FASD TRAINING STUDY:
Final Report

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Caring Society
OF CANADA

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DEDICATION

To the children, young people, men and women who live with FASD and to the families and communities who love them. May we work together to build the supports needed to ensure that the gifts of all peoples will flourish and be celebrated in our communities.

HONOURING

The First Nations Child and Family Caring Society of Canada wishes to express our sincere appreciation to Kathryn Irvine and Mélanie Vincent who so generously gave of their talents and commitment to produce this important resource for First Nations communities. We are also very honored to work with Pauktuutit Inuit Women of Canada who prepared the portions of the report pertinent to Inuit peoples.

Most of all, we honour all the individuals and organizations who participated in our study who shared their knowledge, their experience of FASD training events and provided suggestions for future improvements.

We also acknowledge the funding support of First Nations and Inuit Health Branch.

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EXECUTIVE SUMMARY

Background

During 2005, First Nations Child and Family Caring Society of Canada joined in partnership with Pauktuutit Inuit Women of Canada to conduct a study to better understand FASD services and non-academic FASD training in First Nations and Inuit communities across Canada. Our study was designed to capture an overall understanding of the kinds of FASD services available in First Nations and Inuit communities and, the extent of FASD training opportunities available to First Nations and Inuit service providers and community members. While a growing body of research and promising practice materials have begun to address the complex FASD matters impacting First Nations and Inuit peoples across Canada, our joint effort to map training opportunities is part of a relatively uncharted territory. We hope to contribute to the growing body of practical knowledge and research in this area in three principal ways:

- By mapping the kinds of FASD services and training opportunities for First Nations and Inuit service providers and communities members across Canada.
- By reporting on the process of our study and highlighting our findings about the kinds of FASD services and FASD training opportunities in First Nations and Inuit communities.
- By formulating recommendations that will provide understandings and insights into why the sustainable development of FASD services and training opportunities must take a priority place in health funding for First Nations and Inuit communities across Canada.

Research Method

According to Indian and Northern Affairs, there are 614 First Nations, Métis and Inuit communities in Canada. Of these 614 communities, 53 are Inuit and 561 are First Nations and Métis. In the collaborative research project between Pauktuutit Inuit Women of Canada and First Nations Child and Family Caring Society of Canada, a total of 724 surveys were sent to 487 or 79% of all Inuit, First Nations and Métis communities and organizations in Canada.

For the 53 communities and organizations serving Inuit peoples, Pauktuutit Inuit Women of Canada distributed 290 surveys by mail, fax and e-mail during a four-week period in September-October 2005. This garnered 63 completed surveys and a response rate of 22%.

During the same one-month time frame, First Nations Child and Family Caring Society of Canada conducted their study by mailing the FASD services and training survey to 434 communities and organizations serving First Nations and Métis peoples resident on reserve. The number surveys completed and returned was 44 - a response rate of 10%. While this response rate may at first glance appear low, a ten percent response rate is within expected levels for survey methodology based studies. In addition, the 44 respondents served at least 236 First Nations and Métis communities or 42% of all First Nations and Métis communities in Canada.

A Summary Of Key Findings

In general, findings from both the First Nations and Inuit surveys mapping FASD services and non-academic training suggest that more FASD training is needed to ensure community-based awareness/primary prevention and to support the delivery of comprehensive and sustainable services for parents, adults, young people, children and infants living with FASD along with their families/caregivers. Despite the sometimes stark political, social and geographical differences between First Nations and Inuit communities, respondents in our study universally recognized the need for a greater breath and depth of on-going training in the areas of prevention, intervention skills/supports, diagnostics and assessments in addition to more comprehensive FASD-related services.

By looking more closely at the findings from our study, specific strategies are urgently needed to ensure that First Nations and Inuit service providers and community members have opportunities to access the comprehensive training in order to provide the supportive and wholistic services capable of reaching our common goal – the eradication of FASD.

SUMMARY OF RECOMMENDATIONS

The following recommendations are based on the survey results. Respondents were universal in their belief that increased investments in holistic community based FASD training and services were critically required. All of the following recommendations mention funding as respondents believed, and we concur, that full realization of the benefits identified in the recommendations will not be possible unless communities receive sustainable and adequate funding. A research project to identify the actual costs to support FASD prevention and intervention services and training is recommended.

Funding

- **It is recommended that adequate and on-going FASD funding is distributed to all First Nations and Inuit communities** to ensure that service providers and community members receive the ongoing and comprehensive training that is needed to provide the essential FASD services that are urgently needed. Findings from the study show that 59% of First Nations and 51% of Inuit service organization do not provide training. Both First Nations and Inuit service respondents also indicated critical gaps in the delivery of services for women and their partners, families/caregivers for people living with FASD across the lifespan.

- Without comprehensive and targeted funding for FASD training, organizations cannot provide the services that will enable First Nations and Inuit communities, families and individuals living with FASD to flourish. To disregard the urgent need for comprehensive and targeted FASD funding will result in on-going and astronomical economic and social costs. For example, data from Health Canada (2001) reported that the lifetime economic, health care, education, corrections and social service costs for a person living with FASD is at least 1.4 million American. At an exchange rate (1.19), a conservative estimate of the lifetime costs for one person living with FASD is about 1.67 million Canadian.

- Given the incredible costs associated with FASD, the 1999 federal budget allocated 3.8 million over three years starting in 2001/2002 to address the issue among First Nations and Inuit communities. However, Health Canada (2001) notes that with more than 600 communities First Nations and Inuit communities, the funding amounts to approximately $2,000 annually per community. It would appear that no matter how strategically the funds are distributed, the urgent need for comprehensive and sustainable FASD training and services will not be met. With a current federal budget surplus of 11.2 billion and a projected surplus over 5 years of 54.5 billion, the cost of doing nothing is reprehensible.

FASD Training

- **It is recommended that First Nations and Inuit organizations provide a full spectrum of on-going and comprehensive FASD training in their communities.** Findings from the study indicate that 94% of Inuit and 87% First Nations respondents stated the need for adequate resources to support additional training opportunities ranging from on-going FASD awareness/primary prevention to advanced and in-depth training in the diagnostic process, assessments, and interventions for *all* groups of people including, parents, adults, young people, children and infants living with FASD.

- **It recommended that First Nations and Inuit organizations ensure that comprehensive, sustainable and accessible FASD training programs are available and accessible to women who are pregnant, young people and adults living with FASD**. Findings from both Inuit and First Nations respondents indicate that some of the most significant gaps in training exist among these groups. Providing sustainable funding to train these groups will result in prevention, decrease health problems and promote the ability for people to flourish in our communities. Here, the necessary supports for this training also include authentic access to transportation and child care.

- **It recommended that First Nations and Inuit organizations provide training for key professional groups who work closely with children, young people, adults and families living with FASD receive training.** First Nations and Inuit respondents indicated that while a number of groups received training, specific professional groups are not targeted. As those most likely to come into contact with First Nations and Inuit children, young people and adults, it is imperative that police and probation/parole officers, judges, lawyers, corrections workers, physicians, psychologists, health workers, teachers and school staff. The profound need for adequately funded training opportunities for these groups is unequivocally recognized among First Nations and Inuit respondents.

- **It recommended that First Nations and Inuit organizations are adequately funded to access *Train the Trainer* workshops.** First Nations and Inuit respondents identified that Train the Trainer workshops would ensure the transfer of FASD knowledge and skills within communities. In turn, this kind of training contributes to and enhances the self-determination and capacity building within communities. This is especially important for rural, remote and isolated communities.

- **It recommended that First Nations and Inuit organizations have provisions for culturally and linguistically congruent FASD training and related materials.** Findings from the study show that 63% of Inuit organizations indicated that FASD training is offered in English and only 30% of training is offered in Inuktitut. First Nations respondents also indicated that 50% of all FASD training is conducted in English. Given the personal and sensitive nature of FASD, both First Nations and Inuit participants stated that FASD training and related materials must meet the cultural and linguistic needs of the community. First Nations and Inuit organizations must have access to trainers fluent in the language of their respective cultures along with access to the resources of interpretation and translation. Currently funding for these services is very limited and needs to be enhanced.

- **It recommended that funding is made available for independent external evaluation of First Nations and Inuit FASD training programs.** Findings show that 69% of Inuit and 46% of First Nations respondents do not use a tool to evaluate the impact of FASD training programs over time. In just the same way that outcome-evaluations are required to ensure that FASD projects, services and activities are accountable to the people they serve, so independent external evaluations of training will ensure that the objectives and outcomes of training are fully transparent and accountable for the services provided to First Nations and Inuit community members, front-line workers and professional groups.

FASD Services

- **It is recommended that First Nations and Inuit organizations be supported to provide the full spectrum of FASD services that are essential to community well-being.** While First Nations and Inuit service organizations provide a range of services, key services for some of the most vulnerable groups are offered with considerable less frequency. Both First Nations and Inuit respondents indicated that employment services, respite for caregivers, group counseling and peer support for women and ongoing support for adults living with FASD are among the least frequently offered services. With the funding to fill these profound gaps in services, community capacity will be enhanced and the well-being of community members will be strengthened.

- **It is recommended that First Nations and Inuit organizations are adequately funded to create and sustain specialized programs capable of addressing the needs woman.** Survey results show that 96% of Inuit organizations 77% of First Nations organizations do *not* provide counseling services for women. Only 30% of Inuit organizations and 36% of First Nations organizations offered counseling services for women and their partners. Adequate funding will ensure programs capable of addressing the broad determinants of health impacting the lives of women who are pregnant and women in their child-bearing years that use alcohol and/or alcohol and drugs. In turn, supporting sustainable secondary prevention programs for women will reduce the risk of FASD.

- **It recommended that First Nations and Inuit organizations have access to funding to develop sustainable FASD infrastructure in the area of diagnostics.** Findings indicate that 89% of Inuit organizations and 98% of First Nations organizations do not provide diagnostic/assessment services. As the foundation of tertiary FASD prevention, access to diagnostic services provides early identification of FASD and access to multidisciplinary care including, medical support, counselling, speech therapy, teaching assistance and family support. In turn, the quality of life is improved for those living with FASD and their families/caregivers.

FASD Partnerships

- **It recommended that First Nations and Inuit organizations receive authentic support in developing sustainable partnerships and networks of collaboration.** Respondents from our study indicated that spectrum of on-going training is needed ranging from basic FASD prevention/awareness to advanced in-depth workshops dealing with diagnosis and interventions. In addition, findings suggest that additional services are needed across all Inuit and First Nations regions. Creating linkages between and among First Nations and Inuit communities will ensure that culturally-grounded expertise, information and resources can be shared. In turn, networks of support will be established across sector and regional boundaries. For example, a comprehensive and updated national database of First Nations and Inuit FASD training opportunities and service providers in addition to provincial and national Aboriginal FASD websites are just two mechanisms capable of promoting collaboration across all sectors. In turn, strengthening relations between and among First Nations and Inuit communities will enhance the capacity of communities and support the creative and innovative development of FASD resources, training and services for and by First Nations and Inuit communities. Authentic support to establish and maintain partnerships and collaborative networks is especially vital for the development and implementation of culturally meaningful projects, activities and the delivery of services for all First Nations and Inuit peoples - especially for those living in rural, remote and isolated communities.

FASD TRAINING SURVEY

This report presents the findings of a national survey mapping out the Fetal Alcohol Syndrome Disorder (FASD) training opportunities for First Nations peoples – specifically, the kinds of training programs provided, who delivers FASD training programs, associated fees, barriers for potential participants and structures of support available before, during and after training.

Overview of the Study

During August to October 2005, the First Nations Child and Family Caring Society of Canada undertook a study to gather information about FASD services and non-academic FASD training opportunities in First Nations communities across Canada. Working in partnership with Pauktuutit Inuit Women of Canada, the objectives of the study were to:

- Conduct a survey of FASD services and non-academic FASD training opportunities in First Nations communities across Canada

- Formulate recommendations based on the findings that First Nations communities can use create and sustain truly responsive, accessible and culturally congruent FASD services and training initiatives.

In addition to exploring the specific types of FASD services and training available in First Nations communities including, diagnostics and home visits, the design of the questionnaire also included a number of questions related to the nature of FASD training in First Nations communities including:

- What groups are being targeted for existing FASD training?

- Are there any financial costs associated with FASD training?

- How is FASD training evaluated?

- What are the potential barriers and risks associated with FASD training for First Nations service providers and community members?

- What mechanisms of support are available for First Nations community members and service providers before, during and after FASD training?

Methodology

The questionnaire employed in this study was adapted from an online survey used by Canadian Center for Substance Use (2005). Modifications and additions to the original survey increased its scope and provided a format specific to First Nations FASD service providers. As the development of the questionnaire progressed, the First Nations Child and Family Caring Society research team met with our project partner, Pauktuutit Inuit Women of Canada along with the project stakeholder from First Nations and Inuit Health Branch (FNIHB) and research consultants from the Public Health Agency of Canada and the Canadian Center on Substance Abuse to review a draft version of the questionnaire. Feedback from the group meeting was incorporated into a revised version of the questionnaire.

Minor edits ensured the smooth translation of the questionnaire into French. Both the French and English versions of the questionnaire were designed to be completed in hardcopy/paper format and could be downloaded in HMTL format from the First Nations Child and Family Caring Society website (www.fncfcs.com). The layout of the questionnaire consisted of four parts:

- Organizational Information (Part I, 8 questions)
- FASD Services (Part II, 3 questions)
- FASD Training (Part III, 17 questions).
- Overview of FASD Training (Part IV, 1 question)

The questionnaire primarily consisted of short, closed-ended questions with exhaustive response categories depending on the question (e.g., other, please specify/describe). The final section of the questionnaire (Part IV) consisted of one open-ended question. The questionnaire has been included in Appendix A of this report.

Sampling

Currently, there is no pre-existing national list of FASD training opportunities for First Nations service providers and community members. As a result, a sample of 434 potential participants was purposively selected from a variety of sources including, a membership lists obtained from the First Nations Child and Family Caring Society, provincial Aboriginal Health Access Centre Internet listings and from regional FASD directories.

When possible, telephone calls prior to the mailing of questionnaire provided updated contact information. Personal contacts also played an important role in establishing connections with front-line FASD workers, First Nations social workers, healthcare providers, government officials and agency directors. Members of the e-mail discussion group, FASlink[1] also provided a rich network of important information and extremely helpful contacts across Canada.

The Questionnaire

Once the questionnaire was developed and formally approved by First Nations Child and Family Caring Society and First Nations and Inuit Health Branch, contacting potential respondents was handled in two ways. In the Québec region, the majority of participants were contacted by telephone during August and September 2005. Here, the researcher in Québec followed the exact interview schedule from the FASD questionnaire. As the researcher conducting the study in Québec fluently spoke the French language and had extensive connections with First Nations service providers, this method of completing the surveys was most effective and resulted in a higher response rate.

During September and October 2005, the FASD questionnaire package was mailed to First Nations service providers throughout Canada. The package contained a cover letter printed on the letterhead of the First Nations Child and Family Caring Society, the FASD questionnaire and a self-addressed return envelope. The cover letter has been included in Appendix A of this report.

The cover letter provided an introduction to the research project and the contact information (names and e-mails) for the project coordinator, the respective research associates conducting the study in French and English along with the name of our project partner, Pauktuutit Inuit Women of Canada. We also outlined the importance of the study in providing the evidence-base supporting the needed funding to provide responsive FASD training and services in First Nations communities.

With our respectful request to participate in the study, the cover letter also provided our assurance that all information gathered would be treated confidentially and that we would not be releasing any identifying organizational data. Finally, we clearly stated our ethical commitment that each organization participating in the study would receive a copy of our final report. Each cover letter was hand-signed by one of the project researchers.

The return of the questionnaires was considered to be consent to participate in the study. In some instances, participants chose to download the questionnaire from the First Nations Child and Family Caring Society website and e-mail their responses directly to either of the two research assistants. These questionnaires were downloaded and stored in a password protected file on a secure and password protected computer. All the questionnaires completed and returned were stored in a locked filing cabinet in a secure office.

Follow Up

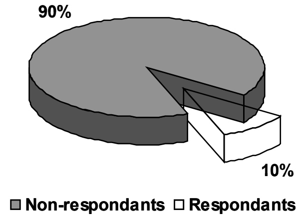
When possible, reminder phone calls were made to potential participants two weeks following the mailing. During the telephone calls, the research project was discussed and potential participants were invited to complete the questionnaire in a number of different ways including, a telephone interview, downloading the questionnaire from the website or, having it re-mailed or faxed. While pressing time constraints and financial limitations severely diminished the opportunity to call those who did not initially respond, phone conversations with key-contacts provided in-depth understandings surrounding the non-return of the questionnaire. The limitations section at the end of this section more fully describes the follow-up process and suggests some of the reasoning about non-responses.

If e-mail correspondence had already been established, a reminder note was sent two weeks following the mailing. In each reminder e-mail, the purpose of the study was briefly reviewed and an invitation was extended to complete the questionnaire through a telephone interview, downloading it from the website, or by having it e-mailed or faxed.

Every effort was made to locate potential participants whose questionnaires were returned as a result of incorrect addresses and/or contact information. This involved checking and cross-referencing information with the initial contact sources and/or publicly available directories. When possible, directly contacting the respective organization and speaking with key-contact personnel provided in-depth understandings surrounding the return of the questionnaire. The reasons given for non-participation are also addressed more fully in the limitations sections.

Working from a population sample of 434, the overall response rate was 10% or, a sample size of N=44 as shown in Figure 1. Tables 1 and 2 provide a more detailed breakdown of the response rates overall and by region. By clustering responses into geographical regions, the anonymity of each organization is protected.

Figure 1 Sample Size



DATA ANALYSIS

The data analysis section summarizes and descriptively describes the information submitted. Part I provides an overview of the organizational information including, the job title of respondents, the location of the organizations (on/off reserve), the number of communities served and the geographical location of the organizations (urban, rural and remote). Part II describes the kinds of FASD services provided including, diagnostics/assessments and home visits. Part III, provides a description of the types of FASD training, fee structure, potential barriers and risks along with systems of participant support, the training evaluation process, accreditation and, respondents thoughts on the kinds of FASD training opportunities that are needed. Part IV consists of one open-ended questions asking participants if there is any addition information about FASD training that might be helpful in our study. Part V provides a discussion of the findings and recommendations for improved FASD training and services.

Background

More than thirty years ago, researchers coined the term Fetal Alcohol Syndrome (FAS)[2] to describe a group of irreversible symptoms that result from prenatal exposure to alcohol including, pre/and or postnatal growth deficits, facial abnormalities and damage to the functioning of the central nervous system. However, as study in the area continued, it was recognized that while some people met the full criteria for FAS, others present along a continuum of severe to mild to cognitive damage, with and without the classic facial features and face a broad spectrum of developmental, behavioural, cognitive, social and emotional challenges. Here, the term Fetal Alcohol Effects (FAE) was used to describe those who have some but not all of the characteristics of FAS. More recently, the term Fetal Alcohol Spectrum Disorder (FASD) is used to capture the sometimes complex continuum of FAS effects ranging from partial FAS (pFAS), Alcohol-Related Birth Defects (ARBD) and Alcohol-Related Neuro-developmental Disorders (ARND) (Chudley et al., 2005; Sampson et al., 1997).

Prevalence

Eight years ago, Able (1995) estimated the overall incidence of FAS to be between 0.97 per 1000 live births. Only three years later, research based on three population studies estimated the incidence of FAS to be between 2.8 per 1000 live births and 4.8 per 1000 live births with the combined incidence of FAS and ARND to be at least 9.1 per 1000 and 4.8 per 1000 live births (Sampson et al., 1997). However, caregivers, front line workers, and researchers recognize that the accuracy of FAS and FASD prevalence rates are consistently under-identified and routinely undiagnosed[3] (Sokol, Delaney-Black, & Nordstrom, 2003; Stoler & Holmes, 1999; Sampson, et al., 1997).

Despite the difficulty in determining prevalence rates, a preponderance of research has focused on the high rates of FAS and FASD among Aboriginal peoples in Canada. For example, twenty years ago, researchers determined that the prevalence rates of FAS and/or FAE was 46 per 1000 among Aboriginal children in the Yukon and 25 per 1000 among Aboriginal children in northern British Columbia (Asante & Nelms-Matzke, 1985). Researchers also estimated that among Aboriginal children (1 to18 years of age) living on-reserve in a remote community in British Columbia, the prevalence of FAS and/or FAE was 190 per 1000 live births (Robinson, Conry & Conry, 1987). In a study of another First Nations community in Manitoba, researchers declared that FAS/FAE had reached epidemic proportions with an approximate prevalence rate of about 100 per 1000 live births (Square, 1997). Reporting on their work in a northern community in Manitoba, researchers estimated that the prevalence of FAS was 7.2 per 1000 live births (Williams, Odaibo & McGee, 1999).

While this body of research tends to suggest that FAS and FASD are more prevalent among Aboriginal women than non-Aboriginal women, researchers caution against such an interpretation. Here, missed diagnosis, differences in diagnostic criteria, non-representational sampling and the lack of studies on the prevalence of FAS/FASD among the non-Aboriginal population in Canada suggest some of the factors that make such a comparison difficult if not invalid (Chudley, et al., 2005; Roberts & Nanson, 2000; Abel, 1995)

Risks not Rates

Rather than focusing on prevalence rates, some researchers have suggested that the development of responsive prevention and effective intervention programs might best begin by examining the factors contributing to an increased risk of FAS and/or FASD (Sampson et al., Abel, 1995). Here, factors such as poverty, poor nutrition, exposure to violence, psychological stress, social isolation and use of other drugs as just some of the variables associated with an increased risk of FAS and/or FASD (Abel & Hannigan, 1995; Bray & Anderson, 1989). A number of risk factors linked to pregnancy outcomes have also been linked to male partners (Gearing et al., 2005; Abel, 2004; Frank et al., 2002).

In considering risks rather than prevalence rates, factors such as poverty and marginalization, not ethnicity, tends to create conditions that are likely to give rise to FAS and FASD. As Poole (2003) explains, this broader understanding of women's health is vital in FASD prevention:

> *To be effective in FASD prevention efforts, we need to move from a focus on women's alcohol use alone to increased understanding of related health and social problems experienced by women that contribute to FASD, and to provide a network of supports that directly address these contributing factors* (p.5).

With an understanding of the broader determinants of health that impact women's well-being, Poole (2003) maintains that the foundation for effective FASD prevention can begin to be built. Here, understanding the broad determinants of health is especially important given the chronic poverty impacting Aboriginal women's lives along with the frequent and often extreme experiences of personal, social and institutional discrimination on the basis of race, gender and class (Brown & Fiske, 2001; Department of Indian Affairs and Northern Development, 1996; Royal Commission on Aboriginal Peoples, 1996a, 1996b). As well, Aboriginal women's disproportionate experience of violence and sexual abuse, over-involvement with child welfare, extraordinarily high rates of incarceration and the intergenerational impact of the residential schooling system all play a role as possible factors in their maternal health (Bennett, Blackstock & De La Ronde, 2005; Neve & Pate, 2005; Blackstock, 2003; Tait, 2003; Greaves, Varcoe, Poole, et al., 2002; Dion Stout, Kipling & Stout, 2001; Fournier & Crey, 1997).

As a more holistic understanding of health is applied in understanding the maternal well-being of Aboriginal women, a growing body of literature has also pointed to the importance of understanding FASD within the context of community wellness. Here, authors have documented the innovative FASD services and training programs designed by and for Aboriginal communities (Ontario Federation of Indian Friendship Centers, 2005; Maguire et al., 2003; Anderson, 2002; Pauktuuit Inuit Women's Association, 2001). As authors have pointed to the strengths and rich resources of Aboriginal communities addressing FASD, they also have stressed the paramount importance of community-based services and training.

This report presents the findings about the kinds of FASD services available in First Nations Communities and the types of FASD training that is accessible for First Nations community members and service providers.

Limitations

The data in the study provides a rich sense the comprehensive skills and resources needed provide meaningful FASD training and services. However there are several limitations to this study that should be addressed. First, although the data in this study represents 44 organizations serving more than 236 communities (42% of all First Nations and Métis communities), the size of the sample (10%) suggests that caution should be taken in generalizing from the findings. Second, the sampling methodology was varied. While those invited to participate by phone showed a higher response rate, questionnaires returned by mail provided more detailed information and richer qualitative data.

Time constraints also factored as a limitation in the study as the survey had to be completed and returned in four weeks. This limited the opportunity to increase participation rates through the use of reminder cards. For example, with 434 potential respondents, financial constraints limited the opportunity to proceed with mailed follow-up reminder cards, place follow-up phone calls or systematically clarify information on the 44 questionnaires submitted.

Within the context of these methodological concerns, the technique of a self-administered mailed questionnaire in addition to the high service demands may have contributed to the low response rate. As discussed, data from the 44 organizations that did respond indicated that they provided FASD services in at least 236 communities. In addition, 12 organizations that returned their surveys after the data was analyzed and complied indicated that they served at least 38 communities. Here, the pressing service demands within many First Nations organizations may have contributed to the low response rate. As one potential participant explained, "*It's just me. I'm not sure when I will have time to open the package let alone read it*." This response was echoed by others who mentioned that our questionnaire was one of 6 they received during the week.

The methodology of a self-administered questionnaire also does not address the numerous social science survey research projects that have failed to contribute to the development of authentic services and support the creation of programs to address the needs of First Nations communities. As one respondent stated, "*We've been surveyed to death*!" Here, the time and financial constraints of our study prevented the possibility of comprehensive telephone and face-to-face contacts that may have significantly reduced the reluctant participation of potential respondents.

Finally, of the 12 organizations retuned their surveys after the data was analyzed and compiled, eight indicated that while they had received the survey package, their respective First Nation communities did not provide any of the FASD services mentioned in our questionnaire nor had they received any FASD training during April 2004 and March 31, 2005. As two respondents stated in writing across the tops of their blank returned surveys, "*This does not apply – we have no FASD services or training*." Here, a greater opportunity to conduct follow-up phone calls and contacts may have revealed that notable number of non-responses could be attributed to the lack of FASD services and training. That is, the survey did not apply to those organizations and communities that did not have FASD services or access to FASD training. At the very least, these eight respondents provide all the reasons we need to start to take seriously the funding that is urgently needed to support First Nation FASD service providers in the professional training that will ensure that early intervention and prevention can begin.

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FASD Training Survey: A Summary of the Findings

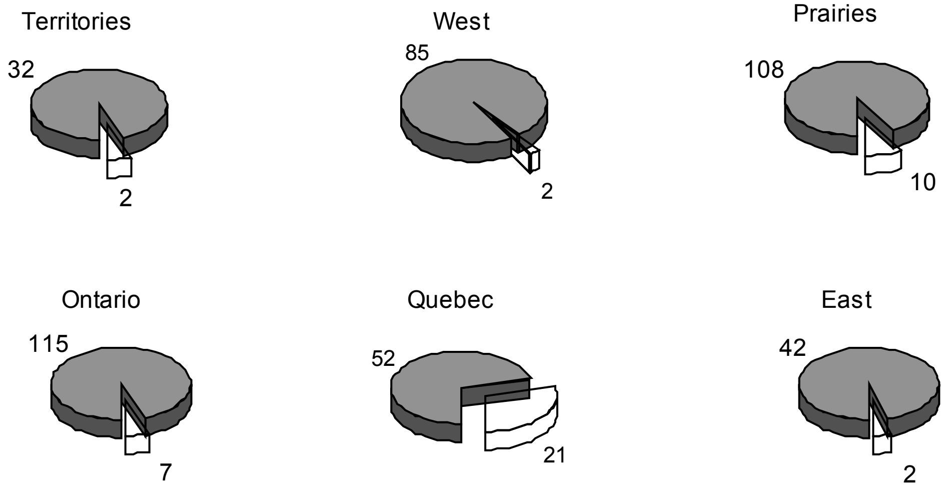
Participation Rates

As Figure 1 showed, the overall response rate was 10% or a total sample size of N=44. Table 1 (below) provides a more a breakdown of the geographical regions and detailed summary of the participation rates by each region.

Table 1 Participation Rate by Region

Region	Provinces/Territories	Sample		
Territories	NWT, Yukon	32	2	6%
West	British Columbia	85	2	2%
Prairies	Alberta, Manitoba Saskatchewan,	108	10	10%
Ontario	Ontario	115	7	6%
Québec	Québec	52	21	40%
East	New Brunswick, Nova Scotia, PEI, Newfoundland	42	2	5%

Figure 2 Completed Questionnaires by Region



FASD Training Survey

The following report presents a summary of the FASD training survey as documented by 44 organizations. The report has been divided into four categories:

- **Organizational Information**
- **FASD Services**
- **FASD Training**
- **Additional FASD Information**

In order to ensure the confidentiality of organizations, many of the responses to the questions have been presented in aggregated data only. In addition, it is important to remember that the number of responses for each question is sometimes greater or less than the total sample size of 44. For example, in question A4 some organizations identified as being both a non-profit and as a community grassroots organization so there are more than 44 responses. Non-responses or skipped questions often account for a sample size of less than 44. For each question, we have documented the number of respondents and Appendix B provides a detailed summary of the aggregated data.

In the first section of the report, a series of eight background questions were asked in order to clarify basic administrative information including: respondents job positions, the date the organization was established and the kind/type of organization. In addition, this fist section also asks about general demographic information including: the number of communities each organization serves, the distance the communities are from the main office, the geographical location of each organization and the distance each organization is from a town/city with full services. Part I provides the summary findings for each of these questions.

FASD Training Survey

Summary of the Findings

PART I Organizational Information

A1 In general, the majority of respondents (N=42) indicated that they held positions as Program Administrators within their organizations. By geographical region, respondents from Territories indicated that they held positions as Senior Administrators. In the West, participants identified as Program Administrators. In the Prairie region, half the respondents identified as Senior Administrators. In Ontario, Program Administrators, Senior Administrators and Frontline Workers responded equally. In Québec and the East, the majority of respondents indicated that they held positions as Program Administrators. Overall, the majority of respondents identified as Program Administrators (40%). Table 2 shows the breakdown of participants' job positions within their organizations.

Table 2 Job Position with Organization

Position with Organization	Overall #	Territorieß #	West #	Prairies #	Ontario #	Québec #	East #
Program Administrators*	**17** (40%)		2	2	2	9	2
Senior Administrators**	**11** (26%)	2		5	2	2	
Front Line Workers***	**7** (17%)			1	2	4	
Nurses	**4** (10%)			1		3	
Consultants	**3** (7%)			1		2	

***Program Administrators**

▣ Managers of Services
▣ Project Coordinators
▣ Program Coordinators

**** Senior Administrators**

▣ Executive Directors
▣ Organization Managers
▣ Chief Executive Officers

*****Front Line Workers**

▣ Support Workers
▣ Drug/Alcohol Workers
▣ Women's Health Workers
▣ Health Worker

A2 In question A2, participants were asked to identify the year that their organization was established. Table 3 shows that of 26 of 44 participants (59%) responded to this question. One participant identified that the organization had been established prior to the 1950s and one was established in the 1960s. Of the remaining 24 organizations, three were formed in the 1970s and six were founded in the 1980s. The majority of organizations (N=10) were established in the 1990s. Five participants indicated that their organizations had been founded in 2000 to present.

Table 3 Date Organization was Established

Date	Pre 1950s	1950 - 1959	1960-1969	1970-1979	1980-1989	1990-1999	2000 to Present
# of Organizations	1		1	3	6	10	5

A3 This question asked participants to identify the location of the organization's main office. Here, 31 of 44 respondents indicated that their main office was on-reserve. In the Québec region, participants overwhelming identified as being on-reserve while in the Territories, participants identified as off-reserve. As one respondent from the Territories noted, this region tends not be comprised of reserves. Table 4 shows a detailed summary of the responses for organizational location

Table 4 Location of Main Office

Location of Main Office	Overall #	Territories #	West #	Prairies #	Ontario #	Québec #	East #
On-Reserve	**31** (70%)		2	6	3	19	1
Off-Reserve	**13** (30%)	2		5	3	2	1

A4 In this question, participants were asked to identify the type of organization they belonged to. Of 44 respondents, 21 identified their organizations as non-profits and 11 identified their organizations as community/grassroots. In the category of "Other," 16 respondents identified their organizations as Health Centers and Regional Health Authorities. Table 5 shows a more detailed breakdown of the types of organizations with multiple responses.

Table 5 Type of Organization

Type of Organization	Overall #	Territories #	West #	Prairies #	Ontario #	Québec #	East #
Social Service	**9** (20%)			3	3	3	
Non-Profit	**21** (47%)	2	2	9	5	3	
For-Profit	**3** (7%)					3	
Community	**11** (25%)			7	1	1	2
Government	**3** (7%)		1		1	1	
Other	**16** (36%)			1	1	14	

A5 This question asked participants to identify how many communities their organization serves. Here, data indicated that 44 organizations serve a total of 236 communities. However, this astoundingly disproportionate figure may be a conservative number as 15 respondents checked the community served but did not specify a number (for example, 3 First Nations). These check marks were counted as "1." Findings also indicate that more than half of the 236 communities served, 130 were First Nations. In sum, data indicates a very small number of organizations (N=44) are providing FASD services to a disproportionately large number of communities (236) the majority of which are First Nations communities. Below, Table 6 shows a detailed summary of the numbers of communities served.

Table 6 Communities Served

Communities Served	Overall #	Territories #	West #	Prairies #	Ontario #	Québec #	East #
First Nations	**130**	4	1	13	30	65	17
Inuit	**18**	2				16	
Innu	**2**					2	
Métis Settlements	**17**	2	5	7	2	1	
Rural Town(s)	**48**	2		27	19		

Small City/ies	**13**	2		4	7		
Military Base(s)	**1**			1			
Other	**7**	2		1	1	2	1
TOTALS	**236**	**14**	**6**	**53**	**59**	**86**	**18**

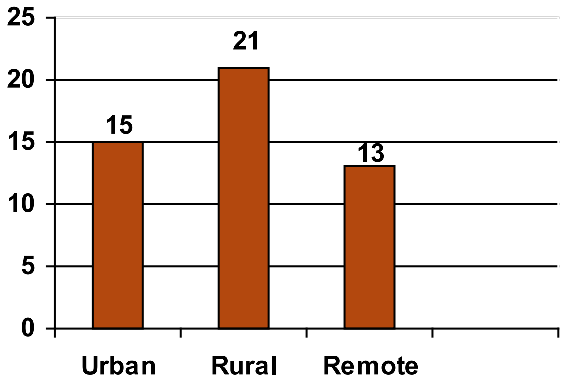
A6 Looking at the distance between the organization's main office and the communities served, a total of 38 respondents indicated that their travel distance ranges from 0 km to 2000 kms. Because each organization served on average 5 communities, multiple responses were given. Table 7 reports the findings of average travel distance in aggregate form.

Table 7 Travel Distance to Communities Served

km Traveled	0-50 km	51-100 km	101-200 km	201-300 km	301-400 km	401-700 km	701-2000 km
	26	5	4	3	2	2	1

A7 Considering the geographical location, findings from 44 respondents indicated that 21 organizations are situated in rural areas. In Ontario and the Prairie regions, the majority of organizations who responded identified as being from rural communities. In Québec, organizations were equally representative in the urban and rural settings. Because some respondents identified as both urban and remote or rural and remote, Figure 3 shows the aggregated data with multiple responses for geographical location.

Figure 3 Geographical Location



A8 In the final question of Part I, participants were asked to identify the distance from their main office to the nearest city/town with full services. Of a total of 31 respondents (with multiple responses), the majority reported traveling between 0-100 kms while others indicated that they traveled up to 900 kms to access a city or town with full services. Table 8 shows the aggregated distances that workers must travel to access a city or town with full services.

Table 8 Distances to City/Town with Full Services

Kms Traveled	0-100 Kms	101-200 Kms	201-300 Kms	301-400 Kms	401-500 Kms	501-600 Kms	601-700 Kms	701-800 Kms	801-900 Kms
	30	5	6	3	2	1	1	2	1

Part II Kinds of FASD Services

This section of the questionnaire asks about the kinds of FASD services available and whether diagnostics/assessment services and home visits are provided.

B1 In this question, 44 respondents were asked to identify the kinds of FASD services provide by their organization. Table 9 provides a detailed breakdown of responses.

Table 9 Kinds of FASD Services

Kinds of Services	Overall #	Territories #	West #	Prairies #	Ontario #	Québec #	East #
Peer mentoring for women . . .	**17**	1	1	4	1	10	
Support for families with children	**24**	1	1	7	3	12	
Group counselling for women...	**10**	1		3	1	5	
Individual counselling for women and partners...	**16**	1	1	3	2	9	
Advocacy . . .	**12**	1		5	3	2	1
Support for adolescents . . .	**20**	1	1	6	2	10	
Nutritional programs . . .	**21**	1	1	3	2	13	1
Referrals in community . . .	**36**	2	1	10	5	16	2
Teen awareness . . .	**29**	1	1	5	4	17	1
Respite for caregivers...	**12**			3	1	7	1
On-going support for adults...	**14**	1	1	3	1	8	
Community education/training. . .	**33**		1	10	4	16	2
Employment services . . .	**4**	1		2			1
Profession training (for credit). . .	**10**	1	2	3		2	2
In-service training(not for credit)	**27**		1	8	3	13	2
Research . . .	**7**			2	1	3	1
Recreation for people living with FASD . . .	**9**	1		2	3	3	
Recreation for caregivers . . .	**6**	1		2	2	1	
Resource/lending library...	**19**		1	2	2	13	1
Other . . .	**20**		1	1	1	16	1
TOTALS	**346**	**15**	**14**	**84**	**41**	**176**	**16**

Considering that only 44 agencies provide FASD services for at least 236 communities (Table 6), the data indicates a certain range and diversity of FASD services. For example, 44 organizations provide 346 services across 20 different programs. As Table 9 indicates, more than half the responding organizations reported offering FASD services in 5 critical areas:

- Referrals in the community (N=36)
- Community education/training (N=33)
- Teen awareness/education/prevention (N=29)
- In-service training (not for credit) (N= 27)
- Support for families with children (N=24)

However, on average, fewer organizations offer FASD services in the following areas:

- Individual counselling for women and their partners (N=16),
- Peer mentoring for women (N=17),
- Resource lending library (N=19),
- Ongoing support for families with adolescents (N=20)
- Nutritional program (N=21).

A group 20 FASD services providers also indicated the provision of "Other" services in the areas of community awareness, support for caregivers and services for those living with FASD including:

- FASD Day community activities
- Translation services
- Community FASD newsletters
- FASD prevention T-shirts
- Support groups for adults living with FASD
- Community forums on FASD
- Development of special learning materials
- Integrative play
- Community-based psychosocial interventions
- Community information booths
- Poster contests in the community
- Support groups for caregivers
- Community coffee meetings

Although Table 9 summarizes the broad range of FASD services that are provided by a very few number of organizations, there is evidence of significant gaps in services. The data indicates that almost half the range of FASD services were provided by 14 or fewer of the 44 organizations. Here, some of the most foundational FASD services are among the least available including:

- Employment services (N=4)
- Recreation for families/caregivers (N=6)
- Research (N=7)
- Recreation for people living with FASD (N=9).
- Group counselling for women and their partners (N=10)
- Ongoing professional training for credit (N=10)
- Respite care (N=12)
- Advocacy (N=12)
- Ongoing support for adults living with FASD (N=14)

As shown in Table 9, it appears that the Québec region offers the most extensive FASD services. However, this interpretation of the data partly reflects the different methodology used to survey FASD service providers across Canada as discussed in the Methodology section. Looking at the results from the Territories, West, Prairies, Ontario and the East provide a different understanding of range of FASD services provided by the 23 representative organizations. Working with the information about FASD services provided from these five regions (N=23), we see that only 8 or less organizations provide the bulk of some of the most essential FASD services including:

- Employment services (N=4)
- Research (N=4)
- Respite for caregivers (N=5)
- Group counselling for women (N=5)
- Recreation for families/caregivers (N=5)
- Ongoing support for adults (N=6)
- Recreation for those living with FASD (N=6)
- *Resource/lending library (N=6)
- *Peer mentoring for women (N=7)
- *Individual counseling for women and their partners (N=7)
- *Nutritional programs (N=8)
- Professional training for credit (N=8)

On one level, it appears that although Québec organizations offer 51% of the total number of FASD services based on a response rate that represents 48% of the total sample, their rate of services is generally the same as the rest of Canada. However, on closer analysis, the services identified with an asterisk (* Resource/ lending library, Peer Mentoring for women, Individual counselling for women and their partners and Nutritional programs) are being delivered in the rest of Canada with considerably less frequency than in Québec. For example, 13 of the 21 organizations in Québec (62%) offer FASD resource/lending libraries. In the rest of Canada, only 6 of the 23 organizations (26%) offer the same service. A similar scenario is repeated in the frequency of nutritional services offered. In Québec, 13 of the 21 organizations (62%) offer nutritional services. In contrast, only 8 of the 23 organizations (35%) in the rest of Canada offer the same program.

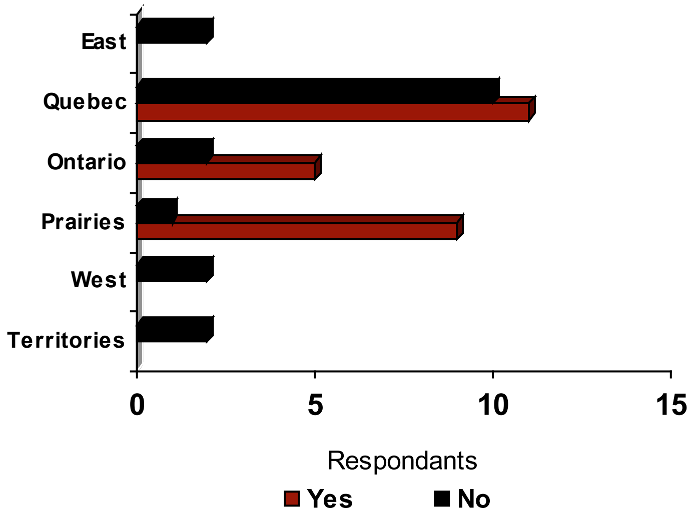
B2 In this three-part contingency question, we asked (1) if organizations provided diagnostic/assessment services, (2) if so, the total number of people diagnosed with FASD in 2004 and (3) the total number of people diagnosed (by age group).

Information provided by the 44 organizations indicated that FASD diagnostic/assessment services are overwhelmingly *not* available within communities. There was only one exception to this. With an extremely limited number of diagnostic/assessment services accessible for First Nations communities, anonymity is required to protect the one respondent and the data they provided for the remaining 2 parts of question B2. In sum, 43 of the respondents indicated that their organizations do *not* provide FASD diagnostic/assessment services. As one frontline First Nations FASD worker explained, even if there were diagnostic/assessment First Nations communities, Band Orders often prevent this type of statistical information from being released without prior Tribal approval.

B3 With regard to home visits, 25 organizations responded that they offered home visits and 19 indicated that this service was *not* available. In other words, of 44 organizations responding, 57% offered home visits and 43% did not. As Figure 4 shows the distribution of home visits are across the regions, it is interesting to note that no organizations in the East, West and Territories provided this service. However, as shown in Table 1, the respective respondent rates for the East (5%), West (2%) and Territories (6%) suggests that a generalized statement about the lack of home visits in these regions cannot be made.

Although the responses indicate that more than half the organizations (57%) provide home visits, this figure may be inflated as the question did not specify whether the home visits were directly related to FASD needs. In addition, because the frequency and duration of FASD-related home visits was not addressed, we have no idea of how comprehensive home visitations are.

Figure 4 Home Visits

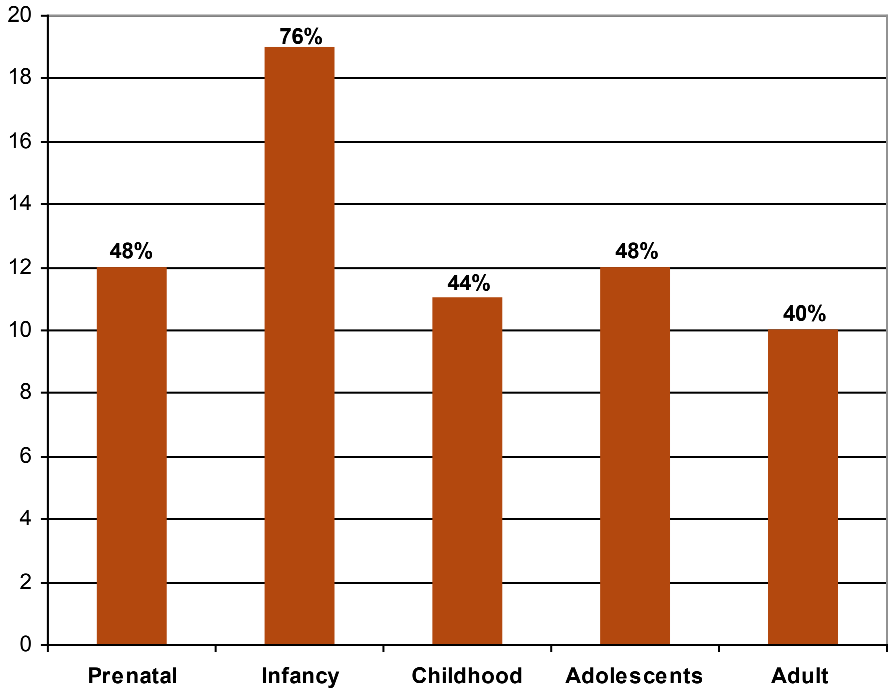


In addition to asking about home visits, we also addressed two related questions: (a) who provides home visits and, (b) at what developmental stage do the home visits take place. Of the 25 respondents who indicated that home visit take place, 48% reported that the people providing the service are nurses. Social workers comprised 28% of the total number of people providing home visits and outreach workers represented 16%. It is interesting to note that 68% of FASD home visits are provided by the following workers whose job positions were not included in the question categories:

- Restorative Justice Workers
- Executive Directors
- Community Alcohol & Drug Counsellors
- Mothers to be Mentors
- Family Counsellors
- Community Health Representatives
- Child Care Educators
- Parent Association Workers

In the second part of question B3 we asked respondents to indicate during what developmental stage home visits take place. Of the 25 organizations that provide home visits, 19 (76%) indicated that this service is provided during infancy (birth to 4 years of age). Home visits during all other stages of development were provided by only 40% to 48% of the 25 organizations. For example, home visits during the prenatal and adolescents (13-18 years of age) were offered by 12 or 48% of the organizations. During childhood (5 -12 years of age) 11 organizations (44%) provided home visits. Only 10 or 40% offered home visits during adulthood (18 years of age and up). Figure 5 shows the development stage of home visits and Appendix B (question B3) shows the aggregated data.

Figure 5 **Developmental Stages of Home Visits**



PART III FASD TRAINING

Throughout the world, there is a growing recognition that while the effects of maternal exposure to alcohol are irreversible, FASD is preventable. Increasingly, governmental and non-governmental organizations have recognized that professional service providers play a critical role in community awareness and prevention. Through the training of professional service providers including, nurses, counselors, community heath workers, educators, physicians, social workers and psychologists will be prepared to address FASD prevention and integrate proposed FASD interventions into practice. In Canada, recommendations since 1979 have recognized that professional training is essential in building knowledge about FASD, increasing public awareness, developing prevention strategies, providing accurate assessments, enhancing counseling skills and is instrumental in the design of effective services[4].

The purpose of this section is to explore the training opportunities available in First Nations communities. Specifically, we asked about the kinds of FASD training programs, the funding structure for training and who create the FASD training program(s). In addition, we also asked about the language of training, availability of child, accessibility of training sites, methods of evaluation and the potential barriers, risks and supports associated with FASD training.

C1 In this question, organizations were asked about where their FASD training sessions were held. Of the 35 organizations that responded, 11 (31%) responded that they were held in schools and 22 (63%) indicated that training was held in locations throughout the community (for example, Band offices, community halls). Of the 9 organizations that responded to "Other," 7 indicated that they traveled outside the community to attend training and two did not specify the locations. Table 10 presents the aggregated data with multiple responses.

Table 10 Location of FASD Training

Location	Total Number
In-house (at your agency)	10 (29%)
On-line	2 (6%)
Video	1 (3%)
In school(s)	11 (31%)
Various Locations In the community	22 (63%)
In conjunction with other agency's program	9 (26%)
In private residence	2 (6%)
Other	9 (26%)

C2 This question asked respondents about whether or not the organization they are affiliated with created its own FASD training program(s) and, if not, what programs were adopted or adapted. Among the 8 organizations that created their own training program, one training program was created in the 1980s while the remaining 7 created their FASD training programs between 2000 and 2005.

As Table 11 shows, an overwhelmingly number of respondents indicated that their FASD training programs were not designed by their respective organizations. As the aggregated data indicates 36 of the 44 organizations or 82% did not create their own FASD training programs.

Table 11 Creation of FASD Programs

Creation of Own Program	Total Number
Yes	8 (18%)
No	36 (82%)

For the majority that indicated "no," we asked respondents to describe what programs were adopted or adapted by their organizations. Here, two respondents indicated that their organizations worked with community-based resource people to create their own program and one organization worked in collaboration with another community organization. While two organizations indicated that they had used the services of both an American and Canadian consultant, the overwhelming majority indicated that their organization adapted or adopted FASD programs from the training provided by a single Canadian consultant.

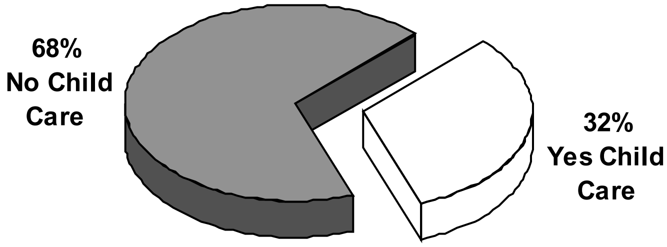
C3 This question asked participants whether their training facilities were accessible for people with disabilities. Of 39 organizations that responded, almost one third (31%) indicated that their training facilities are not accessible of people who are disabled.

Table 12 Accessibility for People who are Disabled

Accessible	Total # Number
Yes	27 (69%)
No	12 (31%)

C4 In this question, participants were asked if childcare was available during FASD training program(s). Table 13 shows the aggregated data from 41 respondents indicated that 68% did not provide child care.

Figure 6 Child Care



C5 In this question participants were asked to identify the kinds of FASD training programs provided by their respective organizations. Here, 18 of 44 organizations (41%) responded that they conducted 16 different FASD training programs. As Table 13 shows, the training program most frequently offered is the basic FASD information/awareness. This introductory program is offered by 16 organizations. The second most frequently provided program is FASD training for service providers and this is offered by 6 organizations. Of the total 16 different programs identified, only 3 organizations offered training working with expecting mothers and only 1 of the 18 organizations offered training in the area of FASD prevention. Please see Appendix B for the aggregated data.

Table 13 FASD Training Programs by Organization

Training Program	# of Organizations Offering Program
Basic FASD Information	16 (36%)
FASD training for Service Providers	6 (14%)
Prenatal FASD	3 (7%)
Prevention	1 (2%)

In question C5, we also asked about the number of times training programs were offered and the number of hours. Here, 18 organizations responded however, not all of the responding organizations indicated the frequency and duration of the programs offered. Therefore, the data shown in Table 14 varies from the responses given in Table 13.

Table 14 shows the median frequency the programs are offered ranged from 1 to 12 times during April 1, 2005 and March 31, 2005. The median length of training ranged from 2.5 to 18 hours. Table 14 shows the median number of times that specific programs were offered between April 1 2004 and March 31, 2005 and, the length of training in terms of the number of hours.

Table 14 Training: Number of times and length

Training Program	# of Organizations	# of Times	# of Hours
Basic FASD Information	9	2	6 hrs
Prevention	1	3	4 hrs
FASD Community Development	2	4	7.5 hrs
Working with Adults	2	6.5	7 hrs
Working with Caregivers	1	1.5	4.75 hrs
Working with Moms	1	12	7 hrs
Service Providers	4	1	18 hrs
Grief	1	2	2.5 hrs

Question C5 also asked about the learning goals associated with the training programs. Of the 18 organizations that responded, 8 learning goals of training were identified.

FASD Awareness	☐	introductory information: history, impact of alcohol, incidence rate, recognition of symptoms, behavioural characteristics, diagnostic terms, primary and secondary disabilities, demystification (17 organizations, 94%).
Interventions	☐	strategies/interventions for families, service providers and for teachers in the classroom. (13 organizations, 72%).
Diagnosis	☐	making referrals for diagnosis, accurate identification of FASD, interdisciplinary team work (5 organizations, 27%).
Prevention	☐	group activities, connecting with the community, information sharing with other agencies, training, recreational activities, connection with culture (2 organizations, 11%).
Support	☐	sharing circles, groups for Adults living with FASD, organizing community activities, skills of advocacy and building networks of support (2 organizations, 11%).
Risk Assessment	☐	identifying resources and structural supports, making community connections (1 organization, 5%).
Service Coordination	☐	developing local interdisciplinary teams, identifying and reducing gaps in services and creating seamless service delivery (1 organization, 5%).
Community	☐	building local teams and sustainable FASD services: initiating, managing and maintaining FASD services (1 organization, 5%).

In the second part of this question, we asked participants to identify the target group for training programs. Of the 18 organizations that provided training programs, 16 different programs were offered to a number of different groups. As Table 15 shows, FASD training programs are targeted most frequently to two groups: Child and Family service workers and parents/caregivers of people living with FASD. In contrast, the groups that received the least amount of targeted training include: adults living with FASD, high school students (teenagers), employment counselors, lawyers and judges.

Table 15 FASD Training Target Groups

Title of FASD Training Program	1	2	3	4	5	6	7	8	9	10	11	12	13	14
Basic FASD Information	13	9	8	11	8	7	8	4	9	6	5	5	10	
Working with Families	3	3	2	3	3	2	1							
Prenatal FASD			2	2			2							
Working with Young Children	2	2		2										
Working with School-aged Children	2	1	1	2	2		1	1	1				1	
Working with Youth	3			4									1	
FASD Community Development	2	2	2	2	2	2	2	2	2	2	2	2	2	
FASD Summer Camp	1	1	1	1	1	1	2			1	1	1	2	
Prevention	1													
Working with Adults	1	1	1	2	1	1	1		1	1		1	2	
Working with Caregivers	1													
Working with Moms			1	1			1							
FASD Training for Service Providers	2	2		3	2	1	1		1	1		1	1	
Grief	1													
Train the Trainer		1	1	1	1	1	1		1	1		1		
Training for Educators	1	1		1	1	1								
TOTALS	**33**	**23**	**19**	**35**	**21**	**16**	**20**	**7**	**15**	**12**	**8**	**11**	**19**	

1. Parents/caregivers of children with FASD
2. Early childhood educators/organizations
3. Substance treatment organizations
4. Child & Family Services
5. Educators/school personnel
6. Correction workers
7. Health care professionals (doctors, nurses, psychologist, psychiatrists)
8. Adults living with FASD
9. Police/RCMP
10. Lawyers/judges
11. High school students
12. Employment counselors
13. Members of the community
14. Other (*Please specify*)

In question C6, we also asked participants to provide the average and maximum group size of their training programs. Among the total of 18 respondents, 12 indicated that the median group size was 52, ranging between 25 and 60 participants. The maximum training group size was 55, ranging between 45 and 200 participants. Please see the aggregated data in Appendix B, question C6.

C7 In this question, we asked respondents about how participants are selected for FASD training. Of the 18 organizations that responded, 56% indicated that participants were selected for FASD training by invitation and 44% indicated that participation was voluntary. For 7 or 39% of the organizations, participation in FASD training is mandated. Table 16 shows the aggregated data.

Table 16 Process of FASD Training Selection

Process of Selection	Total Number
Voluntary	8 (44%)
By Invitation (selective)	10 (56%)
Mandated for Professionals	7 (39%)

C8 In this question, we asked respondents to identify both the language of their training programs and how their training programs are advertised. In part 1 of the question, 36 organizations responded to the question of what language is used in FASD training. As Table 17 shows, half the training programs are conducted in English and 13 or 36% in the French language. Five organizations (14%) indicated that FASD training programs are conducted in the First Nations of Cree, Ojibwe, Atikamekw and Kanienkehaka.

Table 17 Language of FASD Training

Aboriginal	5 (14%)
English	18 (50%)
French	13 (36%)

Question C8 also asked about advertising for FASD training. Here, Table 18 shows that 38 respondents indicated that their organizations used flyers (39%) and word of mouth (39%). In the category of "Other," 15 organizations responded that they used multiple and various ways of advertising including, radio announcements, community newsletters, newspaper announcements, posters/banners in the community and television.

Table 18 Advertising for FASD Training

Type of Advertising	Flyers	On-line	E-mail	Word of Mouth	Other
	15 (39%)	1 (3%)	6 (16%)	15 (39%)	15 (39%)

C9 In regard to funding for the FASD training programs in the 5 regions, responses from 20 of the 23 organizations indicated that a total of 15 (75%) received no targeted funding, 3 received funding from First Nations and Inuit Health Branch (FNIHB) and 2 received funding from Health Canada.

Table 19 also shows that of the 18 organizations responding from Québec, 17 receive targeted funding from Health Canada. However, even though it appears that Québec receives a more significant level of funding that many of the other organizations in Canada, the qualitative data indicates that for many organizations in Québec the level of funding is insufficient to provide the comprehensive training that is needed to address the complex and multi-faceted health and social issues related to FASD in their communities. As one participant from Québec stated: "*We need more training! Sure we have funding but its subsistence. We still need the basic information - the tools and resource materials in our community.*"

Table 19 Targeted Funding For FASD Training

Targeted Funding for FASD Training	Territories	West	Prairies	Ontario	Québec	East
No Funding	2	1	7	5	1	
Health Canada			1	1	17	
FNIHB		1	1			1

C10 With a total sample of 44 respondents, 33 organizations responded to our 3-level contingency question about fees for FASD training: (1) were fees charged and if so, (2) who is billed, (3) do the fees cover all the costs associated with training and, (4) do the fees vary for different FASD training programs.

Of the 33 organizations, 25 (76%) reported that no fees were charged for FASD training and 8 (24%) indicated that fees were charged. In the two regions charging for FASD training, 4 Prairie organizations reported fees ranging from $25.00 per person for a 1 day workshop (6 hours) to a flat rate of $800.00 per day (6 hours). Of the three organizations in Québec that reported charging for FASD training, the fee schedules ranged from $40.00 per person per day (2-3 hours) to a flat rate of $165.00 per hour based on a 6 hour day).

Of the eight organizations that charged fees for FASD training, 75% indicated that individuals were charged for their services while 87% billed directly to organizations. Chief and Council were billed by 25% of the respondents.

Of the eight organizations that responded to the question of whether the fees charged cover the costs of FASD training, 7 or 88% indicated no and additional costs included photocopying training materials, meals, mileage, fuel and group snacks. Only 1 organization responded that the fees charged do cover the all the costs associated with FASD training.

Of the eight organizations that charged fees, 4 indicated that the fees do not vary and 4 said that fees do vary. Of the 4 organizations whose fees vary, 3 reported that fees would be substantially lowered and/or waived for communities experiencing financial constraints. One organization indicated that fees vary according to the location of the FASD training program, materials needed and the length of the training session.

C11 In this question, respondents were asked about any potential barriers that participants may experience when attending FASD training sessions. Of the total number of respondents (N=27), from 11 organizations (41%) indicated that they were not aware of any possible barriers for participants. The remaining 16 organizations (59%) indicated that there were a series of barriers that might prevent or deter community members and service providers from participating in training:

Barriers for Service Providers

- Lack of organizational funds to access training
- Scheduling time off work (heavy case loads/ lack of staff to cover absence)
- Mandated attendance
- Lack of professional training opportunities
- Lack of trainers within the community
- FASD is not a priority area for some workers.
- Lack of interest

Barriers for Community Members

- Lack of access to reliable and affordable childcare
- Lack of access to transportation.
- Taboo topic within the community.
- Personal feelings of guilt/shame.
- Fear of being labeled as "bad" parents.
- Fear that children will be labeled.
- Fear that children will be diagnosed then apprehended.

C12 Closely connected to the barriers associated with FASD training, question C12 asks respondents about the risks that either the trainer or participants might encounter during FASD training. With a total of 27 respondents, 16 (60%) reported a series of risks associated for both trainers and participants. These risks are organized into three themes:

Stigma

- Familial guilt/grief.
- Stigmatizing labeling for families and people living with FASD.
- Shaming reprimands from community members directed toward pregnant woman and/or birth mothers.
- Reactions of fear toward people with FASD and fear of being labeled with FASD
- Anger in response to information or personal realizations
- Denial that FASD is even a problem in the community

Burnout

- Feelings of helplessness – lacking tools to intervene.
- Inundated with information – overwhelmed.
- Sense of professional/personal isolation.

Resources

- Enough facilitators to handle training content/process.
- Availability of facilitators after training.
- Facilitators skilled in understanding and addressing the impact of training on participants and in the community.

C13 In this question, we asked about the kinds of supports that are available before, during and after training. Of the total sample (N=44), 28 organizations responded. Of the 28 organizations, 7 (25%) reported that no supports were available and 21 (75%) indicated that supports were available either before, during or after training. Respondents also explained what kinds of supports are available and these can be summarized thematically:

☐ *Access:* Contact information for training facilitator (phone number and e-mail).

☐ *Support/Social Services*: Individual and group counseling provided by facilitator after training, counseling for families/caregivers of people living with FASD, participant sharing circles, child care, access to community-based health workers, nurse, drug and alcohol workers and 24hr on-call mental health workers.

☐ *Referrals*: Supportive links to community-based workers/services and assistance with FASD diagnostics/assessment appointments.

☐ *Networking*: Group discussions, e-mail/phone contacts.

☐ *Information*: Follow-up FASD information and materials provided for service providers and educators, access to updated information about FASD. .

☐ *Training*: Consistent annually-based FASD training.

C14 With regard to training evaluation tools, 26 of the responding organizations, 12 (46%) indicated that they did not use a tool to evaluate the FASD training and 14 (54%) indicated that they used a training evaluation tool. Here, the majority of respondents reported that at the end of their FASD training, a satisfaction survey was completed. Respondents reported that the information/feedback from the satisfaction tool was used to improve the training session by guiding the delivery of information in order meet the needs of participants. One respondent reported that the satisfaction training evaluations were submitted directly to an accreditation body. Another respondent indicated that minutes were taken during group forums and plenary discussions following training. These minutes were circulated to service providers and professional groups within the community.

C15 This question asked respondents to identify who facilitates their FASD training programs. Of the 20 respondents that receive training, 5 organizations (25%) indicated that their own staff facilitated FASD training and 5 organizations (25%) received training from federal, provincial and First Nations governing bodies. Ten 10 organizations (50%) identified that they use private contractors for FASD training. Just one private contractor provided FASD training for 8 or 80% of the 10 organizations.

C16 This question asked respondents if the training programs they presented are accredited and if so, what professional body accredits the program(s). Of the 18 organizations that responded, only 2 reported that their FASD training program(s) were accredited. Put another way, 11% were accredited and 89% did not have accreditation.

C17 Here, respondents were asked if any addition training opportunities are needed in their communities. Here, 30 organizations responded and 26 (87%) indicated that 23 items that need to be included, added or created as part of more comprehensive FASD training. These 23 items can be broadly grouped in 4 themes:

Targeted Training

- Funding to access training.
- Funding to ensure support staff to cover work while at training.
- Targeted professional training for Aboriginal police officers, correction workers, teachers, daycare workers, social workers, employment counselors and health care providers.
- Repeated training opportunities to address work scheduling conflicts.
- More *Train the Trainer* programs for First Nations communities.
- Ongoing training (vs. one-off) training opportunities.
- Training specific to working with FASD adults.
- Training about male partner dynamics.
- Training addressing nutrition/diet for people living with FASD.
- Professional training for credit.
- Training opportunities to build awareness among teenagers and parent awareness.
- Training by and for Aboriginal peoples – specific to on-reserve realities.
- More affordable training opportunities.
- Specific training to address the issues of employment, school, recreation and drug/alcohol use among people living with FASD.
- Telehealth training.

Diagnostics/Assessment

- Training in *updated/current* diagnostic tools.
- Training in case assessment in schools.

Information

- *More* information, knowledge and skills sets.
- *Updated* information about FASD.
- Training about strategies for self-care for service providers.
- Creation of Aboriginal peoples FASD website.

Parents/Caregivers

- Training about supports for parents/caregivers.
- Training about creating networks of community support.

PART IV

Additional FASD Training Information

Part IV consists of one open-ended question asking respondents if there is any further information about FASD training that might be helpful in our research project. Of the total number of respondents (N=44), 24 organizations (55%) responded and provided a rich source of information about innovative programming, resources and needed supports. Participants emphasized the urgent need for comprehensive FASD funding arrangements, targeted and in-depth training opportunities, broad-based services capable of addressing community awareness and prevention in addition to the creation of collaborative resource and support networks for First Nations communities. The responses in this section highlight 4 themes in the comments of 24 organizations:

☐ **Comprehensive and targeted FASD funding is urgently needed** to ensure access to training that will enhance community capacity through culturally meaningful awareness and prevention services. As one respondent stated, "If we can't afford the training, we can't provide the services." Adequate funding for organizations providing FASD services also ensures that they have the capacity to cover work leaves and travel expenses. First Nations organizations also clearly stated the need for funding capable of authentically addressing the need for translation services from English to French training manuals and the translation of FASD service material from English/French to First Nations languages such as Cree, Ojibwe, Atikamekw and Kanienkehaka.

☐ **Ensuring the delivery of the full spectrum of FASD training** in the community will raise awareness, increase competencies and provide practical skill sets for FASD interventions. As one participant stated, "Training for all!" As more than 80% of respondents noted, additional training opportunities are need on several different levels including: (1) on-going introductory FASD training for all service workers, (2) in-depth training for service providers in the areas of diagnostics/assessment and specialized services/interventions and, (3) training for *Train the Trainer* programs in order to enhance the capacity of First Nations communities.

☐ **Community FASD awareness** is one of the first steps in prevention. Here participants pointed to the need to provide on-going education and awareness at all levels in the community starting with grade school students through to high school students. In turn, organizations understand that by being able to provide these primary prevention activities they are ultimately reducing the incidence of FASD in the community.

☐ **Building and sustaining a collaborative network of resources and supports** would provide First Nations service providers with a rich source of information about FASD services, training facilitators, referral sources, FASD programs and promising practices. As participants noted, developing collaborative organizational partnerships across sector and regional boundaries provides the opportunity to explore often neglected topics and develop initiatives in the area of FASD including, Aboriginal youth transitioning to adulthood, Aboriginal youth and adults living with FASD and their involvement in the criminal justice system and, Aboriginal women's experiences of male partner violence and prenatal alcohol use. The creation of supportive and collaborative networks is also evident in another participant's suggestion of creating an Aboriginal specific website dealing with the wide range of issues surrounding FASD. From the perspective of rural, remote and isolated organizations, the benefit of these supportive services is unquestionable.

PART V

Discussion

The results of the current study indicate that both the provision of services and access to training is severely and chronically limited by the lack of consistent and targeted funding. In the area of FASD services, the most critical programs are reported to be the least available including, programs for women, nutritional services, access to respite care and employment services. The findings also indicate that funding for First Nations FASD services must support access to on-going training in the communities. In turn, on-going, accessible and culturally relevant training will provide the foundational sustainable social capital needed to care for all members of the communities. Clearly, the systematic barriers created by inadequate FASD funding calls into question the possibility of developing and sustaining the awareness and prevention services that are of paramount importance. In the following section, the chronic lack of FASD funding for training is shown to result in four critical conditions.

- Without the funding that enables access to training, First Nations service providers cannot obtain the updated skills, knowledge and interventions needed to provide an adequate level of service in their communities. Without targeted services, people living with FASD, their families and caregivers will fall through the proverbial cracks. The alternative is to leave the community to access services and potentially become separated from foundational systems of support.

- The scarcity of FASD funding also impacts the extent of training programs offered by First Nations organizations. That is, without the funding needed to fully support the level of FASD training required in First Nations communities, key people are often not included. As fiscal constraints work to prioritize training, respondents identified the following groups as those needing FASD training but are most frequently left out: employment counselors, correction workers, Aboriginal police officers, lawyers/ judges and health care providers. As key members of the community, the absence of training opportunities for these groups prevents the sharing of cross disciplinary knowledge/skills, awareness and the techniques of compassionate intervention.

- The inadequate level of funding also prevents First Nations organizations from developing and providing FASD training information in ways that are understandable, useful and relevant to on-reserve community members. For example, without financial support to secure the translation services, many FASD training manuals, information brochures, library materials and newsletters are inaccessible. Funding to ensure and sustain the development of culturally accessible material will also support First Nations organizations in community-based research activities needed to support and sustain the creation of FASD training programs developed by and for First Nations peoples.

- There does not appear to be a system of certifying instructors for FASD training in First Nations communities. The lack of certification for trainers suggests that that the quality of the training can vary significantly. Without an independent means of evaluation, there is no way to assess the efficacy of training programs.
- There is a scarcity of FASD trainers even under the current conditions. It appears that governments may contract with one or two individuals to provide FASD training to a broad number of First Nations. Every trainer has his or her strengths and areas of growth - meaning no one person can meet the diverse training needs of First Nations. There is also no information on to what degree government involves First Nations in identifying a trainer that would best meet the unique needs in their respective communities.

Although this study represents a small sample of First Nations service providers, the information provided by people working on the frontlines, senior administrators, health care providers and program managers contains valuable insights into the challenges facing First Nations communities as they work to address the devastating impact of FASD. As one of the most consistent themes to emerge from the data, First Nations FASD programs across Canada face a chronic lack of funding necessary to provide the breadth and depth of services and training that is clearly needed. Flowing from the finding, several recommendations are in order:

- It is recommended that First Nations service organizations receive adequate and consistent funding for current and ongoing FASD education and training.

- It is recommended that funds be directed to First Nations organizations to develop a larger pool of qualified FASD trainers who can provide training that is reflective of the diverse needs and experiences of First Nations communities. We believe that in moving away from a reliance on external consultants for training to affirming the skills and knowledge of workers in First Nations communities will result in more relevant training and ensure that training is more frequently available.

- That funding is available for advanced professional training in screening, the diagnostic process, assessments and interventions for *all* groups of people including parents, adults, young people, children and infants living with FASD.

- That funding arrangements for First Nations FASD service organizations include provisions for the delivery of culturally meaningful FASD training, services and resource materials.

- That targeted funding is made available for the comprehensive training needed to ensure that FASD service providers are able to develop and sustain specialized community-based services and supports for women who are pregnant and are experiencing difficulties with alcohol and drug use.

- That First Nations service organizations receive targeted funding to create and maintain community-based training programs for parents and adults living with FASD in order to provide specialized family services, supported living arrangements and meaningful employment opportunities.

- That core funding is available to ensure that First Nations service organization are able to provide targeted FASD education and awareness training for service providers most likely to come into contact with Aboriginal children, young people and adults including, judges, lawyers, court workers, probation officers, teachers and school staff.

- That First Nations FASD service organizations received core funding to create and sustain collaborative organizational partnerships across sector and regional boundaries in order to support respectful research initiatives and disseminate information about most promising FASD-related practices.

- That funding for First Nations FASD service organizations include authentic financial support to design and conduct assessments of community needs and capacities along with existing resources that can be utilized in responding to FASD.

- That an adequate level of funds be made available for the ongoing evaluation of FASD training programs by an independent evaluator using tools to determine the impact of training for First Nations service providers over time.

- That funding for ongoing primary FASD prevention initiatives is made available to every First Nations service organization as the key to eradicating or substantially reducing FASD.

While much more work needs to be done to ensure that First Nations communities have the resources and supports to provide early intervention and preventative FASD programming, assurance of an adequate level of funding will provide the foundational professional training that is required to authentically address the needs of First Nations communities and support the work that is required to reach our common goal - the eradication of FASD.

Appendix A

Cover Letter and FASD Training Questionnaire

September 10, 2005

Dear Colleagues,

First Nations Child and Family Caring Society of Canada (www.fncfcs.com) is currently working on a national survey of FASD services and non-academic training programs for First Nations communities in Canada. Our assistant Kathryn Irvine (keirvine@ucalgary.ca) is conducting the research in English and Mélanie Vincent (mvincent@gripma.ca) is guiding the research project in French. We have also partnered with Pauktuutit Inuit Women's Association to capture the same information among Inuit communities. The results of our national survey will be presented in a report designed to give the evidence supporting the needed funding to provide responsive services and training, enhanced program development and research capacities within First Nations and Inuit organizations.

As you will see from the enclosed questionnaire, we are covering a range of questions about the various kinds of services that are offered through your organization including, the different groups that might access your services, the availability of diagnostic and assessment services along with home visitation. To better understand the training programs in First Nations communities, we ask a series of questions including, the kinds of training offered, the number of participants in each training session, fee structure, funding sources and any evaluation tool(s) that you use.

I am writing to respectfully request the assistance of you and your staff in completing our questionnaire. I have enclosed a copy of the questionnaire and a self-addressed envelope. Once it is complete, the questionnaire will be returned to First Nations Child and Family Caring Society for analysis along with the results from the other participating organizations. We are committed to confidentiality in this process and will not be releasing specific organizational data. We are also committed to ensuring that all participating organizations have full access to our final report that we anticipate completing in November, 2005.

Thank you for your consideration of our request and please do not hesitate to contact me by phone (613) 230-5885 or e-mail (cblackst@fncfs.com) if you have any questions. With the participation of organizations like yours, we can work together to provide the knowledge needed to better support First Nations children, families and communities.

Respectfully,

Cindy Blackstock, Executive Director
First Nations Child and Family Caring Society

FIRST NATIONS CHILD AND FAMILY CARING SOCIETY
FIRST NATIONS AND INUIT HEALTH BRANCH

FASD TRAINING SURVEY

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I ORGANIZATIONAL INFORMATION

A1

Name of Contact Person:

Name of Organization:

Job Position with Organization:

Address:

Postal Code:

Phone Number: **Toll free Number:**

E-mail: **Website:**

A2 **In what year was the organization first established?** ________________ (Year)

A3 **Where is your main office located?** On-reserve Off reserve

A4 **Type of Organization** (*please check all that apply*):

Social Service organization
Non-Profit
For Profit
Community/grassroots
Government (*please specify level/department*): ________________
Other (*please specify*): ________________

A5 How many communities does your organization serve?
(*Please specify the number of each, for example, 3 Métis Settlements*)

________________ First Nations	________________ Rural Town(s)
________________ Inuit	________________ Small City/ies
________________ Innu	
________________Métis Settlement(s)	________________ Military Base(s)
	Other ________________

A6 On average, how far are the communities from your head office? : ________________ (km)

A7 How would you describe the geographical location of your organization?

Urban Rural Remote

A8 If rural/remote, how far is the nearest town/city with full services? : ________________(km)
What is the name of that town/city? : ________________

II FASD SERVICES

B1 What kinds of FASD services does your organization offer? (*Please check all that apply*):

Peer mentoring for women
On-going support for families with FASD infants/children
Group counselling for women
Individual counselling for women and their partners
Advocacy (*please specify*): ________________
On-going support for families with FASD adolescents
Nutritional programs
Referrals to community services
Teen-based awareness, education and prevention
Respite for families/caregivers of people living with FASD
On-going support for adult living with FASD
Community education and training
Employment services for people living with FASD
On-going professional training for service providers/professionals (for credit)
In-service training for service providers/professionals (not for credit)
Research
Recreational activities for people living with FASD
Recreational activities for families/caregivers of individuals living with FASD
Resource/lending library (adaptive equipment, toys, books, videos)
Other (*please specify*): ________________

B2 Does your organization provide FASD diagnostic/assessment services?

No
Yes

What is the total number of people (*all infants/children/adolescents and adults*) diagnosed with FASD in 2004? ________________

Please identify the total number of people in each group that were diagnosed with FASD in 2004

Total number of infants diagnosed (*birth – 4 years*): ________________
Total number of children diagnosed (*5 -12 years*): ________________
Total number of adolescents diagnosed (*13 – 17 years*): ________________
Total number of adults diagnosed (*18 years – up*): ________________

B3 Does the organization provide home visits?

No
Yes

If yes, who provides home visits?
* (*Please check all that apply*)

Peer
Nurse
Social Worker
Agency outreach worker
Other (*Please specify*): ________________

During what developmental stage do home visits take place?

* (*Please check all that apply*)
Prenatal
Infancy (*birth – 4 years of age*)
Childhood *(5 -12 years of age)*
Adolescents *(13-18 years of age)*
Adult *(18 years – up)*

III FASD TRAINING

C1 Where are your FASD training programs held? (*Please check all that apply*):

In-house (at your agency)
On-line
Video-Consultation
In school(s)
Various locations in the community: (*For example, community center, daycare facility*)
In conjunction with other agency's programs
In private residence(s)
Other (*please specify*): ________________

C2 Did the organization create its own FASD training program(s)?

Yes **In what year?** ________________ (Year)
No

If no, please describe what programs were adopted or adapted:

Person(s) consulted: ________________
Contact Information: ________________

C3 Are your FASD training facilities accessible for people who are disabled?

Yes No

C4 Is child care available during FASD training program(s)?

Yes No

C5 What kinds of training programs does your organization provide?

*(*Please note the number of times that the training program(s) were offered between April 1, 2004 and March 31, 2005).*

1.			
2.			
3.			
4.			
5.			

C6 Corresponding to each of the program(s) you have noted above, please tell us a little bit about the goals of each training event, the average and maximum group size. For the target group for training programs, please use the following scale:

15. Parents/caregivers of children with FASD
16. Early childhood educators/organizations
17. Substance treatment organizations
18. Child & Family Services
19. Educators/school personnel
20. Correction workers
21. Health care professionals (doctors, nurses, psychologist, psychiatrists)
22. Adults living with FASD
23. Police/RCMP
24. Lawyers/judges
25. High school students
26. Employment counselors
27. Members of the community
28. Other (*Please specify*)________________

1.			
2.			
3.			
4.			
5.			

C7 How are participants selected for FASD training?

Please describe the process of selection:

C8 **Language** **Advertising**

Language of Training Program(s)

Aboriginal language (please specify)

____

English

French

Other(s) (*please specify*)

____

How is Training Advertised?

Flyers

On-line

E-mail/fax distribution lists

Word of mouth

Other ways (*please specify*):

____

C9 Do you receive targeted funding for FASD training program(s)?

No Yes

If yes, please describe how training funds are allocated:

Training Program(s)	Source of Funding	Dollar Amount

C10 Are fees charged for any of the FASD training programs?

No Yes **If yes, what is the approximate amount charged? $** ________________

Who is billed for your training services?

Individual participants
Participant's agency/organization
Chief & Council
Other (*Please specify*): ________________

Do the fees charged cover all the costs associated with training? (*for example, workbooks, manuals, training materials*):

Yes No

If no, please describe additional costs:

Do the fees vary for the different FASD training programs?

Yes No

If yes, please describe how the fees vary:

C11 Are you aware of any barrier(s) potential participants may experience in attending training sessions? (*for example, fees, transportation, scheduling)*

Yes No

If yes, please describe any potential barrier(s):

C12 Are you aware of any risks associated with FASD training for either the participants or trainer(s)?

Yes No

If yes, please describe any associated risks:

C13 Are supports available for participants and trainer(s) before, during and after training?

Yes No

If yes, please describe the kinds of supports available *(for example, this there a process of follow-up in place, e-mail or phone conferencing?):*

C14 Do you have tools to evaluate the impact of the training programs over time?

Yes No

a) If yes, please describe the kinds of tools you use:

(if possible, please enclose a sample of the training evaluation tool(s) that you use)

b) How do you use the information you collect?

C15 Who facilitates your training program(s)?

Name(s): ________________

Contact Information: ________________

C16 Is your FASD training program accredited? Yes No

If yes, what professional body accredits your program? ________________

C17 Do you think any additional FASD training opportunities are needed in the community/ (ies) that you serve?

Yes No

If yes, please describe:

D1 Is there any additional information about FASD training programs that you think would be helpful as we work to complete our national survey of First Nations FASD training in Canada? *(Please use as much space as you need):*

THANK YOU FOR YOUR CONTRIBUTION TO OUR IMPORTANT RESEARCH PROJECT!

For more information about this study, please contact:

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APPENDIX B

Aggregated Data
Questionnaire Part I

A1 *Job Position with Organization*

N=42
Response Rate: 95%

Organizational Position	Overall	Territories	West	Prairies	Ontario	Québec	East
Program Administrators*	17 (40%)		2	2	2	9	2
Senior Administrators**	11 (26%)	2		5	2	2	
Front Line Workers***	7 (17%)			1	2	4	
Nurses	4 (10%)			1		3	
Consultants	3 (7%)			1		2	

***Program Administrators**

▣ Managers of Services
▣ Project Coordinators
▣ Program Coordinators

**** Senior Administrators**

▣ Executive Directors
▣ Organization Managers
▣ Chief Executive Officers

*****Front Line Workers**

▣ Support Workers
▣ Drug/Alcohol Workers
▣ Women's Health Worker
▣ Health Worker

A2 *Year Organization was established*

N=26
Response Rate: 59%

Date	Pre 1950s	1950 to 1959	1960 to 1969	1970 to 1979	1980 to 1989	1990 to 1999	2000 to Present
# of Organizations	1		1	3	6	10	5

A3 *Where is your main office located?*

N= 44
Response Rate: 100%

Location of Organization	Overall	Territories	West	Prairies	Ontario	Québec	East
On-Reserve	31 (70%)		2	6	3	19	1
Off-Reserve	13 (30%)	2		5	3	2	1

A4 *Type of organization (please check all that apply)*

N= 44 (with multiple responses)
Response Rate: 100%

Type of Organization	Overall	Territories	West	Prairies	Ontario	Québec	East
Social Service	9 (20%)			3	3	3	
Non Profit	21 (47%)	2	2	9	5	3	
For Profit	3 (7%)					3	
Community	11 (25%)			7	1	1	2
Government	3 (7%)		1		1	1	
Other	16 (36%)			1	1	14	

A5 *How many communities does your organization serve?*

N= 44
Response Rate: 100%

Communities Served	Overall #	Territories #	West #	Prairies #	Ontario #	Québec #	East #
First Nations	**130**	4	1	13	30	65	17
Inuit	**18**	2				16	
Innu	**2**					2	
Métis Settlements	**17**	2	5	7	2	1	
Rural Town(s)	**48**	2		27	19		
Small City/ies	**13**	2		4	7		
Military Base(s)	**1**			1			
Other*	**7**	2		1	1	2	1
TOTALS	**236**	**14**	**6**	**53**	**59**	**86**	**18**

* Seven respondents identified "Other" communities served as: "All" or "the whole province."

A6 *On average, how far are the communities from your head office?*

N=38 (with multiple responses)
Response Rate: 86%

km Traveled	0-50 km	51-100 km	101-200 km	201-300 km	301-400 km	401-700 km	701-2000 km
	26	5	4	3	2	2	1

A7 *How would you describe the geographical location of your organization?*

Geographical Location	Urban	Rural	Remote
	15	21	13

N= 44 (with multiple responses)
Response Rate: 100%

A8 *If rural/remote, how far is the nearest city/town with full services?*

N=31 (with multiple responses)
Response Rate: 70%

Kms Traveled	0-100 Kms	101-200 Kms	201-300 Kms	301-400 Kms	401-500 Kms	501-600 Kms	601-700 Kms	701-800 Kms	801-900 Kms
	30	5	6	3	2	1	1	2	1

Aggregated Data
Questionnaire Part II

B1 *What kinds of FASD services does your organization offer? (Please check all that apply)*

N= 44

Response Rate: 100%

Kinds of Services	Overall #	Territories #	West #	Prairies #	Ontario #	Québec #	East #
Peer mentoring for women	**17**	1	1	4	1	10	
On-going support for families with FASD children/ infants	**24**	1	1	7	3	12	
Group counselling for women and their partners	**10**	1		3	1	5	
Individual counselling for women and their partners	**16**	1	1	3	2	9	
Advocacy* (*please specify*)	**12**	1		5	3	2	1
On-going support for families with FASD adolescents	**20**	1	1	6	2	10	
Nutritional programs	**21**	1	1	3	2	13	1
Referrals to community services	**36**	2	1	10	5	16	2
Teen-based awareness, education and prevention	**29**	1	1	5	4	17	1
Respite for families/ caregivers of people living with FASD	**12**			3	1	7	1
On-going support for adults living with FASD	**14**	1	1	3	1	8	
Community education and training	**33**		1	10	4	16	2
Employment services for people living with FASD	**4**	1		2			1

Kinds of services cont ….

Kinds of Services	Overall #	Territories #	West #	Prairies #	Ontario #	Québec #	East #
On-going professional training for service providers/professionals (for credit)	**10**	1	2	3		2	2
In-service training service providers/professionals (not for credit)	**27**		1	8	3	13	2
Research	**7**			2	1	3	1
Recreational activities for people living with FASD	**9**	1		2	3	3	
Recreation for families/ caregivers of individuals living with FASD	**6**	1		2	2	1	
Resource/lending library (adaptive equipment, toys, books, videos)	**19**		1	2	2	13	1
Other* (*please specify*).	**20**		1	1	1	16	1
TOTALS	**346**	**15**	**14**	**84**	**41**	**176**	**16**

Other

- FASD Day community activities
- Translation services
- Community FASD newsletters
- FASD prevention T-shirts
- Support groups for adults living with FASD
- Community forums on FASD
- Development of special learning materials
- Integrative play
- Community-based psychosocial interventions
- Community information booths
- Poster contests in the community
- Support groups for caregivers
- Community coffee meetings

B2 *Does your organization provide FASD diagnostic/ assessment services?*

N=44

Diagnostic / Assessment Services	Overall #
Yes	1
No	43

Response Rate: 100%

B3 ***Does the organization provide home visits?***

N= 44
Response Rate: 100%

Home Visits	Overall #
Yes	25 (57%)
No	19 (43%)

If yes, who provides home visits?
N= 25 (with multiple responses)
Response Rate: 57%

Who Provides Home visits	Total Number
Peer	--------
Nurse	12 (48%)
Social Worker	7 (28%)
Agency Outreach Worker	4 (16%)
Other	17 (68%)

During what developmental stage do home visits take place?

N= 25 (with multiple responses)

Response Rate: 57%

Stage of Home Visit	Total Number
Prenatal	12 (48%)
Infancy (birth-4 years of age)	19 (76%)
Childhood (5-12 years of age)	11 (44%)
Adolescents (13-18 years of age)	12 (48%)
Adult (18 years and up)	10 (40%)

Aggregated Data
Questionnaire Part III

C1 *Where are your FASD training programs held? (Please check all that apply)*

N= 35 (with multiple responses)
Response Rate: 80%

Location	Total Number
In-house (at your agency)	10 (29%)
On-line	2 (6%)
Video	1 (3%)
In school(s)	11 (31%)
Various Locations In the community	22 (63%)
In conjunction with other agency's program	9 (26%)
In private residence	2 (6%)
Other	9 (26%)

C2 *Did the organization create its own FASD training program(s)?*

Creation of Own Program	Total Number
Yes	8 (18%)
No	36 (82%)

N=44
Response Rate: 100%

C3 *Are your FASD training facilities accessible for people who are disabled?*

Accessible	Total Number
Yes	27 (69%)
No	12 (31%)

N= 39
Response Rate: 89%

C4 *Is child care available during FASD training?*

N=41
Response Rate: 93%

Child Care Available	Total Number
Yes	13 (32%)
No	28 (68%)

C5 *What kinds of training programs does your organization provide?*

N=18
Response Rate: 41%

Training Program	# of Organizations Offering Program
Basic FASD Information	16
Working with Families	5
Prenatal FASD	3
Working with Young Children	2
Working with School-aged Children	4
Working with Youth	3
FASD Community Development	3
FASD Summer Camp	2
Prevention	1
Working with Adults	2
Working with Caregivers	1
Working with Moms	1
FASD training for Service Providers	6
Grief	1
Train the Trainer	1
Training for Educators	2

Training Programs: Number of times offered and number of hours
N=18 (with multiple responses)
Response Rate: 41%

Training Program	# of Organizations	# of Times	# of Hours
Basic FASD Information	9	2	6 hrs
Prevention	1	3	4 hrs
FASD Community Development	2	4	7.5 hrs
Working with Adults	2	6.5	7 hrs
Working with Caregivers	1	1.5	4.75 hrs
Working with Moms	1	12	7 hrs
Service Providers	4	1	18 hrs
Grief	1	2	2.5 hrs

C6 *Corresponding to each of the program(s) you have noted above, please tell us a little bit about the goals of each training event, the average and maximum group size. For the target group for training programs, please use the following scale:*

N= 18
Response Rate: 41%

Training Program Goals

FASD Awareness ☐ introductory information: history, impact of alcohol, incidence rate, recognition of symptoms, behavioural characteristics, diagnostic terms, primary and secondary disabilities, demystification (17 organizations, 94%).

Interventions ☐ strategies/interventions for families, service providers and for teachers in the classroom. (13 organizations, 72%).

Diagnosis ☐ making referrals for diagnosis, accurate identification of FASD, interdisciplinary team work (5 organizations, 27%).

Prevention ☐ group activities, connecting with the community, information sharing with other agencies, training, recreational activities, connection with culture (2 organizations, 11%).

Support ☐ sharing circles, groups for Adults living with FASD, organizing community activities, skills of advocacy and building networks of support (2 organizations, 11%).

Risk Assessment ☐ identifying resources and structural supports, making community connections (1 organization, 5%).

Service Coordination ☐ developing local interdisciplinary teams, identifying and reducing gaps in services and creating seamless service delivery (1 organization, 5%).

Community ☐ building local teams and sustainable FASD services: initiating, managing and maintaining FASD services (1 organization, 5%).

Training Target Group
N=18 (with multiple responses)
Response Rate: 41%

Title of FASD Training Program	1	2	3	4	5	6	7	8	9	10	11	12	13	14
Basic FASD Information	13	9	8	11	8	7	8	4	9	6	5	5	10	
Working with Families	3	3	2	3	3	2	1							
Prenatal FASD			2	2			2							
Working with Young Children	2	2		2										
Working with School-aged Children	2	1	1	2	2		1	1	1				1	
Working with Youth	3			4									1	
FASD Community Development	2	2	2	2	2	2	2	2	2	2	2	2	2	
FASD Summer Camp	1	1	1	1	1	1	2			1	1	1	2	
Prevention	1													
Working with Adults	1	1	1	2	1	1	1		1	1		1	2	
Working with Caregivers	1													
Working with Moms			1	1			1							
FASD Training for Service Providers	2	2		3	2	1	1		1	1		1	1	
Grief	1													
Train the Trainer		1	1	1	1	1	1		1	1		1		
Training for Educators	1	1		1	1	1								
TOTALS	**33**	**23**	**19**	**35**	**21**	**16**	**20**	**7**	**15**	**12**	**8**	**11**	**19**	

1. Parents/caregivers of children with FASD
2. Early childhood educators/organizations
3. Substance treatment organizations
4. Child & Family Services
5. Educators/school personnel
6. Correction workers
7. Health care professionals (doctors, nurses, psychologist, psychiatrists)
8. Adults living with FASD
9. Police/RCMP
10. Lawyers/judges
11. High school students
12. Employment counselors
13. Members of the community
14. Other (*Please specify*)________________

Training: Average group size and maximum # of participants

N=12

Response Rate: 27%

Training Program	Average Group Size	Max # of Participants
Basic FASD Information	50	200
Prevention	25	50
FASD Community Development	60	75
Working with Adults	45	70
Working with Caregivers	45	60
Working with Moms	25	45
Service Providers	30	50
Grief	30	50

C7 *How are participants selected for FASD training?*

N=18 (with multiple responses)

Response Rate: 41%

Method of Selection	Total Number
Voluntary	8 (44%)
By Invitation (selective)	10 (56%)
Mandated for Professionals	7 (39%)

C8 *Language of training program(s)*

Language of Training Program	Total Number
Aboriginal	5 (14%)
English	18 (50%)
French	13 (36%)

N= 36
Response Rate: 82%

How is training advertised?

N=38
Response Rate: 86%

Type of Advertising	Flyers	On-line	E-mail	Word of Mouth	Other
	15 (39%)	1 (3%)	6 (16%)	15 (39%)	15 (39%)

C9 *Do you receive targeted funding for FASD training program(s)?*

N=38
Response Rate: 86%

Targeted Funding for FASD Training		West				East
No Funding	2	1	7	5	1	
Health Canada			1	1	17	
FNIHB		1	1			1

C10 *Are fees charged for any of the FASD training programs?*

Fees Charged	Overall #
Yes	8 (24%)
No	25 (76%)

N=33
Response Rate: 75%

Who is billed for your training services?

Fees Charged	Overall #
Individual	6 (75%)
Agency	7 (87%)
Chief & Council	2 (25%)

N= 8 (with multiple responses)
Response Rate: 18%

Do the fees charged cover all the costs associated with training?

Costs Covered	Overall #
Yes	1 (12%)
No	7 (88%)

N= 8
Response Rate: 18%

Do the fees vary for the different FASD training programs?

N= 8

Varying Fees	Overall #
Yes	4 (50%)
No	4 (50%)

Response Rate: 18%

C11 *Are you aware of any barrier(s) potential participants may experience in attending training sessions?*

Barriers	Overall #
Yes	16 (59%)
No	11 (41%)

N= 27
Response Rate: 61%

C12 *Are you aware of any risks associated with FASD training for either the participants or trainer(s)?*

Risks	Overall #
Yes	16 (60%)
No	11 (40%)

N= 27
Response Rate: 61%

C13 *Are supports available for participants and trainer(s) before, during and after training?*

Risks	Overall #
Yes	21 (75%)
No	7 (25%)

N=28
Respondent Rate: 64%

C14 *Do you have tools to evaluate the impact of the training programs over time?*

Evaluation	Overall #
Yes	14 (54%)
No	12 (46%)

N=26

Respondent Rate: 59%

C15 *Who facilitates your training program(s)?*

Facilitators	Overall #
Own Staff	5 (25%)
Government	5 (25%)
Private Contractors	10 (50%)

N= 20

Response Rate: 45%

C16 *Is your FASD training program accredited?*

Accreditation	Overall #
Yes	2 (11%)
No	16 (89%)

N=18

Response Rate: 41%

C17 *Do you think any additional FASD training opportunities are needed in the community/ies that you serve?*

N=30

Additional Opportunities	Overall #
Yes	26 (87%)
No	4 (13%)

Respondent Rate: 68%

NOTES

1. FASlink is a moderated e-mail discussion group for individuals, families and professionals groups around the world who are caregivers and professionals working with those living with FASD. FASlink is funded through voluntary donations and does not accept funding from the beverage and alcohol industry or associations. More information about FASlink is available at: http://www.acbr.com/fas/faslink.htm

2. While the effects of prenatal exposure to alcohol were first described in the medical literature by a team of French researchers, Lemoine, P., Harousseau, H., Borteyru, J., Menuet, J. (1968). Les enfants de parents alcooliques – anomalies observées: A prospos de 127 cas. *Ouest Medical*, 21, 476-482, the term "Fetal Alcohol Syndrome" was coined by American researchers, Jones, K., & Smith, D. (1973). Recognition of the fetal alcohol syndrome in early infancy. *Lancet* 2(7836), 999-1001.

3. It is generally accepted that the incidence of FASD is routinely under-identified and under-diagnosed. As the Canadian Paediatric Society maintains, FAS is a "common yet under-recognized condition" (p.161). Bruce Ritchie, Moderator of FASlink Fetal Alcohol Disorders Society states: "If FASD is undiagnosed it is not part of the statistics" (¶ 20). Ritchie, B (n/d). FASD grossly under-diagnosed and under-reported. Retrieved October 2, 2005 from http://www.faslink.org/FASD%20grossly%20under-diagnosed.htm

4. In 1979, the Canadian Task Force on the Periodic Health Examination suggested increased training to promoted greater awareness of FASD among professional health providers. In 1996, Health Canada joined with 17 governmental and non-governmental organizations to recommend training and education to all health professionals in order to provide family-centered and culturally sensitive programs and services. These recommendations were reaffirmed again in 2004.

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