common behavioural symptoms of FASD and corresponding interventions for clinicians and service providers.

- ***The Broken Cord***

Although dated, this non-fiction book was regarded as a classic narrative of a family’s struggle with FASD, describing the scope and impact of this condition. This publication was identified as a useful resource for communicating families’ experience with FASD to service providers and clinicians.



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- **The Canada Northwest FASD Research Network**

This network and website resource was viewed as an important source of information for clinical and diagnostic team members. The website includes a search engine to identify key resources about FASD project inventories and diagnostic practices.

- **The Lakeland Centre for FASD online**

This website was identified as a useful resource for identifying online references, key documents and publications related to FASD and content for diagnostic training.

- **DVDs on FASD diagnosis**

A few participants referred to the DVD training resource produced by the University of Washington, entitled the Fetal Alcohol Syndrome Tutor. This resource is intended to introduce professionals to the FASD 4-Digit Diagnostic Code and to provide instruction to clinical professionals on effective screening and diagnostic processes.

- **Recent refereed academic and professional publications**

Participants highlighted the use of literature and evidence-based publications in the identification of core training content. Access to such publications was linked to collaborative working alliances with researchers, university services or local health authorities.

- **Site-based documents**

Some participants reported that their respective site teams had been active in producing educational material that they were currently using in their diagnostic training programs with other professionals. Such materials included diagnostic handbooks, compilations of relevant studies, intake forms, and screening questionnaires.

## **CORE CONTENT AREAS**

Participants outlined various key areas of content that have been included as part of diagnostic training services in the Canadian context. Participants cited core content areas related to:

- **Screening and referral processes**

Essential training information included:

- synthesizing referral and assessment data;
- using screening protocols to investigate potential history of alcohol use and prenatal alcohol exposure; and
- applying respectful and non-judgmental approaches for working with clients and their families.

Participants indicated that such training content was often included as part of training components delivered by psychologists and social workers on the given training teams. The Canadian Guidelines for Diagnosis were identified as a key resource.

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- **Diagnostic criteria and differential diagnosis**

This content area was identified as a major focus of training services. Areas of focus for this area included the 4-Digit Diagnostic Code, IOM criteria and information from the Canadian Guidelines for Diagnosis. Participants indicated that this content area is routinely presented by the physicians and psychologists on given training teams.

- **Standardized assessment instruments and protocols**

This content area was regarded as a major focus of training services. Various participants highlighted the importance of including suggestions about the application of specific standardized measures as well as the need to include information related to cultural sensitivity in training content for this area. With respect to assessment instruments, participants referred to example test batteries for assessing the brain domains recommended by the Canada Northwest Fetal Alcohol Spectrum Disorder Research Network. Participants indicated that these content areas were often delivered by psychologists as well as speech language pathologists and occupational therapists on given training teams. Participants asserted the importance of the Canadian Guidelines for Diagnosis as a key resource related to this content area.

- **Example cases and diagnostic applications**

The development of case examples and diagnostic applications for use in training sessions was described as a collaborative effort undertaken by the designated training team members. These case illustrations were often based on first-hand experiences from their clinical work.

*“Team members bring interesting and complex cases to the table and consider ways in which to integrate them into the training programs.”*

- **Case planning and sources of community support**

This content area focused on identifying community linkages, services, intervention services and supports needed to help clients and their families following diagnosis. In this training component, emphasis was placed on understanding the social determinants of health, increasing service providers’ knowledge of local and regional continuums of services and providing outreach and advocacy as needed to ensure accessibility to needed supports for clients and their families. With respect to follow-up, a few participants asserted the importance of elaborating on training content to include increased emphasis on report development and its relevance to communication with family members, legal authorities and other service providers.

*“Addressed a bit in the overview, but don’t go in great detail . . . No formal content. . . Need to tear down hierarchical ranks and encourage respect for each other and all the disciplines involved.”*

- **Interprofessional education**

In conjunction with discussion of core training content areas, participants stressed the importance of key concepts related to interprofessional team functioning related to:

- understanding and respecting professional roles and practices;
- improving interpersonal and team communication; and
- applying effective team problem-solving approaches.

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Although interprofessional education was identified as an important focus for training, participants indicated that such content was often dealt with informally, and was not formalized as part of key instructional components of current FASD diagnostic training programs.

- **Cultural considerations**

Participants were invited to describe the extent to which training programs or services take into account cultural considerations or content related to clients and their families. Most participants reported that training team members have a “respectful awareness” of specific cultural or ethnic groups. Others indicated that some training services:

*“Cultural considerations are always a core part of the decision-making process for those around the table.”*

- incorporate cultural sensitivity education as core program content; or
- include recommendations related to the involvement of cultural or ethnic representatives as key members of the diagnostic team.

## TRAINING EVALUATION AND OUTCOMES

- **Training accomplishments**

Participants were asked to identify specific positive outcomes associated with diagnostic training services in the Canadian context. Highlighted accomplishments included:

*“The team is very proud of the work they are doing and are grateful for the opportunity to give back by sharing their knowledge and expertise.”*

- *enhanced service accessibility*: The training of new diagnostic teams has resulted in increased reach in some regions for the provision of assessment and intervention services for children, youth, adults with FASD as well as their family members;
- *increased awareness about FASD*: The provision of diagnostic training was regarded as beneficial for enhancing clinicians and service providers’ knowledge of FASD and associated challenges facing clients and their families. In turn, increased knowledge among team members from the same region was viewed as advantageous for enhancing wider community awareness regarding FASD in their respective jurisdictions. In some instances, increased awareness was associated with “new and appropriate” referrals being made by health professionals to diagnostic teams. Participants asserted the importance of continuing awareness efforts to further promote wider spread interest from professionals in seeking opportunities to receive diagnostic training;
- *strengthened or extended service provider networks*: The provision of team and mentorship training opportunities was viewed as contributing to strengthened as well as elaborated service provider networks related to FASD;
- *improved research and knowledge exchange*: The increase in awareness related to FASD diagnosis was regarded as beneficial for promoting wider-spread professional interest in research and knowledge exchanges activities focusing on FASD prevalence, diagnosis, and treatment; and
- *increased government recognition of FASD-related concerns*: Diagnostic training and service delivery activities have raised awareness among government authorities about:
  - › the magnitude of this health concern; and
  - › need for prevention, diagnostic and intervention resources to be applied to address this area of provincial, territorial and national attention.

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- **Training challenges**

Participants underscored ongoing challenges associated with the provision and accessibility of diagnostic training services. These included:

*“We now ask for permission to carry out training. . . it’s sometimes challenging to balance both training needs and clinical service demands”*

- *the tension between being a training and direct service program:* Participants referred to this challenge as the “pull” between being a training site and the wait list demand for provision of timely FASD diagnostic services in their local regions and provincial jurisdictions;
- *recognition of a limited number of training services:* Although opportunities for FASD diagnostic training have expanded over the past several years, there was acknowledgment among participants about the limited options or absence of training services or sites in eastern and northern Canadian jurisdictions; and
- *lack of financial resources:* Identified financial challenges included securing financial support to facilitate clinical teams’ attendance at diagnostic training sessions.

- **Program review and evaluation activities**

Participants were invited to highlight specific structured processes for reviewing or evaluating training content and delivery formats. They identified a range of arrangements, running from:

- formalized evaluation and review approaches; and
- informal methods to gather feedback; to
- no specific mechanisms being in place.

The participants cited several examples of program review and evaluation, including:

- completion of an annual review of service content and delivery methods through working group sessions with training team members;
- monthly team meetings to discuss better practices from the literature and ways in which to incorporate new knowledge into training service approaches (e.g., journal clubs); and, cited most often,
- the administration of satisfaction and feedback surveys to attendees at the close of training sessions. The reported intent of such data collection activities was to investigate:
  - › the comfort level of attendees;
  - › the perceived quality of training content;
  - › the reported impact of the training on attendees’ knowledge and skill developments;
  - › the overall usefulness and applicability of the training program or service; and
  - › suggestions for improving future training sessions.

Two participants reported that, in conjunction with program review processes, they included methods for assessing participants’ acquisition of key learning content. Although these evaluations were used to provide feedback to participants, they were noted as particularly beneficial for diagnostic training teams in terms of assessing the educational impact or level of participant learning resulting from the provided sessions.

## CREATION OF A NATIONAL TRAINING PROGRAM

### • Participant perspectives

Participants were asked to share their perspective on the potential creation of a national diagnostic training program for service providers and clinical assessment teams. Almost all participants (93 per cent) supported such a development, whereas a few were uncertain whether a nationwide diagnostic training initiative would be viable. Several participants with extensive background and experience in the evolution of FASD-related services and research were strongly interested in collaborating on the creation of such a national strategy.

*"Yes, so there would be consistency and so work can be guided by best practices. . . ."*

*"Yes, it would increase diagnostic capacity and therefore serve more children."*

According to most participants, a national training program would potentially contribute to:

- enhancing how knowledge from multidisciplinary fields may be used to improve diagnostic practices;
- improving opportunities for interprofessional knowledge exchange and debate on key practices related to FASD diagnostic and intervention practices;
- providing more opportunities for diverse professionals to gain competencies in the provision of diagnostic services, as well as in working on interprofessional teams;
- increasing consistency across organizations in the delivery of better practice diagnostic training services;
- increasing reach of diagnostic training services to all major Canadian regional jurisdictions, in particular to the eastern and northern regions of Canada;
- encouraging greater incorporation of FASD knowledge and diagnostic training competencies in medical and clinical internship programs; and
- increasing timely access for clients and their family members to FASD diagnostic and intervention services.

In contrast to the preceding perspectives, a few participants raised specific concerns about the implications associated with establishing a national training initiative. These included:

- the importance of ensuring that national diagnostic standards remain flexible enough so that diagnostic and intervention practices may respond effectively to the needs of culturally diverse populations;
- the importance of having adequate resources to undertake such a national effort; and
- the challenges of securing the agreement of all provincial and territorial health authorities.

*"On paper it looks good, but if it's the responsibility of one organization, I'm not sure who would do it."*

*"There already exists diagnostic training. . . perhaps we should just find a way to make training more accessible."*

Participants asserted that the creation of a national diagnostic training program would need to be a long-term commitment with adequate financial resources to sustain its ongoing development and effectiveness. In this regard, such a program would need to be linked with better practice research networks and diagnostic sites to ensure ongoing knowledge exchange and refinement of standards of practices to mitigate issues related to "clinical drift."

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- **Potential actions**

Participants supporting the development of a national diagnostic training program highlighted a range of preliminary actions or steps that could be envisioned in the development of such an initiative. These suggestions included:

- *Creation of a national planning committee*
  - › Establish a national planning committee (“think tank”) of key professionals involved in FASD diagnostic programs or services.
  - › Ensure regional and cultural representation on the national planning committee.
  - › Promote awareness among national, provincial and territorial government representatives and elicit their support and feedback.
  - › Hold national planning meetings in conjunction with established FASD national conferences or research workshops (e.g., FACE Research Roundtable).
- *Formation of university and professional association alliances*
  - › Create linkages with universities and incorporate FASD diagnostic practice standards within professional programs that train clinicians.
  - › Elicit support from provincial and national professional organizations about the creation of a national training initiative.
- *Revision of better practices*
  - › Begin with a review of better practices related to FASD diagnosis.
  - › Bring together teams from diagnostic training services to share lessons learned.
  - › Revise the Canadian Guidelines for Diagnosis in light of better practices and practice-based insights.
  - › Work toward the development of accreditation standards that could be applied nationally to ensure the delivery of diagnostic services by qualified professionals.
- *Adoption of effective training approaches*
  - › Identify and invest in training methods that ensure the farthest reach and impact (e.g., video-conferencing, telehealth, on-line approaches, train the trainer, mentorship approaches, internships and practicums).
  - › Identify training methods that address the needs of families before, during and following participation in the assessment and diagnostic processes (e.g., community outreach and support).
  - › Incorporate effective diagnostic training methods already in place in program sites or services in other national jurisdictions (e.g., University of Washington online training services).

*“For longevity, someone will need to be identified as lead...”*

*“There are certainly key people identified in each jurisdiction with experiences in the FASD field- bring them to the table.”*

*“There are no superstars...we need to leave out competition.”*

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- **Key partnerships and stakeholders**

Participants were also invited to identify key partnerships and stakeholders who should be involved in creating a national training program for diagnoses of FASD. Many participants asserted the importance of identifying a national-led organization to play a co-ordinating role in planning such an initiative. National and interprovincial bodies such as the Public Health Agency of Canada, Health Canada and the Canada Northwest Fetal Alcohol Spectrum Disorder Research Network were identified as key groups having the potential reach and capacity to provide leadership in this regard. Other participants emphasized the importance of obtaining support from senior level provincial and territorial health authorities early on in the planning of a national diagnostic training program.

In addition to obtaining leadership support, participants stressed the importance of carrying out consultations and engaging the participation of individuals and groups at local, regional and provincial levels. The development of key partnerships with an array of FASD stakeholders was viewed as critical for supporting the success of such a national training endeavor. Specific key stakeholder groups cited by participants included:

- First Nations and Inuit community members and health-service providers;
- clinical teams involved in carrying out diagnostic training and providing direct FASD services to clients;
- representatives from provincial and national professional associations;
- parents, caregivers and those who have gone through FASD diagnostic processes; and
- applied health and education researchers at the university level.

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## Appendix A: Key informant interview guide

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### INTRODUCTION

The purpose of this data collection effort is to provide a scan of existing FASD diagnostic training programs and services in Canada. This scan will include investigation of their scope, service delivery methods, service capacity; as well as identification of lessons learned from training co-ordinators and staff.

### DEMOGRAPHIC INFORMATION

- Participant ID \_\_\_\_\_
- Role: \_\_\_\_\_
- Name of organization: \_\_\_\_\_
- Type of organization:
  - Government
  - Non-government organization / community-based
  - Private sector
  - Professional association
  - Community college       Private       Government-funded
  - University                       Private       Government-funded
- Location of organization:
- Does your organization or agency provide FASD diagnostic training services?

### SCOPE OF TRAINING SERVICE

- Does your program or service address training in FASD diagnoses for children or adults?
- Does your service provide training, as well as direct services related to FASD diagnoses?
- For which regional or provincial jurisdictions do you provide training services?

### TRAINING PARTICIPANTS

- For whom are training services intended (service providers, professionals, etc.)?
- Do participants require a background in FASD to attend or take your training?
- If yes, what background?
- Are you aware of any barrier (s) potential participants may experience in accessing training sessions (e.g., fees, transportation, scheduling)?

If yes, how are these addressed?

### TRAINING CREDITS

- Does the completion of training result in accreditation or professional credits from an organization or professional association (e.g., college of physicians and surgeons, registered nurses association, etc.)? If so, specify.



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## TRAINING RESOURCING

- What costs are associated with participation in your training service?
- Describe any financial or in-kind support that your training service receives from any government departments or non-governmental agencies.

## PROMOTION OF TRAINING OPPORTUNITIES

- How do people find out about your training services?
  - flyer
  - brochure
  - e-mail
  - telephone
  - word-of-mouth
  - mailing lists
  - Canadian Centre on Substance Abuse (CCSA) website
  - Internet / other website (specify): \_\_\_\_\_

## TRAINING STAFF

- How many training staff or faculty does your service have?
- What are their academic backgrounds and FASD clinical and assessment experience?
- Where did your faculty members receive their training on FASD diagnoses?
- What are their specific training roles and responsibilities?
- How do they collaborate to deliver training?
- Are individuals with FASD or parents of children with FASD involved in the delivery of training or presentation of core content? Explain.

## TRAINING FORMAT AND DELIVERY

- Is your training designed for individuals, groups or both? Explain.
- What is the format of your training service?
  - in-house (at your agency)
  - in-house (participants community)
  - virtual training (i.e., through video conference)
  - computer-based
  - other
- What is the duration of training?
- How often is training offered?
- In what languages is training offered?
- What is the maximum number of participants who can participate in your given service training format?

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## **TRAINING MODELS AND MATERIALS**

- Does your service refer to or pattern its approaches according to a specific established training program model? Elaborate.
- What specific reference materials have you used to inform your training service?
- Do you make use of the Canadian Guidelines for Diagnosis in your training service?
- How useful have the Canadian Guidelines for Diagnosis been for development of your training service?
- Do the guidelines need to be refined or elaborated? Explain.

## **ASSESSMENT CONTENT AND TRAINING (CANADIAN GUIDELINES FOR DIAGNOSIS)**

- Describe the training content and activities associated with the following diagnostic themes:
  - screening and referral
  - differential diagnosis
  - neurobehavioural assessment
  - treatment and follow-up
  - maternal alcohol history in pregnancy
  - diagnostic criteria

## **INTERPROFESSIONAL EDUCATION**

- How does your training service address aspects of integrative or multi-disciplinary team functioning? OR What is the training format used to teach and reinforce such interprofessional or team competencies?
- What training content related to team functioning is included? (e.g., role clarification, team processes)? OR What specific interprofessional competencies are addressed?

## **CULTURAL CONSIDERATIONS**

- To what extent does your training program take into account cultural considerations related to:
  - instructing and collaborating with participants?
  - planning training content?
  - carrying out training activities?
  - creating sensitivity regarding circumstances faced by specific ethnic and cultural groups?

## **TRAINING CHALLENGES, SOLUTIONS AND SUCCESSES**

- What successes have been realized as a result of the implementation of your training service?
- Since inception of your service, what challenges have you experienced with respect to the delivery of FASD diagnostic training?
- How have specific challenges been worked through? What solutions have been implemented?

## **MODIFICATION OF TRAINING CONTENT AND DELIVERY**

- How are evidence-informed practices or new knowledge incorporated into your existing training service?
- What sources of better practice information do you use?
- Is there a structured process for reviewing training content or delivery? Explain.

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## **EVALUATION OF TRAINING SERVICES**

- Who is responsible for overseeing the delivery of your training services?
- How are your training services evaluated? How often?
- What kind of evaluation questions do you ask?
- How are evaluation outcomes used or applied?

## **POST-TRAINING ACTIVITIES AND SUPPORTS**

- How have participants applied their training knowledge and skills following the program?
- What type of follow-up support or assistance is provided to participants following their initial training?

## **TRAINING COLLABORATIONS**

- Does your service or program collaborate with other training services? Explain the nature of this collaboration.
- Does your service or program collaborate or contract with specific government or departmental organizations to provide training services? Explain the nature of this.

## **CAPACITY: EXISTING AND DIRECTIONS FOR ENHANCEMENT**

- How does your training service contribute to building local, provincial or national diagnostic services for FASD?
- Are you aware of other training programs in other jurisdictions? What are the names of these services and briefly describe their scope of training and approach?
- Do you think it would be beneficial to have a national training program that could be made available to service providers in Canada and elsewhere? Explain why or why not.
- How should we begin the development of such a national training program?
- Who or what organizations should be involved in the creation of a national training program for the diagnosis of FASD?