

Aboriginal People with Disabilities: *A Vacuum in Public Policy* by Dr. Doug Durst and Mary Bluechart*

The old man said, to have been born imperfect was a sign of specialness... The old man explained carefully that in the old days, if a child came with a hare-shorn lip, it wasn't a terrible thing or a hurtful thing; it meant the child's soul was still in touch with the Spirit World. Yvonne Johnson, Journal 9, 1994. p. 423.

Aboriginal people with disabilities are caught in a public policy vacuum with little hope for amelioration. Aboriginal persons are individuals who identify themselves as having Indigenous or North American Indian ancestry and may or may not have status under the federal *Indian Act* (1876). If they hold "status", as "First Nations" peoples they may be living on reserve or off reserve in an urban community. In recent years, Canadian Aboriginal peoples have been assuming greater control over social services programs, including disability services in their communities, and some organisations have been providing important services to persons of Aboriginal ancestry in urban communities. However, little is known about Aboriginal persons who have a disability and are living in urban communities (Durst and Bluechart, 2001). There is a paucity of research on Aboriginal persons with disabilities, and the programs and policies differ depending upon a number of criteria. For example, services and programs can come from different funding sources depending upon whether or not the Aboriginal person has status. In addition, whether they live on an official reserve or off reserve in an urban community will also influence their accessibility and eligibility for programs.

This article presents the results of a two-year exploratory study examining the issues facing urban Aboriginal persons with disabilities in Canada (Durst and Bluechart, 2001). Due to the topic, this research crosses cultures and was approached in a culturally sensitive manner involving Aboriginal persons in all stages of its development, from initial planning through to dissemination. A triangulation of data sources was used, collecting data from a comprehensive literature review, including secondary data, focus groups or "talking circles" with Aboriginal persons with physical disabilities, and in-depth interviews with professional service providers.

In Saskatchewan, there are about 130,000 Aboriginal persons, representing 13.6 per cent of the province's population (Statistics Canada, 2001). This study was conducted in Regina and Saskatoon where the percentages of Aboriginal persons are 8.2 and 9.1 respectively (Statistics Canada, 2001).

Research Methods

An essential component to the research team was the participation of two First Nations women who are quadriplegic. Each of these outstanding women had a depth and breadth of personal experiences from the "inside". Their personal insights and understandings were critical in both collecting and interpreting the data. It was primarily through their personal and social connections to the community of Aboriginal persons with disabilities that the research participants were located and encouraged to participate in the study. Interviews were conducted with Aboriginal persons and service providers in employment, recreational, and social and health

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services in various agencies. In addition, Aboriginal researchers and interviewers were used to ensure culturally appropriate research practices. The study was designed to produce tangible and realistic program/policy recommendations, and its methods were based upon a participatory research model, often designated as “*action research*” (Alary, 1990).

Identifying and contacting potential participants is frequently a problem, especially in cross-cultural research. First, the research team found that many service and voluntary organisations had little contact with Aboriginal persons and had not developed the relationship necessary to recommend or suggest appropriate individuals. Curiously, the staff of these organisations purported to serve these individuals but had little contact and/or tracking systems to communicate and serve that important community. The professionals in rehabilitation held the most knowledge of this hidden population, probably because their clients had to access their services, and they were most aware of the conflicts and difficulties facing these people. However, it was the two women on our research team who were the most helpful in identifying research participants. The lack of connections of Aboriginal persons to the service sector raises questions as to how these clients are perceived. Often, the professionals understand “disability” as a “health” issue rather than an economic, social or recreational one. Furthermore, it creates a situation where First Nations or Aboriginal identity is second in priority to the health or physical needs of the person. The cultural context is lost in the attention to the concreteness of the physical disability.

To a non-Aboriginal person, this may not seem significant but it is a major concern for these clients who are struggling to maintain their cultural and ethnic identity in a hostile environment, which readily expresses overt and covert racism. Identity with their home reservation is a major psychological foundation and necessary support for First Nations persons in Western Canada. Even though it may have been years since they have visited their home, it remains a first point of identity and recognition among First Nations people. Just as Saskatchewan Mennonites identify themselves through relations and family, so too do First Nations people. It is not uncommon to hear, “Oh, I know, you’re Charlie’s daughter”.

Using focus groups as a method of collecting data was found to be a successful research technique for First Nations/Aboriginal persons with disabilities (Packer, Race and Hotch, 1994). Seven in-depth sessions were held with Aboriginal persons with disabilities. They came together to participate in these group discussions using the traditional methods of “talking circles”. These circles have a traditional protocol where leadership is diffused and there is great respect for each speaker as the participants take turns speaking. The sessions were lead by a First Nations graduate student who developed a close and on-going rapport with the participants. Using a researcher from the same cultural group is an effective strategy in culturally sensitive research. The support and affirmation generated through the focus group process encouraged active participation and openness of discussion that would not have occurred in a more formal interview format. The participants expressed pleasure in participating. Finally, during the data analysis, check-backs were made to ensure accurate interpretation of the findings. These research techniques are highly recommended for future research endeavours with the Aboriginal population and are suitable for other persons who feel marginalized and excluded.

Research Findings

Aboriginal People and Disabilities: Secondary Data/Literature Review

Canada has a population of close to 30 million people of which approximately 4.2 million have a disability; this figure represents 16 per cent of the population (Canada, 1995, p.5). Most adults with disabilities have mild disabilities (47 per cent), while 32 per cent have moderate disabilities and 22 per cent with severe disabilities. The level of disability (mild, moderate and severe) has been determined by using the Statistics Canada scale of degree and/or combinations of disabilities. For a partial loss of an ability, one point is counted and for a full loss of an ability, 2 points are counted. A person with less than 5 points is considered mildly disabled, 5 to 10 is moderate and greater than 10 is considered severe. This definition has some limitations but it establishes a baseline and allows for some comparative analyses. In Canada, 817,300 adults or 4 per cent of the total population had disabilities that were severe.

The estimated First Nations population, both on and off reserve in Canada is 638,445 (Canada, 2001) and the population of persons identifying themselves as “Aboriginal” is well over 1 million. Previous research has shown that

31 per cent of Aboriginal peoples reported a disability (NAND, 1994, p.33). Although Aboriginal peoples have congenital disabilities at about the same rate as the rest of Canadians, they have a higher rate due to environment and trauma-related disabilities (Halliday, 1993, p.6). “The disparity between Aboriginal and non-Aboriginal rates of disability corresponds to disparities in rates of injury, accident, violence, self-destructive or suicidal behaviour, and illness (such as diabetes) that can result in permanent impairment” (RCAP, 1996, p.148).

In addition, Aboriginal people suffer higher rates of specific diseases. For example, the high rate of Type II diabetes has been recognized as “one of the most serious chronic diseases among Aboriginal populations in Canada” (Canada, 1992, p.33; Canada, 1999, p.7). The rates of the disease vary from 1.5 to 3 times the average of total number of persons in Canada (Chelimsky, 1992, p.4). These rates have serious implications for prevention, education and service.

The rate of disability among Aboriginal peoples is more than double (2.3 times) the national average (NAND, 1994, p.33). Therefore, one can estimate that there are approximately 184,000 First Nations persons and approximately 310,000 Aboriginal persons with a disability in Canada. These people have become a hidden population and lost in the overall health and social service delivery to persons with disabilities.

Based upon census data, Table 1 presents a reasonably accurate reflection of types of disabilities among Aboriginal peoples. In the first two columns, percentages of six categories of disabilities have been reported from the total population of persons with disabilities comparing the Canadian and Aboriginal populations. The other columns present the percentage of North American Indians living on a reservation

and those not, by Metis persons (Aboriginal persons from mixed backgrounds) and Inuit persons. The census was self-reported; hence the figures represent the respondent’s perception of his/her disability.

Results indicate that mobility is a serious problem for all groups and is reported equally except for the Inuit. The Inuit primarily live in small Arctic communities where their perceptions of “getting around” are seen as less of a problem. They are also close to family so help is generally available. The same explanation is offered for the lower rates of agility. Aboriginal peoples seldom live alone so having somebody to assist with putting on a coat, or opening a tight fitting jar is less of a problem. There is evidence to suggest that it is the perception of the disability that plays out in the reporting and in other cultural contexts, they would be reporting a “disability”.

The higher rates of a visual disability (seeing), which is twice or three times the national average, is alarming. Visual disabilities among Aboriginal persons are related to the high rates of Type II diabetes, a condition that can be ameliorated or perhaps prevented with lifestyle changes. Loss of vision has a high personal cost and can lead to isolation and loneliness, in addition to the high financial costs associated with health care and caring. Hearing disabilities are also a concern and its prevalence is much higher among Aboriginal persons; it is twice the national average among the Inuit. It is suspected that this disability is related to two environmental concerns. First, as children living in cramped quarters, high rates of childhood ear infections have been consistently reported. These ear infections have resulted in permanent but preventable hearing loss. The lack of prompt action at the onset of the infant’s infection can have permanent effects, demonstrating the need for education and prevention. Further, the hunting culture so prevalent among the Inuit involves guns,

Table 1. Percentages of Adult Persons with Physical Disabilities

Disability	Total	Total	First Nations (Status)		Metis	Inuit
	Population	Aboriginal	On-Reserve	Non-Reserve		
Mobility	45	45	47	45	44	36
Hearing	23	35	39	33	34	44
Visual	9	24	32	21	22	24
Agility	44	35	34	36	38	26
Speaking	10	13	14	13	13	10
Other	37	36	37	37	35	36

Source: Statistics Canada, 1994, #11-001E.

snowmobiles, and outboard motors and these loud and continuous noises are having their long-term impacts. Again, education and prevention might help but changing a lifetime of behaviour is difficult. Table 1 demonstrates the impact of poverty and the cultural lifestyle of Aboriginal persons.

Services Providers and Professionals: In-depth Interviews

The purpose of this component of the research was to determine the experiences and perspectives of the service providers with regard to urban Aboriginal persons with disabilities in Regina. Service providers include agency personnel in two sectors - the public (government) and non-government (NGO). This component of the research did not include the private (for profit) and the informal (friends and family) health service sectors.

In addition, the study wanted to determine the activities or initiatives these service providers were involved in to enhance the rehabilitation and participation of urban Aboriginal persons with disabilities. An interview guide was developed to ensure that the research questions were adequately addressed and consistent in each interview. The researcher used open-ended, face-to-face interviews and met with twelve (12) professionals. The service providers included rehabilitation counselors, a physical therapist, executive directors, program managers, a program coordinator, and a policy advisor. The agencies were involved in a variety of services such as education and skill development, independent living, personal counseling, and advocacy. They covered a number of disabilities including intellectual, physical/mobility, injury and blindness. Three agencies were “public” and financed by the provincial or municipal governments and seven were non-profit community or social agencies.

The service providers and professionals reported that they had an “open door” and invited all groups to access their programs and services. They boasted that they attempted to reach as diverse a population as possible and that Aboriginal peoples were always welcomed. However, they admitted that there were few Aboriginal peoples accessing their services.

Some professionals complained that in the past they had actively sought Aboriginal participation but no Aboriginal clients came. They reported that they had no Aboriginal staff and those with a Board of Directors, had no Aboriginal board members. While they reported, “But, everyone is welcome!”,

there did not appear to be any serious efforts to include the participation of Aboriginal peoples either as staff, volunteers, or consumers of services. There was a general awareness about Aboriginal culture and issues of culturally sensitive practice, but there was a resistance to making significant changes to service delivery and organizational practice. There were also complaints of “non-compliance” by Aboriginal clients. For example, some professionals complained that the clients did not make appointments or follow health procedures such as medication or exercise. Their language held a “them and us” attitude that separated themselves from the Aboriginal clients and, if this attitude were projected onto the Aboriginal person, they would not have felt welcomed. They might not have returned, furthering their isolation and perhaps exasperating their health condition. For example, controlling diabetes requires strict routines and procedures; failure to do so does not result in immediate health impacts but leads to long-range grim results such as blindness or amputation. This communication issue is a serious problem that agencies need to address if they are sincere in reaching this hidden population of Aboriginal people with disabilities.

Aboriginal Persons Speak: Focus Groups

On the prairies, First Nations people strongly identify with their Bands and their respective reserve where their parents, brothers and sisters, and even their children live. Understanding this connection and the social relationships associated with them are critical for professionals who are providing employment, recreational, social, and health services.

This study found that First Nations persons with disabilities usually left their reserves in order to access health and social services. If their disability came as a result of an accident or deteriorating condition, they found that a “temporary” move to the city was necessary to access rehabilitation or treatment. The days evolved into months and the months into years. Without consciously thinking about it, they had developed a new life off reserve. The dream of returning to the reserve gradually faded from memory. Leaving behind their families, First Nation people found loneliness and isolation. They now live in a “foreign” and hostile urban culture where they feel socially excluded.

The primary reason for moving into the city was to access services. Interestingly, the federal government directs its health funding through the Medical Services Branch of Health

Canada or Indian Affairs. Therefore, in order to access funds for support programs, physical aids and services, First Nations individuals must apply to their Bands for approval for payment, then apply or go to the provincial departments or non-profit organizations for the service or aid. Since they are no longer located on the reserve, these individuals with disabilities get the “ping pong” treatment, shuffled from one agency to another. Provincial government programs are reluctant to become involved and refer these patients to the federal agency: Medical Services refer to the Band government. The Band administrators hold an “out of sight, out of mind” attitude and refer to provincial programs. The situation is extremely frustrating for both clients/consumers of service and professional service providers. The research participants repeatedly and emphatically complained about accessing services and in frustration, they simply “gave up asking”. Many reported managing “on my own” without supports and services to which they were fully entitled.

The research has indicated some serious issues regarding self-government. In this research, it was determined that the right to self-government by First Nations superseded the rights of the First Nations persons with a disability. This means that the Band and Tribal Councils determine how resources are allocated and can deny individuals access to buildings, employment, training opportunities, and services, if they choose to apply for resources elsewhere. One research participant bitterly told how the Board of an Aboriginal community centre had the funds to expand the washroom so that it was wheelchair accessible but chose to spend the funds on re-flooring in the gymnasium. The research participant is a quadriplegic and uses a motorized chair.

The focus groups raised interesting differences in understanding or defining “disabilities”. There are some cultural differences in understanding disabilities and, it seems, that persons with disabilities are accepted more readily in the First Nations communities than mainstream Canada. So-called abnormalities are viewed as natural and normal and little attention is paid to them. As one participant stated, a person with a disability “is a gift from the Creator” and should be cherished and respected. In some First Nations traditions, some persons with disabilities were seen having special powers or gifts, which enabled them to communicate with the spiritual world. However, others felt ignored and dismissed and still others experienced ignorance and ridicule in their home communities.

How a “disability” is perceived changes the meaning of participation. The members of the focus groups did not necessarily want to “participate” in mainstream society as one might expect. Aboriginal culture holds different views of the meaning of social inclusion, self-sufficiency, social and economic independence. Western Euro-Canadian culture values independence and self-sufficiency and, curiously, it values conformity. Mainstream society rejects interdependency and dependency on others. As a communitarian culture, Aboriginal society values interdependency, creating a belief that each individual can, in some way, contribute to the group as a whole. Each person has a role to play regardless of his or her physical, mental or intellectual capacities. There is no shame in asking for and receiving assistance; the shame is in refusing.

The respondents reported that they were aware of services and social activities, but chose not to participate. Some reported that they were not interested in the activity or program. “No one asked us!” one participant succinctly stated and therefore, she just did not participate. Sometimes they were unaware that personal assistance was available and the assistance was part of the program. They saw the need for personal assistance a major barrier and felt that their only option would have been to provide their own informal assistant such as a family member. These family members are already requested to assist in a variety of ways and may be overburdened. Asking for help for a social or recreational activity seemed inappropriate, given the amount of daily personal care provided by these informal helpers. Personal care is also “personal” and many objected to attending activities where strangers were expected to assist in feeding, moving, and more personal and private functions. It is a Catch 22: even if they wanted to attend, they did not want to over-tax these informal helpers for what is viewed as less important activities, let alone have strangers assisting them in the private and personal duties.

The costs of transportation and time involved arranging, planning and waiting for rides created yet another barrier to participation. In addition, the financial costs of participation in even subsidised activities created an additional barrier to full participation and inclusion. When one is living on minimal assistance, the smallest fee is a major decision. If the adult with a disability has children, then personal sacrifice supersedes the luxury of recreation, social or even some health benefits, which have even modest financial costs. One

participant who lives on provincial “disability pension” or social assistance lives well below the poverty line and struggles to meet her monthly expenses. Along the street, she picks the garbage cans for recyclable bottles and cans and estimates that she collects about 28 dollars per month. She gives her “spoils” to her daughter “for extras”.

Some felt that their level of disability and the type of care required influenced their pleasure in participating in social, recreation, and sport activities. Some physical activities, when others were much more skilled and coordinated, seemed too far out of reach and were humiliating and frustrating. Because of their self-consciousness and lack of esteem, they would not even attempt participating.

Participation in non-Aboriginal structured activities for sport, recreational or social reasons may not be culturally compatible for some First Nations persons. They feel excluded because of the level of organization and structures of the activity, and feel further excluded because they are the only “brown skinned” persons participating.

Recommendations and Conclusions

The population of First Nations people with disabilities are severely marginalized in a number of ways. They have a disability; they are Aboriginal; they are off reserve or urban. Women are further marginalized (Lonsdale, 1990).

The jurisdictional issues create serious problems for many Aboriginal persons. What government and what department provides what service or program is a major barrier to access. This is the public policy vacuum. It is confusing and frustrating and many persons just give up or make no attempt; therefore not accessing services or programs to which they are fully entitled. The first step that should begin immediately is solving the jurisdictional issues. Provincial and federal authorities and Band members need to organize themselves to ensure that services are accessible. The “ping ponging” of clients must end. They need to establish an intergovernmental review team (a National Jurisdictional Review Panel) to complete a comprehensive review of the jurisdictional issues and propose a realistic system to adequately resolve it. A review panel should involve all the stakeholders such as federal and provincial program/policy analysts and service providers, community based professionals and the “consumers” themselves: Aboriginal persons with disabilities. Together, the panel needs

to examine the issues from both a national and provincial level and find real solutions to this long-standing problem.

The agencies purporting to serve persons with disabilities need to address the low participation rates of Aboriginal peoples. If the Aboriginal population in the urban centre is about 9 per cent and Aboriginal persons have twice the national rate of disability, then one would expect that 18 per cent of their clients have Aboriginal descent! These professionals need more than cultural awareness but a sound and critical self-examination of their policies and programs, looking for forms of discrimination and racism. These agencies need to employ Aboriginal service providers and include Aboriginal persons in leadership such as on their Board of Directors. This action is a capacity building process as well as a direct improvement of service. One of the key findings or lessons learned is that part of the reason for the low or complete lack of participation in mainstream agencies and service providers, including recreation and sport, are not what they are doing but how they are carrying out “business”. Greater effort needs to be given to involving Aboriginal persons in the service delivery and in its administration.

The First Nations leadership needs to take the problem seriously at the Reserve and national level. There needs to be improvement in the professionalization of services provided by Aboriginal agencies. Frequently, they have not been competent at simple tasks such as following up on telephone messages, keeping appointments and promptly completing promised tasks. There is a need for greater involvement and leadership among the Aboriginal leadership and this could be accomplished through education and awareness training.

This education and awareness training is also needed at the provincial and federal levels. Both the provincial and federal governments in conjunction with national First Nations leaders need to improve awareness education and sensitivity. There is a need for greater coordination of policy at the federal and provincial levels as many of these issues cross programs and are “ghetto-ized” in “Aboriginal” departments.

The belief that persons with disabilities need to be “included” in the daily life of our community is a widely held value. However, the meaning of “inclusion” may be problematic, especially for the Aboriginal person with a disability living off reserve. “Inclusion” may mean participation and social

identification with other Aboriginal/First Nations persons, or it may mean inclusion with other persons with disabilities, or it may mean inclusion with the dominant culture group of able-bodied citizens. At this point in the study, it is not clear what the objective of “inclusion” or integration means to Aboriginal people with disabilities but it appears that inclusion may mean inclusion within sub-communities within larger communities. It does mean that this group is looking for meaningful roles and social relations but they may not share assumptions of mainstream culture. This is an important topic for further research.

This research has found that Aboriginal peoples with disabilities are not living an independent lifestyle, and the numerous barriers that inhibit independent living are deeply entrenched within society. A strong and effective voice is required to initiate change and improve the conditions for persons with disabilities. However, this will not occur until Aboriginal people with disabilities participate in the decision-making processes that ultimately impact their lives.

The establishment of Advocacy Offices in each province would offer a tangible source of support and assistance to Aboriginal persons with disabilities: Ombudsperson for Aboriginal Persons with Disabilities. An intergovernmental office should be established and include the major stakeholders: First Nations, provincial and federal governments and Aboriginal persons with disabilities. This intergovernmental effort would establish Advocacy Offices for each province, with a director whose primary responsibility is to ensure, that Aboriginal and First Nations

persons with disabilities and their families, receive the basic services and programs they are entitled to receive.

Effective and efficient policy development, both nationally and regionally, as well as program planning and service delivery, must be based upon empirical research findings completed under the rigours of accepted systematic inquiry. The relationship between social and policy research, and sound practice has too frequently been ignored. This study has determined the need for three potential research areas. First, there is a lack of knowledge and understanding of disabilities among Aboriginal children. For example, little is known about the disabilities associated with Fetal Alcohol Syndrome and Effects (FAS and FAE). Second, the issues regarding the family care-givers and support from family members are complex and include issues of burn-out. Finally the aspirations, the dreams, and the hopes of Aboriginal persons regarding inclusion and integration need to be researched from a cultural and holistic perspective.

There is a need for concrete and realistic steps to ameliorate the numerous barriers facing Aboriginal persons with disabilities, and their aspirations for participation in the community with full social inclusion under their terms. Aboriginal people with disabilities are seeking an improved quality of life, a life with meaning and joy, within the confines of their disabilities. They are entitled to receive benefits and services provided to mainstream Canadians and much can be done within the existing systems. A vacuum is a space without matter; for Aboriginal persons with disabilities, this policy area remains a public policy vacuum.

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