



Centre of
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Adolescents
with Special
Needs

Substance Abuse Task Force:
University of Northern British Columbia

Rural, Remote and North of 51:
Service Provision and Substance
Abuse Related Special Needs in
British Columbia's Hinterlands

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Substance Abuse

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Sommaire

Le présent rapport, issu de recherches auprès de groupes-cibles et d'entrevues menées par des informateurs-clés auprès de fournisseurs de services dans quatre collectivités rurales du Nord-Ouest de la Colombie-Britannique, souligne les défis et les obstacles que doivent surmonter les personnes qui travaillent avec les enfants et les adolescents présentant divers besoins spéciaux liés notamment au syndrome d'alcoolisme foetal (SAF) et aux effets de l'alcool sur le fœtus (EAF). En plus de documenter et d'aborder les défis associés à la prestation de services destinés aux enfants et aux adolescents ayant des besoins spéciaux dans les milieux ruraux ou éloignés, le rapport met en lumière diverses solutions et réponses élaborées à l'échelle locale pour faire face aux réalités des régions les plus isolées.

Les conclusions de ce rapport sont axées sur quatre thèmes : restrictions diagnostiques, inquiétudes liées aux sources de financement, enjeux préoccupants en matière de santé communautaire, et barrières géographiques et culturelles. Chacun de ces thèmes est abordé en rapport avec la capacité (et la capacité perçue) de fournir des services efficaces et durables aux enfants et aux adolescents ayant des besoins spéciaux dans les collectivités nordiques. Le rapport conclut avec six recommandations, dont chacune est directement issue de la recherche communautaire à la base du rapport.

Executive Summary

This report, resulting from focus group research and key informant interviews with service providers in four rural northwestern British Columbia communities, highlights the challenges and barriers for those who work with children and youth who live with a variety of special needs, including Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effect (FAE). In addition to documenting and discussing the challenges associated with providing services to children and youth with special needs in rural or remote settings, the report outlines a variety of locally developed solutions and responses to the realities present in more isolated settings.

The findings of the report focus on four themes: diagnostic limitations, funding concerns, overwhelming community health issues, and geographic and cultural barriers. Each of these themes are discussed in relation to the ability (and perceived ability) of providing meaningful and sustained services to children and youth with special needs in northern communities. The report culminates in six recommendations, each of which is derived directly from the community-based research that was the foundation of the report.

Introduction

Substance abuse that harms children and adolescents is a serious problem for many Canadians especially those living in rural, remote and northern communities. Hinterland populations often experience marginalization because of their locale. This marginalization is characterized by a lack of services or by significant barriers to healthy choices and effective recovery. Availability, accessibility and quality of services continue to be significant issues. In Aboriginal communities these issues are compounded by the historical, political and social influences that continue to impact and limit their lives and their capacity to effect meaningful change. For example, in the words of community researchers and leaders of the Gitksan Nation, in northern British Columbia:

Drug and alcohol use and addiction have been compelling issues in Aboriginal communities for a long time. It is understood as an individual lifestyle choice that has become out of control. Yet in some communities, alcohol and drug use is a way of life for most residents. Communities subsumed by substance use and addictions are the result of marginalization and destruction of family and culture. Aboriginal people are continually punished for their addictions, more so than others, and are over represented in the criminal justice and child welfare systems. These punitive responses often result in further dependence upon substances. The individual, family culture and community are not healed. It is a vicious circle (Rutman et.al., 2000, pp. 112-113).

Substance abuse not only affects the lives of children and families, it can also affect the lives of unborn children. For example, in the 1997 Report on the Health of British Columbians, Provincial Health Officer's Annual Report, the effects of alcohol use and addiction on unborn children are examined. The report states:

Continued research and evaluation needs to occur in this field (fetal alcohol syndrome). We have inadequate methods for monitoring the extent of the problem whether we are having an impact over time. At the same time, we need to develop more effective prevention, promotion and treatment programs prior to pregnant or during pregnancy and for children exposed. The effectiveness of these programs must be demonstrated through proper evaluation (p. 120).

Drug use and addiction plague rural, remote, northern communities. The incidence of drug affected babies has risen six fold in the past decade. Typically these babies are from “families of inter-generational drug users or from dysfunctional families with a history of sexual and physical abuse” (p. 122). Recommendations in the 1997 Provincial Health Officer’s Annual Report for addressing the numbers of drug affected babies being born include: encouraging community-wide solutions to the problems of alcohol and drug abuse, providing special treatment and recovery programs for women dealing with drug use, and providing integrated care for drug affected babies and their families.

Also identified in the 1997 report is an overall “lack of ongoing, comprehensive data to assess the quality of life for disabled children” (p. 122). In rural, remote and northern communities, the need for identification of needs and services is critical. With resources and services being limited, the need for integration of services and collaborative approaches to these issues becomes critical. “Band-Aid,” “quick-fix” solutions are no longer acceptable. Contextual solutions that examine all aspects of individual, family and community life are needed to promote healthy, self-determining individuals and communities. To that end, we begin to explore and identify contextual solutions for addressing challenges and barriers service providers face in rural and remote communities of northwest British Columbia.



Background

In order to understand challenges to service delivery in rural, northern communities we must first understand the context in which these services are delivered. Geographic, political and cultural factors shape the delivery of services and the research that supports service policies.

Communities in which we conducted our research are commonly designated as rural, remote and northern. This speaks not only to their marginal geographic location but as well to the cultural distances between urban and rural sensibilities (Hansen and Muszynski, 1990; Collier, 1993; and Fitchen, 1991). The communities are located in the northwest region of British Columbia within the Pacific coastal region. This places them at a disadvantage with respect to the urban centers of Vancouver, Victoria, and Burnaby where the major services for special needs children and adolescents are located, and where service delivery policies are often formulated. The geographic location marginalizes them: road travel to Vancouver and Burnaby can take up to 20 hours (when the roads are clear) and airline travel can be readily disrupted by adverse weather. Although closer to Prince George in the central interior of British Columbia, travel from the communities on the Pacific coast to the interior is no easier. Airline service is always directed through Vancouver making utilization of services in Prince George difficult. In so far as they receive special services emanating from Prince George, the lack of direct airline service inhibits the travel of specialists from the interior to the northwest coast communities. However, no specific FAS (Fetal Alcohol Syndrome) diagnostic services exist in Prince George other than one pediatrician. Diagnostic services for children and adolescents are primarily provided by the Sunny Hill Hospital in Burnaby, Assante Center in Maple Ridge, and the British Columbia Women's and Children's Hospital in Vancouver. As we will explain below, barriers to service delivery not only impact direct service deliveries but also negatively affect the ability to conduct meaningful research in the region. "Fly in" specialists and researchers have little opportunity to appreciate local culture and often leave with perceptions of the need for special services which they can not validate because of a lack of meaningful research grounded in the context of community (Collier, 1993). As we will demonstrate

below, barriers to service delivery include the location of research institutions, such as hospitals, universities and non-governmental organizations. In the lack of local research, the particular situation of these communities is often extrapolated from national or provincial statistics or by seeking comparisons with similarly situated communities elsewhere in Canada or even the United States.

Geographical Factors

The economy of the northwest region is grounded in forestry, pulp and fishing (<http://www.city.terrace.bc.ca/>). There is little secondary industry apart from an aluminum smelter located at Kitimat. Markets for these products are primarily located in the United States making the region vulnerable to international trade agreements and the global market for commodities. Being so far from an urban center, and lacking the infrastructure for industrial development, this area is not a prime site to develop a manufacturing based economy. Therefore, as an economy based on resource exploitation declines, the communities become vulnerable from loss of population, which can lead to loss of services and which may in turn make communities less attractive as sites for new economic development (Fitchen, 1991).

Not only are services negatively impacted by the distances from urban centers, they also suffer due to the large distances separating communities from each other with the region. Although the larger communities are linked by a major highway, Highway 16, travel in the region is made dangerous and difficult by winding secondary roads, high mountain passes and adverse weather conditions. Not surprisingly, many community leaders and service workers resist centralization of services (particularly if that centralization is set to occur within larger urban centres), leading to a sense inter-region of competition amongst communities. This is exacerbated as service agencies face multiple demands from the smaller scattered communities, all separated by winding roads, rivers and mountain passes.

Political Factors

Living on the geographic margins locates the people of the northwest region on the political margins provincially and nationally. As in the other large provinces of Canada, British Columbians are clustered in urban centers clinging to the Canada-US border. Political representation in the provincial legislature favors the urban south, leading to a sense of alienation and neglect in Northern British Columbia. This is often expressed as a north south tension, and gives rise to expressions of resentment and frustration. The political tensions of marginalization are compounded by the internal politics of the region. Communities struggle with one another for service development and often find that if they have one service they are denied another in the interest of spreading government funding as broadly as possible. Currently the Liberal government of British Columbia is cutting services and centralizing authority, leaving the region dependent on various sites of decision making for hospitals, health education, social services, etc. This centralization is reflected in our situation as members of the UNBC community. Although University of Northern British Columbia (UNBC) sees itself as a university of and for the north, it too is located outside the northwest region having only a regional campus in Terrace which supports fewer than five full time faculty and a single full time faculty member in Prince Rupert, the largest city in the region.

Political struggles to develop consistent and stable service delivery for special needs children and adolescents are compounded by the division between First Nations communities and the larger dominant Euro-Canadian communities (Brown & Fiske, 2001). The Nisga'a Nation of the Nass River Valley, lying to the north of the larger communities in the area is the first Aboriginal nation to achieve self-government status in British Columbia. Self-governing treaty gives the Nisga'a control over a significant portion of their traditional territory and the authority to develop social, health and education services for its members. The neighboring nations have yet to achieve self-government through treaties. However, through agreements with the federal and provincial governments other First Nations are moving towards transfer of health and social services (Rutman et.al., 2000). Where this might benefit the First Nations themselves, it can appear to others (primarily non-First

Nations) as a duplication of services rather than a coherent regional development of services. First Nations jurisdiction does not extend beyond reserve lands, creating service gaps for their members when they move on and off reserve. Transfer of services does not necessarily translate into adequate funding and infrastructure for special needs children and adolescents (Rutman et.al., 2000).

Despite the perception of the autonomy from provincial legislation, First Nations do not escape the impact of neo-liberal fiscal policies. Federal health, social and education policy demands that First Nations mirror provincial policies and practices. As the province diminishes services so too must the First Nations.

Uneasy relationships prevail between First Nations and Euro-Canadian communities. The north west Pacific region is home to the Aboriginal legal struggles that led to supreme court decisions recognizing Aboriginal land and resource entitlements (Rutman et.al., 2000). The provincial and federal governments have come to recognize the need to address Aboriginal rights and in 1990 did so by establishing the modern treaty process in the hopes of clarifying Aboriginal title and governmental jurisdiction. This in itself created political tensions in the northwest. But more recently the provincial government has sought to change the nature of the treaty process. In 2002, British Columbia launched a referendum on the treaty process that was resisted by First Nations and their supporters. Whatever the results might be, the referendum process has further exacerbated political tensions in the region. These political tensions spill over in conscious and unconscious ways and flow into the politics of service delivery.

Cultural Factors

There are two ways of considering the cultural factors that shape policy and service delivery. One is to emphasize cultural differences between Aboriginal and non-Aboriginal (Brody, 1981; Square, 1997), while the other is to emphasize a north south, rural urban cultural difference. A focus on Aboriginal versus non-Aboriginal overlooks a northern sensibility of the rugged individual living on a

wilderness frontier (Fiske, 1997; Fox, 1997). Like many areas described as rural, remote or northern this area has a culture of individualism that values self-reliance, stoicism and actions of personal bravado (deLeeuw, S, 2002). Interwoven in this culture of heightened individualism is an acceptance of alcohol and substance use. To challenge this use of substances is to also challenge an accepted way of life. Urban outsiders who visit the region infrequently may not see beyond this surface culture and thus may carry away an exaggerated sense of alcohol and substance abuses occurring within the area. For children and adolescents with special needs this creates a specific problem. Tied to the perception of the north as a culture of alcohol and substance abuse is the perception that children and adolescents with special needs are most likely to have been damaged by fetal alcohol or other substances (Leischner, 2001). These assumptions are not restricted to the casual observer but are expressed by professional practitioners. While it seems logical that high incidences of alcohol consumption would translate into high incidences of alcohol affected babies a focus on this alone narrows and restricts programs and services for northern communities (Aase, 1995; Canadian Center on Substance Abuse, 1996; Roberts & Nanson, 2000). Additionally when these assumptions are taken for granted, the need for research into the complexities of alcohol and substance use becomes even more paramount.

Challenges

The biases and absences of good research are made evident in a body of literature from the last decade. The lack of solid detailed research on special needs children and adolescents of rural, remote and northern communities is striking given the current emphasis on linking special needs to substance use during pregnancy. Deborah Rutman et.al. (2000) are an exception to this trend. In their study, Substance Use and Pregnancy: Conceiving Women in the Policy-Making Process, Gitksan women link the need for research, and respect for women to questions of governance, popular misconceptions of substance using women and the care needed for their children. This study provides valuable insights to both the challenges facing women using substances during pregnancy and solutions arising from the women themselves. As they point out, it is impossible to address relevant questions for women and their special needs children of the northwest coast without analyzing the social, historical and political context in which they live. They cite inadequate

resources for women-focused alcohol and drug treatment programs and policies of child apprehension as major challenges for their First Nation.

A complementary study by Leischner et.al (2001) in Prince George also links the need for community based research with the development of appropriate services. Going beyond the question of treating children with Fetal Alcohol Syndrome/Fetal Alcohol Effects (FAS/FAE) or regulating substance use in pregnant women, they look to the need for programs for young girls, the relationship between mental health issues and substance use, and the misdirection of services as a consequence of naming and blaming. They ask, for example, whether assumptions of special needs grounded in neurological diagnosis and social practices of mothers direct our attention away from sexual and physical abuses and other stresses on adolescent girls. Like Rutman et.al. (2000) they link the needs of women and children to the context of poverty, violence and marginalization.

As valuable as these qualitative studies are, they cannot address questions of diagnoses. In 1987, Robinson et.al. conducted a clinical profile of the prevalence of FAS in an isolated community in British Columbia. They made a diagnosis of FAS/FAE in 22 children and matched these with unaffected children in the same community. They found that two thirds of the children with FAS/FAE were mentally retarded. This study again emphasizes the need for research into the complex consequences of maternal alcohol abuse including the need for in-depth studies of the children's development and availability of appropriate services directed towards their learning, medical and social needs. This reiterates our position that a major challenge to effective services for special children and adolescents is a lack of local research. Our position is that effective research will combine diagnostic study with community based, qualitative assessment of service delivery.

In the absence of local research and community studies the Canadian Center on Substance Abuse (October, 1996) states that whether an individual child born to an alcohol-using mother will have FAS appears to

depend on a number of factors in addition to alcohol, including prenatal health, other drug use, lifestyle and other social-economic factors. Therefore FAS cannot and should not be considered in isolation from total concern for the health and well being of children and their families (p. 1).

They go on to speak to the unintended harm of assuming that FAS and individual abnormalities are inevitable even at low levels of alcohol consumption. This misperception may lead to labeling that leaves children with lifelong stigma and or create supports that are minimally effective rather than appropriate programs and treatment. They also suggest that a narrow focus on women overlooks the possibility that factors contributing to FAS may be male mediated including physical and psychological harm to the mother.

The Canada wide study by Leslie and Roberts (2001) examined federal programs involved in the delivery of FAS programs and services. They found that Canada lacks a common screening approach and that readiness and skills to assess FAS affected children differ widely across the country with Western Canada having developed the greatest capacity. Challenges to appropriate screening are identified as lack of funding and credentialed staff, an absence of culturally appropriate instruments and the development of projects that do not integrate formal screening.

First Nations Inuit Health Branch, Health Canada (1997), has identified inconsistencies in diagnosis, predictions of incidences of FAS, and use of terminology as problematic. They point to the ambiguity in diagnosis with respect to differentiating between FAS/FAE. This leads to misconceptions respecting the needs of FAE children and to predictions of secondary disabilities and their social consequences. They provide criteria for diagnosing FAS/FAE and a subjective description of the difficulties expressed by FAS/FAE individuals. Their work links the need for grassroots studies with funding to community agencies for services tailored to the local situation.

In a later study prepared by Roberts and Nanson (2000) for Health Canada, discussion of the characteristics of pregnant women at risk, the relationship between mothers drinking, and other substance uses is included. They review statistical studies for the United States and outline

preventive activities. Citing Caroline Tait, they speak to the particular barriers facing Aboriginal women who would seek diagnoses or treatment services. This study also points to the need for consistency in developing diagnostic criteria and population survey methods. In the absence of such consistency it is difficult to know the prevalence of FAS/FAE or the relationship between assumed FAS/FAE and other causal factors.

A number of studies point to the overwhelming health issues faced by mothers of special needs children and adolescents. Leslie and Roberts (2001) identify poverty, nutrition and depression as key factors to consider. York (1990) provides a compelling description of the social context of Aboriginal communities that lead to a sense of despair and alienation that in turn leads to impoverished health. McTimoney (July, 1990) links low socio-economic status combined with poor family structure to school emotional and behavioral problems. These he sees as underlying the high rates of solvent abusers, in particular among males ages 12 to 17 years. These root causes mirror the conditions in which we find maternal substance abuse; this again underscores the need for studies and services that are broadly based in the geographic, social and political context.

The consequences for children and adolescents with special needs, whether they be linked to substance abuse or not, are felt more desperately in rural and remote communities. Problems also found in urban communities are magnified in small rural communities that lack fiscal and human resources. Children with special needs may be more easily isolated from community life due to learning difficulties, behavioral problems, depression and despair. We do not yet have a clear understanding of the links between FAS/FAE and adolescent suicide or self harm. The need for rural services is compounded by the fact that the vast majority of children with FAS lose their biological parent before reaching adolescence. Schmidt and Turpin (1996) cite several studies that find children born to heavy drinking families have "remarkably unstable" family lives, with 69% of the biological mothers dead before their children reach maturity. Many of these mothers died from alcohol related illnesses, homicide, suicide, falls and auto accidents. Taken together small, isolated, rural communities will feel family dysfunction, maternal deaths and psychological impacts on special needs children and adolescents most desperately as a consequence of their

marginalization from the centers where services are designed and funding allocated. When, as is currently the case, the overwhelming focus on special needs children is on one condition, northern and remote communities find it difficult if not impossible to address the full range of service needs. In small, remote communities of British Columbia the division of responsibilities between health and social services, and between federal fiscal responsibility for First Nations and provincial responsibility for others, adds to the difficulty of developing comprehensive service delivery over a wide geographic territory.

Provision of appropriate services to special needs children and adolescents must consider all of the foregoing. Currently, child welfare policies, women's programs and health initiatives fail to offer comprehensive approaches to meeting the unique needs of the communities. Programs that emphasize women's and young girls' needs are recommended, including the recognition "that women's substance misuse is a health issue that requires a contextual solution" (Leischner, C. et.al., 2001, p. 35). Rutman et.al (2000) begin by addressing the issue from the lived experiences from the Gitksan nation. They address the need for services over which the women themselves have some control and which are integrated positively with child welfare services and, in their terms, utilize "a youth empowerment strategy" (p. 131). Other Aboriginal studies (Health Canada, 1997) begin with a cultural context and seek solutions in services whose initiatives arise at the community level with culturally appropriate programs that include longitudinal research. Similarly the Canadian Paediatric Society (1997) recommends that all efforts should be culturally sensitive, but rather than focussing primarily on women it argues for family centered comprehensive services. Strategies for children with special needs are often embedded in early intervention programs focussing on at risk children and families. These strategies seek to address secondary and tertiary effects of special needs through the unique development of these children. Likewise, the strategies provide supports to families that are intended to assist them in addressing their children's needs. Service delivery will falter where child-based programs lead to the removal of children from families in lieu of providing women/family based programming.

Medical based strategies primarily focus on screening and diagnosis. Some seek to prevent fetal harm by focusing on the overall maternal health. However, the role of physicians and health professionals subsequent to the identification of birth defects and developmental disorders is limited. Screening and diagnosis is very limited in rural, remote and northern communities, and of course treatment for the same is equally problematic. While Square (1997) identifies the need for research among the white middle class population, he fails to identify what subsequent action health professionals would take in serving FAS children.

Proposed Solutions and Best Practices

Proposed solutions and best practices have been formulated by substance using women. Women working with Leischner et.al. (2001) understand their substance misuse within a frame of self medication. They recommend a shift in language and beliefs to better understand their circumstances. They understand their substance use as a response to life events and recommend the removal of “the work of recovery from the medical world and placing it into a normalized experience of growth and development” (p. 35). Leischner notes that service delivery overlooks the role of mothers with children over the age of six and recommends that this be remedied. The women in Leischner’s study also call for “physically accessible and cognitively understandable” services particularly for FAS affected women (p.36). Finally, they stress the need for adolescent girls’ programs that understand gender relations.

Roberts and Nanson (2000) provide a list of best practice statements encompassing primary, secondary and tertiary prevention. With respect to interventions during infancy and early childhood, they recommend professional multi-disciplinary teams to address the affected children’s health needs. They also suggest family centered substance abuse treatment, respite care and other support services that would contribute to a stable living environment. At the later childhood stage they recommend medical, educational and psycho-social supports for the child and family. For adolescents, they recommend assistance with basic socialization, fundamental skills of daily living and vocational counseling. Similarly, experts have suggested to them that tailored

programming is needed for adolescents involved with substance abuse treatments. Finally, there is some evidence and consensus among experts that where a mother receives support immediately following birth there are improved outcomes for her and her children.

McTimoney (1990) advocates for an overall community commitment to any strategies used to address substance abuse. He highlights the fact that solutions are larger than singular programs or services and stresses a need for a coordinated effort of all community sectors including governance structures, community merchants, individual programs and services, families and individual community members.

Leslie and Roberts (2001) look to multiple sources of funding for building strong broadly based initiatives. They also recognize the value of provincial and territorial coordination of FAS programs and activities. Building from this coordination is the need to address FAS in a context of the broad determinants of health. Best practices and strategies to reduce harm need to be linked to research on the prevalence and incidents rates.

Additionally, the Canadian Paediatric Society (1997) emphasizes the need for continuing education programs for health professionals and the need for them to be familiar with community services. Health professionals also need to increase their awareness of birth defects and other developmental disorders.

Other Substance Misuse

The focus on FAS/FAE and the need to consider developmental disorders must not take attention away from other special needs. Among geographically remote and economically marginalized adolescents, solvent abuse is a major cause of concern. York (1990) describes the devastating effects of cultural invasion and dislocation on marginalized populations and their relationship to young addicts.

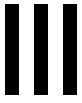
Medical researchers around the world have reported inhalant abuse. ...and in almost every case, there is one unifying factor: the young addicts are poverty-stricken members of a community that has been overwhelmed by a more powerful outside culture. They are victims of cultural invasion or dislocation. The economic influence of the outsiders has forced an ethnic group to move to a foreign place, or it has surrounded and besieged the indigenous culture, destroying the traditional economy and social harmony. In each case members of the minority group are stripped of their identity and their traditional way of life, and they descend into a pattern of self-destructive behavior. Inhalants are the cheapest and most accessible of the weapons of self-destruction (pp. 112-113).

Accessibility to substances plays a major role in adolescent usage. Studies of how adolescents obtain non-regulated substances show that their rates of access are much higher than those substances, such as alcohol, that are regulated. Inhalants, such as gasoline, can be obtained freely and can be more damaging than any other misused substance.

Strategies for developing solutions and best practices for children and adolescents must take into account the prevalence of solvent abuse and the health consequences that follow from it. In Kaweionnehta's 1994 study of solvent abuse, the authors found little change in the inhalant literature in the past 30 years. Inhalant use is still highest where poverty, prejudice and lack of opportunity exist. Likewise, volatile solvent abusers are most likely to be described as multi-problem - coming from backgrounds characterized by unstable or dysfunctional families, parental alcohol abuse, school related difficulties, and often times conflicts with the law (p 3).

The link between substance abuse, learning disabilities and behavioral disorders needs further research. The National Center on Addiction and Substance Abuse at Columbia University recommends studies of this nature. They also note the need for sensitive, careful research in order to avoid stereotyping and stigmatizing children whose socio-economic and family situations make them vulnerable to moral judgements. They comment that some professionals in the field of learning and behavioral disorders are reluctant to address these issues in a contextual framework.

However, the suggestion that learning disabled children turn to drugs for self medication speaks to the need to overcome this resistance and to address the complex relationships of cause and effect within the lived reality of children's lives. With this background in mind, our study sought to identify and documents challenges and barriers facing service providers in rural and remote northwestern British Columbia, in addition to exploring and identifying contextual solutions and recommendations to address these challenges.



Objectives

Bearing in mind the research recommendations and gaps in services identified in the above literature, our study offered community groups and agencies an opportunity to make known their local realities and needs. We focused on identifying the greatest concerns of service providers and their recommendations for meeting challenges and eliminating barriers to local service provision.

The research undertaken in this project began with an understanding that children and adolescents with special needs related to substance abuse were of growing concern to rural and remote northern communities. Tasked with identifying challenges to delivering services to this population, and also identifying 'best practices', specifically those sensitive to diverse need in northern communities, the UNBC Task Force on Substance Abuse undertook a series of community consultations with resource agencies in northwestern British Columbia.

IV

Research Process

A. Introduction to the Research Process

Given the perception that northern BC is plagued by problems of substance abuse and a lack of services to treat this abuse and its consequences, a study of the barriers and challenges to service delivery is significant. Community front line workers, policy makers at the regional and national levels and academics will all benefit from a clearer understanding of the specific challenges and barriers faced by communities who are represented as rural, remote and northern. The Center of Excellence for Children and Adolescents with Special Needs has identified substance abuse research as a primary way to contribute to the well being of the northern BC region. The center operates with the following research principles:

1. to provide information and services that make sense to people in need;
2. to identify gaps in current knowledge; and
3. to provide new information from local and world-wide perspectives.

The overall goal of the Center is to provide access to culturally appropriate services and to make a 'real' difference in the lives of special needs children and adolescents. Information is gathered and refined to provide a foundation for developing services for children and adolescents with special needs.

We chose to do service related research because it holds practical relevance for communities who are often overlooked by large-scale, nation-wide studies.

B. Implementation of the Research Process

We selected researchers with experience in community-based research, knowledge of northern communities and a dedication to social change. For this particular project we engaged five

researchers whose experience and training ranged from graduate students in training, community activists, leaders in child and family services and academic researchers. Working as a team, we developed a research protocol, grounded our research in communities where we had established networks, and most significantly, took our research where we were invited to do so. In preparation for engaging communities we developed letters of invitation and introductory information packages prior to arrival in the communities. Community members, understood to represent leadership in the field of child and youth service delivery, were asked to organize focus groups, ensuring that interested and experienced front-line workers were included and that the focus groups would be held at appropriate times and locations.

These communities are all located in the Pacific Northwest of BC. The economic base of this region is a resource economy of forestry, fishing and mining. Tourism provides additional revenue to the communities on a seasonal basis. Strung along Highway 16 and lying within the Skeena and Nass watersheds, common economic forces, (while being divided by cultural diversity and regional specificity), unite these communities. These communities provide services to the smaller communities of the Nisga'a and Tsimshian First Nations. This study speaks to communities currently experiencing economic disruptions through the decline of fishing and forestry and severe service cutbacks from the provincial government. Therefore it may not address issues that would be more relevant to wealthier and more stable communities, for example, the gas and oil rich communities of the northeastern region of BC. Nor does this report cover the service needs in the smallest and most remote communities of the northwest, many of which are linked to the larger centers only by logging roads or secondary highways, or even those communities that have only seasonal road access. Excluded from our study are the few communities so remote that they lack personal telephone services and basic commercial services.

C. Research Method

The four communities selected for this study have populations of less than 20,000. The closest urban center is Prince George, lying some 600 kilometers to the east. The metropolitan center of

British Columbia, Vancouver/Burnaby, is located 1,500 kilometers away by road. In comparison to these urban centers, the four communities, Terrace, Prince Rupert, Kitimat and New Aiyansh are rural and remote. Agencies, who provide programs and services for special needs children and adolescents, were represented in each of the four communities.

The largest of the four communities, Prince Rupert has a population of 16,700. Lying on the coast it is an important port for cruise ships destined for Alaska and for shipping products to Asia. Two community agencies in Prince Rupert participated in the focus group, one of which provides more than six community service programs.

Although smaller than Prince Rupert with a population of 12,779 the inland community of Terrace was most widely represented in our focus groups. Ten agencies comprising 18 participants were represented. Terrace is connected to Prince Rupert by Highway 16 and by secondary roads, to a number of smaller communities that in turn look to it for health and social services. The forestry industry that has sustained the Terrace economy is now threatened by the loss of revenue resulting from US imposed duties in softwood lumber and a decline in Asian markets. Terrace is intricately tied to First Nations communities in the region, with whom they often find themselves in opposing positions respecting First Nations' struggles for self-governance and recognition of Aboriginal title to traditional territories and the resources lying within them.

One agency from Kitimat participated in our study. This agency provides five programs to a population of 11,136 people. The coastal community of Kitimat economy relies on three resource companies: Alcan, Eurocan and Methex. Although these industries offer a degree of economic stability through diversifying the economy, Kitimat residents currently face disruptions as Alcan shifts its focus from aluminum production to electric power sales to the US.

New Aiyansh, the smallest of the four communities, lies in the Nass River Valley, part of the Nisga'a First Nations territory. With a population of approximately 1,000 New Aiyansh is the most

remote of the four communities and lies the greatest distance from Highway 16 and the community centers where services are clustered.

Focus groups¹ were our selected method. Focus group research is a recent innovation in social science and involves working with small groups of people with shared experience. A focus group facilitator is then able to draw on the realities and experiences of community members. Bringing together community members who are front-line workers and advocates for children and youth with special needs, our focus groups were asked to share their knowledge of the special needs in their communities, the challenges of facing those needs, and strategies to overcome obstacles in the delivery of services. Focus groups provide an avenue for the researcher to listen to the narratives of the participants and to draw from them stories that will explain their lived reality in the context of their roles both as community members and service providers. Unlike research methods that create distance between the researcher and the participants, focus groups enable the researcher to establish a closer working relationship while community members themselves are empowered to shape the process in a meaningful way.

We held focus groups in the four communities described above. We engaged 20 agencies working with children and adolescents with special needs. Agencies were selected to provide a cross section of educators, government, child and youth workers and health workers. This selection ensured the participation of individuals with an understanding of policies and practices and brought together a diversity of experiences to provide the widest view of the community possible in a small research project.

Overall, the focus groups for community workers within and beyond the communities where the meetings were held allowed Aboriginal and non-Aboriginal workers to share their experiences with one another. From this, researchers were able to glean an understanding of the conditions in the

¹ For readers who are interested in focus groups as a research method we recommend that they turn to the following: Frey, H. & Fontana A. (1993); Hess, J.M. (1968); Merton, Robert K., Fiske, Marjorie. & Kendall, Patricia L. (1990); Morgan, David L. (1995); Morgan, David L. (1998).

larger communities where the research was conducted as well as in the smaller more remote communities of the region. Nonetheless, it was not possible for all communities of the region to be represented; the distance, time and cost of travel prohibited some communities from sending representatives. The participants who rarely have been invited to express their views appreciated the focus group processes. The focused purposeful flow of discussions meant that the participants were able to concentrate their efforts on a meaningful task in particular to share strategies for overcoming obstacles and challenges facing service delivery. Ideally research that seeks to build meaningful relationships provides opportunities beyond a focus group discussion. Group dynamics, the history of community relations and tensions that arise between small communities competing for resources can impede the sharing of knowledge. Unlike the standard research method of one-on-one interviews, focus groups cannot guarantee confidentiality, which may also inhibit open discussion. To compensate for these weaknesses we encouraged participants to share additional ideas and insights in writing. Throughout the focus groups records were kept on flip charts for all to see. This allowed participants to know what information we were taking away with us. Participants could respond to the information we recorded correcting and elaborating on the record as it was produced. Gaps in the information could be identified as we proceeded. Participants could respond to one another, prompt one another for additional ideas and weigh the merit of the proposed strategies. Transcriptions were sent back to focus group participants for verification and validation of their thoughts and ideas. Any changes were incorporated into the final report. This process provided a firm foundation for making recommendations to government ministries and other institutions that influence policies and practices.

D. Working with the Data

One member of the research team analyzed the data from the focus groups. Data were organized thematically and these themes were subsequently categorized as: challenges, solutions and best practices. Prior to the analysis, transcripts were returned to participants for validation. The data were then studied to elicit recommendations to be carried to ministries responsible for programs and services.

V

Findings

All four communities identified substance abuse related special needs as a paramount concern to service providers in northern communities. While Fetal Alcohol Syndrome and Fetal Alcohol Effect (FAS/FAE) were voiced to be one of the greatest concerns, other substance abuse related special needs, including drug related birth defects (DRBD), attention deficit disorder (ADD), attention deficit hyperactivity disorder (ADHD) and mental health issues including depression, anxiety and suicide risk behavior (linked by service providers to substance abuse) were all identified as significant concerns to service providers in rural communities. Thus, when barriers to providing services for 'special needs' children are discussed in this report, it can be understood that many of these needs are related to substance abuse, and that substance abuse related special needs are a growing and imperative issue in these communities. Through the focus group format and discussion, four broad themes emerged from the analysis of discussions. These themes, apparent in all communities, consist of issues that can be broadly categorized as:

- *diagnostic limitations*
- *funding challenges*
- *overwhelming community health factors*
- and difficulties resulting from *geographic isolation and cultural specificity*.

This chapter examines and describes these four broad themes, with attention paid to the specific issues within them. Based on the challenges identified by service providers working with special needs children and adolescents, a series of recommendations are presented that identify ways to better serve the special needs children and adolescents in northern communities.

A. Challenges

1. Diagnostic Limitations

Many challenges faced by service providers in rural, remote and northern communities are linked to diagnostic limitations pertaining to children and adolescents with special needs. Diagnostic

limitations fall into two specific categories; a lack of any available 'professional' diagnostic services with regards to special needs associated with substance abuse (FAS, ADHD, ARBD, DRBD, etc), and a lack of flexible diagnostic capabilities where diagnostic services might be available.

Many participants in the focus groups described feelings of frustration regarding community diagnostic capabilities. These feelings stemmed from a belief that their communities were facing considerable challenges but were not being offered the training, opportunities, or flexibilities needed to respond to these special needs. Service providers know that special needs are a reality in their communities, but stated that due to a lack of diagnostic capability, the need was going unattended and unmonitored. The following participant observations capture the sense that special needs are going unrecognized due to a lack of community diagnostic capacities.

“There is a lack of diagnostic tools available. Non-diagnoses result in a cycle of special needs being seen later in life...if there is early diagnosis there [could] be prevention, and this breaks the cycle. Quite often the cycle is linked to substance abuse. There is a lack of specialists and therapists, and this leads to a lack of availability of a diagnosis. In addition, parents can be reluctant to seek a diagnosis for fear of labeling, and physicians are reluctant to diagnose FAS/FAE due to the implications for parents. Diagnostic services are a challenge – there needs to be these services, and the services need to include early diagnoses. The cost for 'outside community diagnosis' is prohibitive [for example flying to Vancouver or another urban centre], so parents don't realize the problem. Finally, there is no one really trained to work with FAS children, so untrained people are doing the job.”

Service providers working with children and adolescents with special needs are very aware that in their communities, special needs related to substance abuse are a reality. Individuals working within the service agencies also state that without early diagnosis occurring, there will be a continuation of these special needs. Their frustrations escalate in their awareness that without locally trained diagnostic specialists, special needs related to substance abuse will continue to go undetected and thus unsupported. In addition, community service providers state that diagnostic

services available in urban centres are not a realistic or viable option for the families with whom they work, as the cost of obtaining these 'far away' services is unaffordable.

While a complete lack of diagnostic tools and capabilities frustrate the efforts of service providers working with substance abuse related special needs children and adolescents in remote communities, the diagnostic capabilities that may be available are viewed as non-flexible and thus add to the sense of frustration felt by service providers. In other words, most often there are no diagnostic services and tools available, but when the services are offered, it is felt they do not meet realities of communities. Frustrations regarding the lack of diagnostic flexibility are summarized in the following observations.

"Functional diagnosis are not used – rather medical diagnosis's are, and this results in cracks – the use of IQ numbers as a deciding factor [in who is diagnosed with FAS as opposed to who is not] creates cracks through which people can fall. The IQ...creates frustrations because workers want to help but there is nowhere for these kids to go for services. Rather than dealing with the problem at its source, then, individuals are left to be dealt with later, and the situations are even worse. Usually substance abuse is involved 'later', and this combined with a greater risk of low self-esteem and pregnancy ensures the continuation of the cycle. A lack of multi/interdisciplinary approaches [to FAS diagnosis's] brings up the discussion of FAS versus FAE versus ARBD. Maybe alcohol related birth defects is a way to approach all birth defects related to substance abuse without falling in to the pitfalls of diagnosis constraints. Community agencies are not funded to work with schools around ADHD because with new regulations, you have to have an IQ of less than 70 to be eligible for a worker."

The bind in which community service providers find themselves in is notably upsetting for them: they want to assist and provide services to children and adolescents who they recognize have functional disabilities, but the limitations of available diagnostic tools prohibit them from doing so. While the desire for increased diagnostic capabilities exists, as noted previously, there is a simultaneous desire to ensure that diagnoses ensure additional service provision as opposed to

more constraints around a community working in the best interests of its special needs children and adolescents. Part of the dilemma facing community service providers with regards to diagnostic capabilities is linked to issues of funding. Funding has been identified as one of the four broad themes through which community service provider's concerns can be viewed.

2. Funding Concerns

A lack of funding, reporting constraints on the funding available, and the diffusion of an already small funding 'pot' were all consistently identified as tremendous barriers facing service providers

“Accountability outcome measures are not realistic – there is not always a clear outcome, sometimes there is just the ability to maintain, and that should be ok.”

working with special needs children and adolescents in remote communities. In all focus groups, in communities separated from each other by hundreds of kilometers, the issue of a lack of funding was identified as the single greatest prohibitive factor in providing the best possible services to special needs children and adolescents. For many of the service agencies, the conflicting demands of funding bodies hindered the agencies' efforts of service provision. For others service providers, multi-divisions in funding sources prove to be a formidable challenge in reporting, and still other service agencies state that funding accountability measures take time away from service delivery. Concerns regarding the conflicting demands and regulations from funding bodies can be understood in the following statements.

“There are regulatory issues with funding. It [comes from] provincial and federal sources, and in some cases there is agreement but not usually. If they worked together, the money could be sorted out and funding provided. Provincial policies and regulations are not necessarily taken into consideration, with funding bodies. This result in a difficulty delivering the service: for example in BC you have to work a minimum of four hours according to [provincial] labour standard codes, but funding bodies do not take this in account when funding, for instance, supportive child care programs...if a child needs to be seen for two hours that's great if there is another appointment

afterwards, but what happens if there is not? You still have to be funded for four hours, not just the time of the appointment.”

Overall, agencies providing services to special needs children and youth in remote northern communities testified to a number of concerns with present funding allocations and reporting methods. Many of the service agencies frustrations stem from conflicting demands of those who provide funding to the service agencies and a lack of cohesion in reporting infrastructure. Additionally, a lack of long term funding or dedicated funding remains a concern for service agencies working with special needs children and youth. The ongoing funding concerns translate into frustration with regards to service delivery, as do anxieties about the overwhelming nature of community's health issues.

3. Overwhelming Community Health Issues.

Barriers to effective service provision for children and adolescents with special needs include the contextual and environmental factors associated with the community in which they live. These factors include: poverty, nutrition, depression, teen pregnancy and suicide rates, and a lack of preventative programs intended for children and youth who may be in a cycle of substance abuse or who may come from an inter-generational reality of substance abuse. In the context of this research, 'overwhelming community health issues' addresses the sense that health issues outside the scope of a particular service provider's mandate nonetheless have significant impacts on the work of the service provider. For example, while a Child Development Centre has no particular mandate to address poverty, poverty may still be a contributing factor in a number of the special needs addressed by the CDC. Frustration elevates on the part of service providers when these external factors continue to increase while the mandates of programs remain constant. This sense of being overwhelmed by community health issues outside the scope and mandate of a particular agency is common to all communities. This suggests that environmental and social factors are increasingly of concern to agencies delivering services to special needs children and adolescents, but that these factors remain frustratingly beyond the control of organizations. These sentiments are reflected in statements made by service providers: particularly statements made pertaining to

environmental factors linked with substance abuse related special needs. For example during the community consultation process, it was observed that teen pregnancy is up [in remote communities] and drug use is higher than alcohol abuse.” Speaking of the overwhelming community health issues impacting on the ability to provide services to children and adolescents with special needs, one community stated that

Poverty impacts the need of families; if you can't put food on the table then you cannot be expected to be able to afford caring for a child's special needs. Poverty is the biggest indicator of coping skills and the ability to deal with special needs, and along with poverty is the need to address nutrition: low birth-weights, hot lunch funding is running out; programs address whole families, but there needs to be a focus on pregnant women and their babies; some services are available, but there needs to be a greater focus on prevention. Nutrition also affects mental health, which are both influenced by poverty, specifically northern nutrition issues need to deal with increasing food prices and poverty.

It was also observed that

“Trying to get kids access to a drug and alcohol counselor is like banging your head against a brick wall”

The impact of residential schools equals an inter-generation of special needs and that there are very limited spaces in alternated education schools that would provide the kids with the support they need. More challenges include an increasing suicide rate, depression, anxiety, and mental health issue increases.

Other 'environmental factors' identified by service providers include the fact that “depression...is really high – it is seen in adults, but must exist in children. Prevention around things like depression should rely on the fact that depression s really a manifestation of earlier special needs. And suicide – the numbers for teens went up”.

Finally, and again speaking to overwhelming community health factors as providing barriers to service provision to children and adolescents with special needs, service agencies noted that “FAS starts with teens and drinking – there are no activities [in remote northern communities] or support. Everything is limited. We don't have fun things or extra curricula things. No 4-H or Big Brothers and those things would be preventative as

opposed to being after the fact and just reacting. You should educate before they are teenagers: esteem, self worth, etc ."

In addition to these 'overwhelming environmental concerns', geographical and cultural challenges also face service providers addressing the needs of children and adolescents with special needs related to substance abuse.

4. Geographical and Cultural Barriers.

The final theme pertaining to effective delivery of services to children and adolescents with special needs involves geographic and cultural barriers. These barriers were identified in all four community consultations, and suggest ongoing concerns for service providers working with substance abuse related special needs. These concerns are specific challenges faced by service providers in rural and remote communities that are perhaps not of consideration to their southern and urban counterparts. Additional concerns for service providers focus on the provision of culturally relevant and culturally sensitive programming and services. Service providers report these geographic and cultural challenges in the following statements.

One community service provider stated that

Isolation is big challenge – activities give healthy alternatives, and there exists a double isolation factor on reserves [outside municipal constructs] - on those reserves there's nobody who doesn't drink, no options, a lack of resources, and nothing to do. Activities [which do not exist in these communities] give empowerment to children, but these challenges have to be locally addressed.

Another challenge identified by focus group participants concerned location and accessibility of services in rural communities. As one participant stated, "a challenge [in the northwest] is the location of services." The same participant suggested "there should be a 'one-stop access' [to services] all in one building." The participant also observed "the turnover of professionals in the north, due to weather, isolation, etc., continues to a challenge." It was also noted that in the north

there are “isolation issues, and regulation issues, which can be linked to not having the services available”.

These isolation factors link, in part, to cultural challenges also faced by service providers in rural northern communities. For instance, the existence of “jurisdictional challenges for on and off reserve issues.” Finally, the statement that “the drug and alcohol counselor who teaches western ways of problem solving do not work in a First Nations community. [A] need [exists] to increase awareness of First Nations culture and problem solving techniques.”

When combined, the four themes of diagnostic limitations, funding challenges, overwhelming community health concerns, and difficulties arising from geographic and cultural specificity all unify into a very particular landscape of service delivery to children and adolescents with special needs: this landscape is riddled with barriers and challenges unique to rural and northern communities. Simultaneously to the existence of these challenges and barriers there exists the identification of best practices that would work in a consequential way in the communities where community consultations were held. The community consultation process allowed a series of possible solutions to be identified that would, from the perspective of service providers, be meaningful to children and adolescents with special needs, particularly substance abuse related special needs.

B. Solutions and Best Practices Identified by Service Providers

The challenges and barriers faced by service providers working in rural northern districts are particular to both their location and the realities of their community. The solutions identified are similarly particular to the location and realities of the service providers. These solutions range from programming mandate changes to services that are specifically tailored to the realities of remote northern communities: solutions also involve development of culturally appropriate models and inclusion of local perspectives into program development.

Consistently throughout the community consultation process “the need for one-stop access centres in small communities” was identified. This ‘one-stop access centre’ would provide everything from medical diagnostic services to family support and community programming. Rather than parents facing a confusing and intimidating process of accessing services, the services would be housed together for efficient and cost effective delivery. Other solutions included changes to funding and evaluation structures, summarized in the statement that

Evaluation techniques aren't right. They are not meeting the needs of community.

Evaluating what a community needs could be done with research, and many of would like to do research, but we lack the number of professionals to meet basic standards let along do research.

Other focus group participants noted that “there should be one person to phone or contact [in a community]...let's say you are new to town, you would phone one number and explain what you are looking for, and they would tell you how to find it.” Solutions also included, as participants stated,

Empowerment and alternatives – this would give people ways to dig their way out of the deep end. There really needs to be more people to provide [these type of] services.

There are so many Ministry of Children and Family positions open with no one to fill them. With a lack of people and a lack of funding it results in the same exhausted people over and over working off the sides of their desks.

Many observations by community participants centered on the concept that preventive programming concentrating on empowerment within their communities would be the most successful type of programming. Rather than being reactive, this proactive programming might (participants believed) offer alternatives so that responsive programming could be lessened. Solutions to providing services for children and adolescents with special needs also include “more information being provided to both professionals and to families” and the need to clarify the relationship between “the real world, the academic world and the bureaucratic world – these worlds need to have a clear understanding of each other.” Finally, service providers identified the fact that any solutions implemented need “more programs with parent involvement and more communication with elders.”

While the community consultation process identified a number of actions needed to implement solutions to the barriers faced by service providers, the process also identified current practices in northern communities that are working and could be advantageously continued. These 'best practices' included "the success of respite programs that allow parents to have a break when needed, without stigma or repercussions – this is effective and there is a need for greater programs

"There is so much to do but no dollars to do it with"

like this." Programs that integrate "teaching by example, honoring people rather than just talking about prevention, the honoring of people who have helped, including teachers etc.," are programs that have been successful and that future programming in northern communities might learn from. Other best practices identified included

A role playing [activity] for youth about the effects of alcohol that also implemented the family into the play to teach youth how to ask for help and support and to show how Elders can and do support each other, along with and youth conferences on a variety of topics: drugs, alcohol, culture, and pregnancy were all successful.

These practices were identified as those that worked in communities because they reconnected youth with their community and provided a wide diversity of information making it accessible and stigma free for the audience. Finally, in one community "Co-op housing and grand parenting programs" were identified as being successful: here the involvement of community grandparents was solicited and grandparents worked in supportive and nonjudgmental ways with the hopes of preventing many of the special needs related to substance abuse.

Drawing from the information regarding both challenges and solutions and provided by participants in the community consultation process, conclusions and recommendations can be generated. These conclusions incorporate what community service agencies identify as aspects of their activities that work well and need to be expanded upon or supported, in conjunction with recommendations that highlight areas in need of further support, additional consideration, or concentrated assistance.

VI

Conclusion and Recommendations

Service providers in remote northern communities face very specific and distinct challenges to their provision of quality services to children and adolescents with special needs, particularly special needs associated with substance use. These barriers and challenges can be understood as falling inside four broad themes: diagnostic limitations, funding concerns, overwhelming community health issues, and geographic and cultural barriers. The findings of this community consultation process detailed the perspectives of community service providers, those on the ‘front lines’ of service provision in rural northern communities, and found that in conjunction with substantial challenges faced in service provision there also existed in communities the capacity to deliver effective and innovative programming as well as knowledge and understanding of what would contribute to successful program delivery. Through the community consultation process a number of recommendations have come to light with regard to the successful delivery of programming to children and adolescents with special needs in northern British Columbian communities.

Recommendations

Guaranteed and Improved Funding

Attention must be paid to the consistent concern voiced by service providers that a lack of funding hinders their ability to provide effective services to children and adolescents with special needs. With continuous gaps in professional positions with the Ministry of Children and Family Development and in health care professionals, more and more service delivery is falling onto community service delivery agencies that are reliant on project funding. This reliance on project funding means staff time is increasingly spent on securing funding: this is often not an area of service providers’ expertise and thus translates into an inefficient distribution of time that could be better spent on the delivery of services needed by families with special needs children and

adolescents. A move to integrate core funding into funding allocations to communities would alleviate this tension and would ensure strong and committed service delivery.

Consolidation of Reporting Measures

Inconsistencies in reporting and evaluation demands between various project-funding bodies translate into confusion and misunderstanding on the part of service delivery agencies. Conflicting demands between funding bodies means that agencies often find themselves having to report the same deliverable in more than one manner: a consolidation of evaluation and reporting methods would allow for increased efficiency and the capabilities of service delivery agencies to allocate more time to children and adolescents with special needs.

Recognition of Geographic and Isolation Factors

Agencies working with children and adolescents with special needs in northern isolated communities have very particular barriers facing them with regards to service provision. A lack of highly trained professionals in conjunction with an inability to access training and professional development options, means personnel are often working at a disadvantage when compared with their southern counterparts. Additionally, increased rates of special needs, particularly those associated with substance abuse, afflict northern communities. The combination of these two, coupled with a lack of service options, means that funding and programming must include opportunities for professional development, networking with other communities and innovative solutions for service delivery.

Responsive Diagnostic Approaches When Identifying Special Needs

The lack of medical diagnostic capabilities in rural northern communities means increased rates of non-diagnosed children and adolescents with special needs. These children and adolescents often are not able to qualify for services, and in the case of children and youth with special needs associated with substance abuse, this can lead to an inter-generational pattern of the special needs. These intergenerational patterns can be understood to arise in part from both a lack of diagnosis and availability of services that would offer proactive (as opposed to reactive) services

targeted at prevention of these special needs. In conjunction with increased access to medical diagnoses (through elevated physician/patient interaction, increased diagnostic capabilities in northern communities, and increased awareness of substance abuse related special needs) is the need to have more responsive diagnoses. These responsive diagnoses would make use of local expertise to increase the availability of services as well as in the identification of children and adolescents with substance abuse related special needs and would employ functional diagnoses rather than just medical diagnoses. Functional diagnoses would then be acceptable methods to gain access to specialized programming.

Inclusion of Local Expertise and Perspectives When Developing Policy

The community consultation process undertaken in this project highlighted the need to integrate and make use of the perspectives of community service providers. Without the consultation of community service providers, policies and programs designed to meet the needs of communities may not be as effective as hoped, and thus when programs and policies are developed in partnership with community service agencies, their likelihood of success is greater. With community partnership in policy development, concerns such as reporting and evaluation mechanisms would be identified from the onset, as would any particularities associated with cultural and geographic particularities.

Incorporation of Specific Cultural Sensibilities in Programming

In conjunction with the incorporation of local expertise and perspectives in policy and program development, the incorporation of specific cultural sensibilities is imperative to successful programming. As noted by one Aboriginal service provider, programs developed with western methodology are bound to fail in First Nations communities. Efforts to meaningfully connect with specific cultural groups, and to incorporate distinct attributes of their culture into program development, will ensure the success of programs delivered in culturally specific communities of children and adolescents with special needs.

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July 10th, 2001

Hello all –

Just a short note to summarize the conversation that _____ and I had this afternoon regarding the _____ hosting a focus group in conjunction with the UNBC Centre of Excellence for Children and Adolescents with Special Needs. As she and I discussed, the Centre of Excellence is visiting four communities in the Northwest during the week of August 7th – 10th. The purpose of the trip is to gather information on local responses, best practices, challenges and general thoughts surrounding services to children and adolescents living with special needs.

The focus of the Centre of Excellence here at UNBC is substance abuse, thus discussions and information on FAS/FAE, ADHA and other substance misuse related special needs are of particular interest. The goal of the focus group and information gathering sessions is to orient community groups to the Centre of Excellence, discuss funding opportunities, document local realities, and collect relevant information to feed into policy making decisions at the national level.

We anticipate the session taking no longer than three hours, and look forward to the possibility of it being held at the _____. I am also happy to forward a list of possible contacts to you, and would be ever grateful for your centre sending out the local invitations.

Should you have any questions, please do not hesitate to contact me.

Take care,

Sarah de Leeuw
Research Coordinator
Centre of Excellence for Children and Adolescents with Special Needs – UNBC Task Force on Substance Abuse.

CENTRE OF
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TASK FORCE ON
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COMMUNITY FOCUS GROUP QUESTIONNAIRE
The Centre of Excellence for Children and
Adolescents with Special Needs



When we use the term special needs child or adolescent, we mean any child or adolescent who might need extra resources or services beyond those normally required to support healthy development. We want to know what are some of the main special needs issues facing your community.

Some special needs are associated with substance use and misuse, especially during pregnancy. Are there any unique issues facing your community when it comes to special needs that are linked to substance abuse?

In your opinion, what might contribute to preventing these kind of special needs?

What do you think are the most successful programs in your community for children and adolescents with special needs?

What makes these programs successful?

List of Participating Agencies

North West Health Unit
3412 Kalum St.
Terrace, BC
V8G 4T1

Northwest Addictions
311 3228 Kalum St
Terrace, BC
V8G 2N1

Kids at Play
Terrace, BC
V8G 4T1

Choices
1 3215 Eby St.
Terrace, BC
V8G 2X8

Child Development Centre
2510 Eby St.
Terrace, BC
V8G 2X3

School District #82
3211 Kenney St.
Terrace, BC
V8G 4T2

Ministry of Children and Families
Development (Terrace Office)
34-3415 Kalum St.
Terrace, BC
V8G 4T2

Child and Youth Program, Special
Services to Children, Healthiest Babies
Possible, Building Blocks, Nobody's
Perfect, Parenting Programs
899 North Lattakas Blvd.
Kitimat, BC
V8C 1E7

Kinderkare/Foster Parent
Association
2407 Kenney St.
Terrace, BC.
V8G 3E2

K'san House Society
4724 Lazalle
Terrace, BC.
V8G 1T2

Ministry of Children and Family
Development
400-4545 Lazalle Ave
Terrace, BC
V8G 4E1

The Family Place
4553 park Ave.
Terrace, BC
V8G 1V3

Kitmkalum Band Office
Public Health Nurse
West Kalum Rd.
Terrace, BC
V8T 1S2

Nisga'a Valley Health Centre
256 Tait Ave
New Aiyansh, BC
V0J 1A0

Ministry of Children and
Families Development
(Prince Rupert Office)

Kitimat Child Development Centre
899 North Lattakas Blvd.
Kitimat, BC
V8C 1E7

Nisga'a Valley Health Centre, Drug and
Alcohol Counseling Program
256 Tait Ave.
New Aiyansh, BC
V0J 1A0

Prince Rupert
Community Enrichment
Society
710 Fraser St.
Prince Rupert, BC
V8J 1P9