CIRCUMPOLAR VOICES

Developing effective, culturally appropriate avenues to FASD diagnosis and prevention in northern Canada

Amy Salmon1,2, Sterling K. Clarren1,3

1 Canada Northwest FASD Research Network, Vancouver, Canada
2 University of British Columbia, School of Population and Public Health, Vancouver, Canada
3 University of British Columbia, Department of Pediatrics, Vancouver, Canada

Received 26 August 2010; Accepted 1 July 2011

ABSTRACT

This article describes 2 research initiatives that are being undertaken by members of the Canada Northwest FASD Research Network, involving collaborations between researchers, clinicians, service providers and community members in the Canadian North. Improving both the diagnosis and prevention of FASD requires evidence-based approaches to clinical and social service delivery that are capable of accounting for the unique contours of the geographic, regional and cultural diversities in which women become pregnant and in which families live. Although FASD has been a priority for communities and governments in northern Canada, research capacity has not been available to support the development of the context-specific knowledge needed to inform policy and practice in this region. Moreover, there have not been adequate mechanisms for transferring practice-based knowledge from the Canadian North to researchers and service providers in the South, who might make use of this knowledge to inform their own practice. Herein, we highlight the ways in which reciprocal knowledge exchange involving CanFASD Northwest researchers at academic health science centres and diverse stakeholder groups is supporting multi-directional capacity building in FASD diagnosis and prevention.

Keywords: Foetal Alcohol Spectrum Disorder, diagnosis, prevention
**The Canada Northwest FASD research network**

Foetal Alcohol Spectrum Disorder (FASD) was first identified in the 1970s as a specific pattern of physical and behavioural characteristics linked to prenatal alcohol exposure. FASD has been described as the leading known cause of developmental delay, and as “100% preventable,” provided that pregnant women abstain from alcohol. For over thirty years, prevention efforts were assumed to be clear, uncomplicated and achievable: warning pregnant women of the hazards of alcohol consumption would lead to consistent alcohol avoidance, and placing those with FASD in programs for people with disabilities would maximize their outcomes. The accumulated experiences of clinicians, women, families and people living with FASD have challenged this assumption. Although many promising practices have been developed and implemented, efforts to achieve and sustain sufficient diagnostic and intervention capacity, coupled with effective prevention initiatives at a population level, remain elusive.

Improving both the diagnosis and prevention of FASD requires evidence-based approaches to clinical and social service delivery that account for the unique contours of the geographic, regional and cultural diversities in which women become pregnant and in which families live. Although FASD has been a priority for communities and governments in the 3 northern Territories (“northern Canada”), sufficient research capacity has not been available to support the development of the new, context-specific knowledge that is needed to reliably inform policy and practice. Moreover, there have not been adequate mechanisms for transferring practice-based knowledge from the Canadian North to researchers and service providers in the Canadian Provinces, who might make use of this knowledge to inform work in their own communities. There has been little formal documentation of approaches taken by northern communities, clinicians and service providers to promote integrated, holistic approaches to FASD prevention. There is little research evidence, then, about compassionate and timely care for pregnant women and mothers with substance use problems in the North; or about accurate and meaningful FASD diagnosis and supportive care for people living with FASD in their communities. Without this information it is difficult to drive the next stages of policy development.

The Canada Northwest FASD Research Network (CanFASD Northwest) began in 2004 after ministers from the governments of British Columbia, Alberta, Saskatchewan, Manitoba, Nunavut, the Northwest Territories and the Yukon realized that they needed meaningful clinical data collected and translated in ways capable of informing public policy in aspects of FASD. CanFASD Northwest was the organizational response to this need (1,2). The structure of the organization evolved through forums that were held with those actively engaged in some aspect of FASD work, including those working in each of the 3 northern Territories. We learned that over 170 demonstration, implementation and research projects on various aspects of FASD were underway in western and northern Canada. Virtually none of them were being assessed, and few of the groups were talking to or learning from one another. In analysing findings from these forums, it was clear that FASD knowledge could only be advanced if all aspects of the condition – diagnosis, intervention, prevention and population health surveillance – were considered together.
These forums also resulted in the identification of 5 priority areas for FASD research. In order to build capacity in each of these areas, CanFASD Northwest developed 5 corresponding Network Action Teams of researchers, clinicians, service providers and concerned community members who are committed to collaborative inquiry on specific research topics related to FASD diagnosis, prevention and intervention. Each Network Action Team is hosted by an academic research centre. Those lead agencies are currently at the University of British Columbia, the University of Alberta, the University of Saskatchewan, the University of Manitoba and the BC Centre of Excellence for Women’s Health at BC Women’s Hospital. Each has an appointed leader or co-leaders who assume responsibility for coordinating their team’s research and knowledge transfer activities, inviting participation from all 7 jurisdictions. The Network Action Teams are supported by a central office hosted by the Provincial Health Services Authority at the Child & Family Research Institute – the research arm of BC Children’s Hospital, affiliated with the University of British Columbia.

It is assumed by many that clinical work in northern Canada would be different than that in the Canadian Provinces because of the nature of the small, relatively isolated communities of the North and the differences in access to professionals of all kinds. But this assumption is far from specifically proven in relation to any aspect of FASD diagnosis, prevention or intervention. The comparisons themselves are worth challenging and studying. This article will describe 2 initiatives that are being undertaken by members of CanFASD Northwest, involving collaborations between researchers, clinicians, service providers and community members in northern Canada. Our aim is to highlight the ways in which reciprocal knowledge exchange involving academic health science research centres and diverse stakeholder groups is supporting multidirectional capacity building in FASD diagnosis and prevention.

**Diagnosing FASD in northern communities: emerging issues**

Accurate diagnosis of FASD is critical for prevention and intervention (2–5). Indeed, the problems that can accrue for individuals and communities when a diagnosis of FASD is made inaccurately or haphazardly – including experiences of stigma and stereotyping of some groups (such as Aboriginal peoples) as having a particular proclivity towards FASD – have been well-described (6,7). Essentially, proper diagnosis involves the association of a credible history of alcohol exposure in pregnancy (as presented by an observer to the pregnancy) or a confirmed, substantial alcohol exposure in pregnancy by the mother herself, with medical and psychological assessments in the offspring that demonstrate a pattern of diffuse brain dysfunction that is more likely due to brain processing difficulties than to environmental circumstance (“diffuse brain disorder”). This highly sophisticated evaluation requires an interdisciplinary team of professionals who understand their roles and are comfortable working collaboratively with professionals from other fields to make a complete, final diagnosis and a corresponding individual treatment plan. While such teams exist in Canada they have a very limited diagnostic capacity.

To illustrate: Assume, as a simple estimate, that the prevalence of FASD in Canada is 1 in 100 people, and that the prevalence of FAS itself is 1 in 1,000 (8). Given the current population of Canada, the approximate number of cases of FAS is likely to be about 32,000, and the number...
of cases of FASD about 340,000. The number of evaluations that can be done annually in all of Canada right now is less than 2,000. The present, combined population of northern Canada, according to Statistics Canada, is 112,000. Using the same equations, that would mean 112 individuals with FAS within a larger population of 1,120 with FASD are present in northern Canada at this time. The Yukon utilizes a visiting team of professionals to work with local professionals to provide approximately 10 to 20 diagnostic evaluations per year, while the Northwest Territories and Nunavut rely on referrals of patient to clinics in the South. It is not known how many suggested referrals are completed annually, but it is assumed to be less than 20 a year. None of these numbers account for the increasing incidence of those with FASD born annually, likely to be another 100 to 200 per year in the North. Such a discrepancy between the numbers of those who might require diagnosis and those who can get it is beyond reason. In northern Canada at this time, there are no FASD diagnostic teams that are fully staffed with local professionals. The teams that do exist in northern Canada see relatively few clients at this time. While it is understandable that the limits of professionals and their time would encourage the use of outside consultants, local professionals are always a better choice as they possess more intimate knowledge of the local community and its challenges, as well as a better working knowledge of the resources available for interventions.

Members of the CanFASD Northwest Network Action Team on Diagnostics are working directly with clinicians in the North on a project to collect consistent, reliable data from multidisciplinary teams working with children and families living in the region. All across Canada, and certainly in the North, diagnosed individuals are needed to prove to governments that there is a need for services. If efforts are not made to systematically collect information demonstrating the scope of need for support services, effective and responsive systems cannot be constructed. Systems will not be built for hypothetical clients. Diagnosis is also the starting point for service planning in intervention or prevention. No diagnosis – no problem. No problem – no need for a solution. In the first phase of this project, the FASD diagnoses, along with functional neurodevelopmental diagnoses (e.g., attention deficit, memory disorder, social communications deficits, etc.), will be collected with all treatment recommendations. Provincial experiences will be compared with each other and with those now diagnosed in the North. Similarities across sites and areas would suggest a common, Canada-wide response, while regional differences will lead to studies of diagnostic idiosyncrasy versus meaningful differences that need attention.

**North-South collaborations in FASD prevention research**

In Washington State a study found that women who have had children with FASD have very high frequencies of mental health problems that go far beyond substance abuse; often, they have also had lifetimes of physical, sexual and emotional abuse. They are often isolated. About half of them may have an FASD themselves (4,5). Badry made similar findings in a population of women who had children with FASD in Alberta (9). FASD prevention efforts undertaken in First Nations communities must account for these general risk factors as well as specific cultural, historic, political and social contexts in which pregnant women in northern communities...
might drink (6,7). Accordingly, these prevention initiatives often take different forms from “main-stream” approaches to prevention. In addition, Aboriginal health research is characterized by unique features that need to be considered when planning research in communities. Historically, Aboriginal health research has been conducted on First Peoples by researchers from outside the community, with the research results published and discussed primarily amongst the scientific community. When this research has focused on highly sensitive and stigmatized issues such as FASD, this approach has also contributed to the further marginalization of First Nations peoples and communities. In the last decade, there has been a wealth of information produced to guide research practice in Aboriginal communities (cf. 10–13). Among the most prominent principles articulated in these documents are common concerns regarding the needs to encourage and support the involvement of community members and leaders in all aspects of the research process, and to demonstrate respect for community decision-making processes. Nowhere are these concerns more prominent than in research on FASD taking place in northern Aboriginal communities.

A team of researchers and service providers in the Northwest Territories has been working since July 2009 to develop a research project on the prevention of FASD that explores the relationships between experiences of trauma and alcohol-use patterns in northern Indigenous communities. This team has come together through networking activities supported by the CanFASD Northwest Network Action Team on FASD Prevention from a Women’s Health Determinants Perspective. This research partnership is predicated on the understanding that FASD prevention requires informed research that translates knowledge into meaningful, practical forms that can be shared with, and implemented by, local communities, and represents the first meaningful opportunity for CanFASD Northwest members to directly undertake in prevention research in the North.

This collaboration is based in the Northwest Territories, with Southern collaborators, and is beginning with a 2-year research development process to create viable and respectful partnerships between researchers and communities that will allow them to collaborate in developing and testing an intervention model. While taking the time to identify shared points of reference and to create agreements on appropriate processes, protocols and priorities for FASD prevention are both integral steps to ensuring that relevant and meaningful research and knowledge exchanges take place, such efforts are rarely funded through traditional scientific funding streams.

**Future directions**

The consideration that geographically and culturally specific models are needed to enhance local capacity for FASD diagnosis and prevention is a guiding assumption for CanFASD Northwest and its partners. While the need for these services has long been identified in the North, there remains a lack of financial and human resources to develop and implement them at the community level, and to support linked, community-based research evaluating their effectiveness. It is our belief that thoughtful, respectful and collaborative approaches that bring together scientific inquiry and service delivery can assist in responding to the needs of communities, and that academic health science centres have both a role and a responsibility to engage in such partnerships. At the same time, it must not be overlooked that the knowledge,
experience and capacity which exists in the North can assist and strengthen research taking place in the South. If we are going to built systems of care for FASD and its prevention that meet the needs of all Canadians, multidirectional knowledge exchange involving researchers, clinicians, service providers and governments is urgently needed.

REFERENCES

1. Clarren SK, Lutke JM. Building clinical capacity for fetal alcohol spectrum disorder diagnoses in western & northern Canada. Can J Clin Pharmacol 2008;15(2): e223–e237.
2. Clarren S, Salmon A. Prevention of fetal alcohol spectrum disorder: proposal for a comprehensive approach. Expert Reviews of Obstetrics and Gynaecology 2010;5(1):23–30.
3. Mattson SN, Riley EP. A review of neurobehavioral deficits in children with fetal alcohol syndrome or prenatal exposure to alcohol. Alcohol Clin Exp Res 1998;22:279–294.
4. Astley SJ, Bailey D, Talbot C, Clarren SK. Fetal alcohol syndrome (FAS) primary prevention through FAS diagnosis: I. Identification of high-risk birth mothers through the diagnosis of their children. Alcohol Alcohol 2000;35(5):499–508.
5. Astley SJ, Bailey D, Talbot C, Clarren SK. Fetal Alcohol syndrome (FAS) primary prevention through FAS diagnosis: II. A comprehensive profile of 80 birth mothers of children with FAS. Alcohol Alcohol 2000;35(5):509–519.
6. Tait CL. Fetal alcohol syndrome among Aboriginal people in Canada: review and analysis of the intergenerational links to residential schools. Ottawa: Aboriginal Healing Foundation; 2003. 337 p.
7. Van Bibber M. It takes a community: a resource manual for community-based prevention of FAS/FAE. Ottawa: Health Canada First Nations and Inuit Health Branch; 1997. 137 p.
8. Centers for Disease Control and Prevention. Fetal alcohol syndrome – Alaska, Arizona, Colorado and New York 1995–1997. MMWR Morb Mortal Wkly Rep 2002;51:433–435.
9. Badry D. Becoming a birth mother of a child with fetal alcohol syndrome [dissertation]. Calgary (Canada): University of Calgary; 2008. 293 p.
10. ACUNS (n.d.). Ethical principles for conduct of research in the North. Ottawa: Association of Canadian Universities for Northern Studies Committee; 2003 [cited 2010 July 31]. Available from: http://acuns.ca/website/wp-content/uploads/2010/09/EthicsEnglishMarch2003.pdf
11. Alberta ACADRE Network. Principles for Aboriginal health research. Edmonton: ACADRE Network; n.d. [cited 2010 July 31]. Available from: http://www.acadre.ualberta.ca/nav02.cfm?nav02=57124&nav01=56454.
12. First Nations Centre. OCAP: ownership, control, access and possession. Sanctioned by the First Nations Information Governance Committee, Assembly of First Nations. Ottawa: National Aboriginal Health Organization; 2007. 18 p.
13. Mi’kmaq Ethics Watch. Research principles and protocols. Antigonish: Mi’kmaq Ethics Watch; 1999. [cited 2010 July 31]. Available from: http://mikmaki.ca/PDFs/Mikmaw%20Research%20Principles.pdf.

Sterling K. Clarren, MD, FAAP
Canada Northwest FASD Research Network and University of British Columbia, Department of Pediatrics
L408-4480 Oak Street,
Vancouver, BC, V6H 3V4
CANADA
Email: sclarren@cw.bc.ca