

# ADDRESSING FASD IN BRITISH COLUMBIA, CANADA: ANALYSIS OF FUNDING PROPOSALS

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## ABSTRACT

### Background

Fetal Alcohol Spectrum Disorder is a preventable health issue affecting about 10% of the population. This research examined proposals submitted to a call for funding for projects to improve outcomes for people with fetal alcohol spectrum disorder (FASD).

### Objectives

The aim was to use the proposals as proxy for perceptions of needs held by practitioners in British Columbia, Canada, where considerable FASD-related education and awareness exists.

### Methods

Content analyses were conducted and Chi-square tests were used to test the relationship between proposal foci, community size and the submitting agency's experience with FASD.

### Results

Nine foci were found: Skill Development, Care, Training, Resource Development, Education, Transition, Peer Support, Research and Other. No statistically significant difference was found in proposal foci according to size of community, and only one focus, Research, was associated with agency experience. Proposals varied in intensity, timing, participants, and focus of change (people or environments).

### Conclusions

Analysis of the proposals provides a unique view into perceptions regarding ways to improve outcomes for people with FASD.

**Key Words:** *Fetal alcohol spectrum disorder, content analysis, funding, support, community, Canada*

British Columbia (BC) has a long history of activity in the area of fetal alcohol spectrum disorder (FASD). That history covers a gamut of activities on the provincial level including care for children, teacher education, diagnosis and assessments at sites throughout BC, awareness campaigns, international conferences, government policy development and research. More was added to that mix in 2006 when the provincial government provided \$10 million in funding to non-profit organizations for prevention, education, and programming to improve the lives of people with FASD.

The extensiveness of action both in governments and in communities indicates the province's responsiveness to this important public health issue. The epidemiological rates are not known in BC because for many FASD is a hidden disability, not yet diagnosed. Researchers, funding agencies, and governments in BC have not focused on ascertaining prevalence rates; instead, the emphasis has been on raising general awareness about the effects of prenatal alcohol exposure, and on prevention, diagnosis, and care of prenatally exposed children.

BC was the first province to develop diagnostic and research activities. Early activity began 45 years ago with Dr. Kojo Asante reporting apparent cases of FASD while working in northwest BC. His observations led to the earliest study of incidence of FASD in Canada.<sup>1</sup> Those early beginnings sparked continued leadership by British Columbians in FASD research, diagnosis, assessment and policy.

Four province-wide initiatives currently provide resources to individuals with FASD and their families. One is diagnosis and assessment for individuals under the age of 19 years, using multidisciplinary teams of health professionals (pediatricians, psychologists, speech and language therapists and others) using the Canadian Guidelines for Diagnosis and Assessment<sup>2</sup> to conduct diagnoses and assessments in local communities. The second is the Key Worker and Parent Support program that employs workers to support families with FASD, assisting them by providing emotional and practical support and connecting them with relevant resources.<sup>3</sup> The third initiative is the Provincial Outreach Program for Fetal Alcohol Spectrum Disorder (POPFASD) funded by the Ministry of Education. It educates teachers on how to teach students with FASD.<sup>4</sup> The fourth initiative is the government's 10-year strategic plan describing policy commitments across ministries, *Fetal Alcohol Spectrum Disorder: Building on Strengths. A Provincial Plan for British Columbia 2008-2018*.<sup>5</sup>

Beyond those provincial initiatives, many community-based activities exist through non-profit organizations, First Nations, colleges and agencies. Researchers have conducted animal and human studies on the effects of prenatal alcohol exposure. The first international conference on the topic of FASD was held in Vancouver in 1986.<sup>6</sup> The conference has become an annual event that attracts nearly 1000 people each year including many from BC communities.<sup>7</sup>

In summary, the province of BC expends considerable resources on FASD in the areas of education, health, justice and social welfare. In 2006 it committed \$10 million by establishing the FASD Action Fund to be distributed through the Victoria Foundation. The purpose was "to promote prevention, public education, parent and

caregiver education, and support multi-year demonstration projects focusing on improving outcomes for people with FASD."<sup>8</sup> The \$10 million fund was divided into three parts: \$1 million legacy fund, \$2 million in funding for projects that focused on prevention and education, and \$7 million for demonstration projects. Demonstration projects were those which could improve outcomes for children and youth with FASD. Demonstration projects were eligible for funding up to 3 years duration, with the intent of illustrating the utility of an approach, implementation of good practices or the discovery of new knowledge. Examples were a program to teach youth skills for employment and a program designed to educate police, social workers and others about how to effectively deal with people with FASD. Inclusion criteria were that the projects be conducted within the province and that the agency receiving the funds was from the non-profit sector. An evaluation of the \$7 million fund and each of its funded projects has been conducted.<sup>9</sup>

Because of this extensive history and the scope of activities already established in the province, we considered the province to have an educated population with respect to the topic of FASD. We viewed the sample of proposals submitted for funding as representing the applicants' informed perceptions of strategies for improving outcomes for people with FASD. We could not find previous studies that analyzed the focus and other components of funding proposals addressing FASD or related topics.

The aim of this study was to analyze proposals to attain a condensed and broad summary of proposal foci, interpreted as reflecting applicants' perceptions of services and supports required by people with FASD and their families and communities. One outcome of analysis was the identification of categories that collectively summarize proposal foci. A second outcome was examination of the association between proposal foci and community size. A third outcome was examination of the association between proposal foci and agency experience with FASD.

Research questions and their rationales are:

- 1) What categories of proposal foci are identified? Given the rich history of experience with FASD in BC, we used proposals as a proxy for applicants' perceptions of the types of services and supports required to improve outcomes for people with FASD and their families and communities.
- 2) Do proposal foci vary by size of community? We examined the assumption that larger communities are advantaged with more resources while smaller communities struggle to provide the most basic services.
- 3) Do proposal foci vary by agency experience? We examined the assumption that agencies' prior experience working with people with FASD would influence proposal foci.

## METHODS

Proposals submitted under the \$7 million fund were eligible for analysis in the present study. The authors of the present study were contracted to evaluate the fund.<sup>9</sup> Applicants consented to participate in evaluation research when they submitted their proposals to the funding competition. The funder agreed to research use of the data on grounds that no participating individual or agency can be identified and only aggregated data are reported. The researchers obtained institutional review board approval from their two universities before collecting data about projects.

A total of 98 agencies submitted a total of 110 proposals. To create a sample where each agency was represented only once, agencies submitting multiple proposals were identified and one of their proposals was randomly selected for inclusion. The sample for analysis was 98 proposals from 98 agencies.

Two researchers independently coded the data using the following analytic process.<sup>10</sup> We read the proposals several times to become familiar with their content. Through discussion of the funder's call for proposals, the content of the proposals, and our research questions, we identified three dimensions (proposal focus,

community size, and agency experience) most relevant to the research questions.

Coding for each dimension proceeded as follows:

Proposal focus was coded inductively. We read the proposals paying particular attention to each project's objectives and main activities. We considered how applicants proposed to improve outcomes for people with FASD. We were mindful that proposal authors strategically used terms from the funder's call for proposals; key words from the call for proposals remained recognizable as coding categories (e.g., "peer support"). We independently coded and then came together to discuss our coding. We resolved coding differences by adding or splitting proposal focus categories until we agreed by consensus that the most prominent proposal foci were succinctly captured in the coding. Proposals could be assigned more than one focus code.

Community size was coded according to the size of the communities where the proposed activities were to be conducted. Coding categories were derived from definitions recommended by Statistics Canada: rural or small town (communities of less than 10,000 people); small cities (more than 10,000 but not metropolitan); or metropolitan areas (the three largest cities in BC).<sup>11</sup> A mixed code was recorded when proposed activities were located in multiple communities of mixed sizes, for example, in a small city and one or more surrounding rural communities. We read each proposal to identify the location of the proposed activities then consulted a list of BC community populations based on the 2006 Canadian Census<sup>12</sup> to record a community size code.

Agency experience was coded based on what agencies said about the nature and extent of their past work with people with FASD. Proposals and public documents such as websites were considered. Agency experience with FASD was coded dichotomously: no or little past experience versus more substantive past experience. For example, an agency providing respite care for physically disabled children that proposed to extend their services to children with FASD was coded as having no or little past experience.

Two researchers independently coded each of the 98 proposals on these three dimensions. We discussed our coding after every 2 or 3 proposals to resolve disagreements by consensus. As coding progressed our agreement increased. After coding about 25 proposals, agreement was very good. Potential sources of bias in coding were reduced by vigorous debate and discussion of coding decisions, particularly in the early stages of coding, and by continually going back to consider our research questions and re-reading the call for proposals and the content of the proposals themselves.

When coding was completed we counted the codes to yield numeric summaries of the frequency of each category within proposal focus, community size, and agency experience. Counts were used in chi-square and binomial tests to analyze associations of project foci with community size and agency experience.

## RESULTS

Summaries of findings related to proposal focus, community size, and agency experience are presented along with analysis of associations. There were no statistically significant associations between proposal foci and size of community, and only one proposal focus, Research, was significantly associated with agencies' experience with FASD.

### Proposal Foci

Nine categories of proposal focus were revealed using content analysis. The number of proposal foci ( $n = 172$ ) exceeds the number of proposals ( $n = 98$ ) because many projects addressed more than one focus, with a range of 1 to 6 codes per proposal.

The nine categories of proposal foci are as follows:

#### 1) Skill Development

Forty-two proposals focused on helping people with FASD and their families to develop life, social, parenting, and/or employment skills. For example, one agency proposed "life skills training such as anger management, improving communication skills, budgeting, nutrition and meal

preparation, drug and alcohol awareness and healthy relationships." Another proposed to "increase the level of skill and communication between parents and community services."

#### 2) Care

Twenty-nine proposals focused on provision of direct services such as housing or care in schools. Examples were to provide "5 hours/week of in-home services for families" and an "intense advocacy and support program for at-risk youth."

#### 3) Training

Twenty-two proposals focused on intensive training for professionals and others who work with people with FASD, or community members. Examples included neurobehavioural training about FASD, how to support mothers with FASD, and how to teach children with FASD.

#### 4) Resource Development

Twenty-one agencies proposed to create various resources about FASD. Examples included libraries and resource rooms, curriculum, program manuals, and community plans.

#### 5) Education

Nineteen proposals focused on providing short-term training designed to raise awareness about FASD. The proposed activities included workshops or community meetings for various audiences, such as the whole community, youth or parents, women at risk, pregnant women, or health and social service providers. For example, one proposal's objective was to "provide the community with knowledge of FASD to help improve the quality of life for those living with FASD." Education was distinguished from training in intensity and duration, that is, Education involved less intensive short workshops whereas Training was more intensive and longer.

#### 6) Transition

Fourteen proposals focused on supports for people with FASD and their families during significant life transitions. Examples included assisting people to move from preschool to elementary school, from adolescence to

adulthood, from school to employment, and from incarceration to community.

**7) Peer Support**

Nine proposals focused on providing peer support for children and youth with FASD or their parents. One example was an addictions recovery group run by peers and another was “to assist with socialization/peer support and promote a sense of belonging and purpose.”

**8) Research**

Five research proposals were submitted. These knowledge development proposals focused on interventions targeting exercise, sleep, social skills and teaching, and on finding ways to involve people with FASD in research.

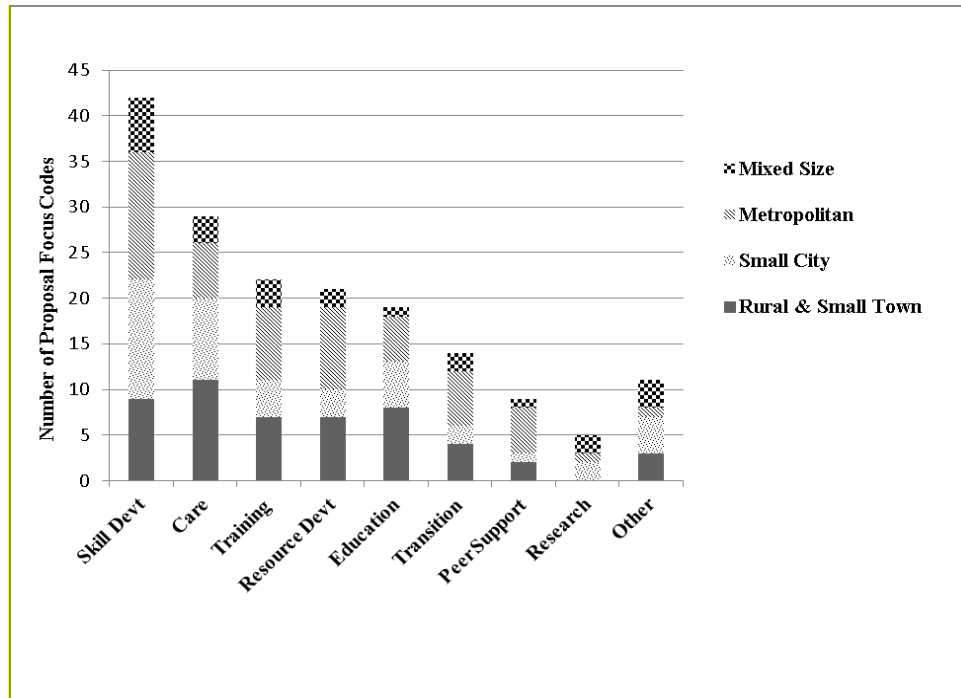
**9) Other**

Eleven proposals had foci that did not fit into other categories. Examples were a diagnostic clinic for adults, creation of networks of professionals or families, and events such as a health fair, an essay contest, cultural events, or summer camps.

**Community Size**

Among the 98 proposals, 27 came from agencies in rural or small town communities, 25 from small cities, 33 from metropolitan areas and 13 from agencies working with networks of communities of mixed sizes. Proposal foci were distributed amongst communities of all sizes, as shown in Figure 1, with no statistically significant associations between any given proposal foci and community size.

**FIG. 1** Proposal foci (n = 172) by community size. Chi-square tests of the distributions of proposal foci by community size were nonsignificant.



**Agency Experience with FASD**

Less than half ( $n = 44$ ) of the 98 agencies submitting applications had substantive experience in the area of FASD, while 54 had no or little previous experience. Most proposal foci were not statistically related to agency experience in the

sense that a given focus was equally likely to be proposed by agencies with and without experience with FASD (see Table 1). The exception was Research; all five research proposals were submitted by researchers with prior experience in the area of FASD.

<b>TABLE 1</b> Proposal foci ( $n = 172$ ) by agency experience with FASD			
Proposal Focus	Agency experience with FASD		Probability
	More substantive	None or little	
Skill Development ( $n = 42$ )	21 (50%)	21 (50%)	ns
Care ( $n = 29$ )	9 (31%)	20 (69%)	ns
Training ( $n = 22$ )	7 (32%)	15 (68%)	ns
Resource Development ( $n = 21$ )	6 (28.6%)	15 (71.4%)	ns
Education ( $n = 19$ )	6 (31.6%)	13 (68.4%)	ns
Transition ( $n = 14$ )	9 (64.3%)	5 (35.7%)	ns
Peer Support ( $n = 9$ )	2 (22.2%)	7 (77.8%)	ns
Research ( $n = 5$ )	5 (100%)	0 (0%)	ns
Other ( $n = 11$ )	3 (27.3%)	8 (72.7%)	.02

**Note:** Among 98 agencies, 44 had experience with FASD and 54 did not.

**Trends**

Many proposals appeared to be based on a belief that people with FASD and their families have skills deficits that can be overcome by intervention, teaching or support. We observed three trends with respect to how the proposals focused on Skill Development varied amongst themselves:

- 1) intensity,
- 2) timing, and
- 3) participants, as follows.

**Intensity**

Varying levels of intensity of skill development were proposed. Some agencies proposed low intensity interventions, such as general information sessions for the public. Others proposed high intensity interventions such as individualized counseling or mentoring and training on particular skills. For example, one agency wanted to provide foster care to young mothers and their children with FASD while mentoring mothers about parenting and life skills.

### **Timing**

Some proposals focused primarily on skills the person with FASD needed immediately (e.g., social or parenting skills) while others focused on skills the person might need in the future (e.g., teaching youth in high school employment skills).

### **Participants**

Some proposals called for peer-to-peer training, while others called for professionals or paid staff to be trainers. In some proposals the learners were people with FASD, while in others the learners were professionals and other people who work with people with FASD. All possible combinations were observed.

Another trend was that many agencies proposed to provide direct services and care to persons with FASD without making efforts to change the environment. However, a number of proposals had a goal of altering the environment in which people with FASD live or work. For example, more than one agency proposed to educate their entire community so that people with FASD would be better understood and treated with less discrimination. One agency proposed a community engagement process where people with FASD would advise businesses and organizations about physical and social barriers to their inclusion. Although the majority of proposals called for skill development and support of people with FASD and their families, there was also evidence of willingness to change environments in order to improve outcomes for people with FASD.

## **DISCUSSION**

In this analysis of proposals submitted for funding, foci of the proposals were used as a proxy for applicants' perceptions of ways to improve outcomes for people with FASD in the province of British Columbia. Proposal foci, community size and agencies' experience with FASD were examined using content analysis and statistical tests of associations. Results of our analyses show that proposals were submitted from communities of all sizes and from agencies with and without previous direct experience with FASD. Nine categories of proposal foci were revealed using content analysis and included, for

example, Skill Development, Care, and Training. Given the emphasis in Canada and elsewhere on determinants of health and social environmental contexts,<sup>13,14</sup> the number of proposals that called for changing people with FASD rather than changing their environment was somewhat surprising. The large number of proposals focused on skill development may reveal a widely perceived need, although perceptions varied with respect to appropriate intensity, timing, and participants. Certainly, there is evidence that many people with FASD have cognitive impairments<sup>15-18</sup> and need specialized instruction and repetition of instruction for learning change to occur.<sup>19</sup> However, longer term goals of equity and inclusion may be achieved more readily with changes to the social environment.<sup>20</sup>

A limitation of this study is our assumption that applicants to the call for proposals were well-informed about ways to improve outcomes for people with FASD because of the extensive history of FASD-related activity in BC. The limitation is that we evaluated agencies' general previous experience only and did not know the applicants' actual level of knowledge of and experience with FASD.

The results of this study could guide decision-makers planning programs and funding initiatives. Evidence-based interventions focused on individuals with FASD, their families, and their communities are needed. Skill development, care, education, changes to social environments, and inclusion of people with FASD are all required, as revealed in the content of these proposals. Additionally, concepts such as equity and social determinants of health should be embedded in work intended to improve outcomes for people with FASD.

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### **Declaration of Interest**

There are no conflicts of interest.

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