

Gaps in Service Provision for Native Disabled Adults on Reserves

A Case Description

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L'article décrit la situation actuelle d'un jeune autochtone handicapé qui vit dans une réserve de l'Alberta. La pénurie de services pour les adultes autochtones handicapés est apparue quand on a tenté d'assurer la sécurité élémentaire du jeune autochtone. Bien que les services sociaux dans les réserves relèvent du gouvernement fédéral, les programmes destinés aux adultes sont depuis toujours administrés par les gouvernements provinciaux. En dépit du fait que la population autochtone compte un nombre de cas disproportionnellement élevé d'invalidité physique et mentale, les programmes destinés aux adultes autochtones handicapés vivant dans les réserves manquent grandement, résultat d'une impasse, car ni le gouvernement fédéral, ni les gouvernements provinciaux ne voient la fourniture des services de réadaptation dans les réserves comme entrant dans leur champ de responsabilité.

Introduction

As defined by the United Nations' Declaration of the Rights of Disabled Persons (1975), "the term 'disabled person' means any person unable to ensure by himself or herself, wholly or partly, the necessities of normal individual and/or social life, as a result of a deficiency, either congenital or not, in his or her physical or mental capabilities."

There is now abundant evidence that the Native population in Canada is highly vulnerable to deterioration of health status, and as a group has historically experienced a disproportionately high incidence of a range of physical and mental disabilities. As economic conditions have been shown to be highly predictive of future developmental status (Drillien, 1968;

Parmelee, 1985; Siegel, 1985), Native Canadians may be seen to be at a significantly greater-than-average risk for the onset of disability. A recent study of institutionalized mentally handicapped children in Manitoba indicates that Native populations have a higher incidence of mental handicap than the rest of Canadian society:

A marked excess of Canadian Indian children was the most striking observation within the distribution of demographic variables which included parental age, occupation and education, place of residence, ethnicity and vital statistics. This over representation was especially interesting due to the paucity of data concerning retardation in North American Indians and because the finding is contrary to the view that 'severe sub-normality occurs equally in all strata of society' (Evans et al., 1985, p. 153).

The authors (along with Morgan and O'Connell, 1987) identify low socio-economic status as a highly significant contributing factor in the high rate of disability in the Native population. U.S. data show that "the percentage of working-age Native Americans reporting having a disability affecting their ability to work was the highest of any racial group reported, and was nearly one and a half times the rate for the general population." (U.S. Bureau of the Census, 1983).

A serious obstacle for the Native disabled adult is the existing paucity of services and programs for the disabled on Canadian reserves, and the inaccessibility of rehabilitation services outside the reserve, since they are found mainly in large urban areas, often a considerable distance away. This results in Native disabled persons either remaining within their sociocultural

support system but having no access to required rehabilitation services, or being forced to leave their families, communities, and culture in order to qualify for programs and receive services outside the reserve.

Federal Versus Provincial Responsibility

Although jurisdiction over social services on reservations is a federal responsibility, there is no specific federal legislation authorizing the federal government to establish and maintain rehabilitation programs on reserves for the adult Native population (Marszewski, 1973). Rehabilitation services to disabled adults have traditionally been considered to be a provincial responsibility, falling outside the jurisdiction of the federal government. At the same time, provincial government departments defer to the federal government's exclusive responsibility and jurisdiction for Native populations on reserves. For example, a memorandum of understanding between the Alberta Deputy Minister of Social Services and the Regional Director General of Indian and Inuit Affairs states: "Canada shall continue to provide social assistance, where it is required, to Indians residing on Indian Reserves" (Memorandum of Understanding IS-99-05-01, 1989, p. 6).

Since the federal government does not provide rehabilitation services to native adults on reserves and provinces consider such provision to be outside their jurisdiction for reserve populations, disabled Natives on reserves are denied rehabilitation services from either body. Neither the federal nor provincial government is precluded from offering rehabilitation services to adult natives living on reserves (Marszewski, 1973); they

simply consider such provision to fall outside their respective jurisdictions. This impasse parallels that of the United States, where jurisdictional issues have resulted in a situation where neither federal nor state governments are providing rehabilitation services on reserves. The main question in the U.S. has been whether the federal Indian Health Service is considered to be the primary or residual (to other governmental or private sources) health care provider. As federal resources are diminishing or being distributed as block grants to states, the position of disabled people in American Indian communities is rapidly worsening (Orlansky and Trap, 1987; Joe, 1988).

Such jurisdictional impasses, together with a lack of adequate information about existing provisions from service providers, have continued to undermine the right to accessible resources for disabled people in Canadian Native communities.

Case Study

History

I (A.V.) became involved with J. in September of 1989. Working with this young mentally and physically disabled native man made me aware of the sad history of his disability and the lack of adequate services he had experienced through a good portion of his life on the reserve. As well, I became aware of the existence of a much larger population of mentally disabled Native adults who lack adequate supports as a result of the existing gap in service provision.

At age seven, J. developed an ear infection that was untreated until it abscessed into his brain. J. was admitted to the Alberta Children's Hospital and was operated on several times to halt the infection. The resulting brain damage caused numerous disabilities — blindness of one eye, complete deafness in one ear, spasticity in all limbs, cognitive damage, balance difficulties and a seizure disorder. When released from the hospital J. returned home to live with his mother. As the school system on the reserve did not have adequate special education resources, he was unable to remain in school, limiting his education to grade three.

When J. was twenty his mother died and he went to live with relatives on the reserve. As his behaviour was difficult, he regularly changed residence. Over time he became less welcome at relatives' homes as he was demanding in his needs and could be physically abusive, especially toward children. During this period, J. was treated inconsis-

tently for ear infections and other assorted physical problems resulting from physical injury, poor hygiene and lack of adequate nutrition. Usually treatment took place after he had a seizure and had been transported to either the local medical clinic or one of three hospitals. Although medication for the seizure disorder was prescribed and supplied, blood levels usually indicated that he had not been taking his medication or that he had toxic levels of medication (overdose).

In December of 1988 guardianship of J. was awarded to the Public Guardian of Alberta. In September of 1989 J. was brought to my attention when a Personal Support Group (a number of people who volunteer to advocate for an individual) was being formed. J. had been found unconscious by the side of the road in winter on several occasions, and it was feared that if this pattern continued he would most likely die of exposure.

... disabled Natives on reserves are denied rehabilitation services from either ... the federal or provincial government.

September 1989 to July 1990:

J.'s Personal Support Group experienced little success in its attempts to access funding to provide services on the reservation where he lived. Alberta Family and Social Services indicated that it would not fund any person on the reserve — this was considered to be a federal responsibility. Although the federal government had jurisdiction on the reserve, the only option considered feasible for J. was institutionalization, despite J.'s strong desire to remain on the reserve. The services that dealt with J. on a regular basis (reserve health centre, reserve social services, hospital) felt that he should be institutionalized for his own safety and so they would not have to deal with his constant admissions and difficult behaviours. Following the principles of integration of the disabled and the philosophy of community living, however, the Public Guardian Representative was not willing to remove J. from the reserve against his wishes.

By late fall, the weather was becoming cold and J. was at a high level of risk. As I lived within a few miles of the reserve I offered to take J. into my home on a

temporary basis until alternative accommodation could be found. Alberta and Family Social Services agreed to fund this arrangement as it was not on the reserve. J. agreed to accept this compromise under pressure from relatives and moved in on January 1, 1990.

Despite continuing efforts to find alternate services for J., the Personal Support Group was unsuccessful. The "short-term" placement in my home continued for five months, during which several relief staff were hired but resigned because of J.'s abusive behaviour. Finally, a Native university student was hired and remained.

Considerable progress was made in assessing J.'s abilities. His anti-seizure medication was stabilized, regular medical treatment was arranged, life skills training efforts were beginning to bear fruit, his debts at the reserve trading post were cleared, and considerable hygiene improvements were made.

One of the conditions which provincial social services placed on funding was that J. have a vocational placement. J. was transported daily to a vocational institute forty miles away where he worked in a variety of areas. J. demonstrated that he had the capability to do slow but adequate work in the janitorial and garage areas at the institute. After eight weeks, the vocational institute decided they could not continue to provide services to J. because of lack of funding and his behavioural difficulties.

After the termination of the vocational placement the residential situation became chaotic. J. would spend many of his days on the reserve. Usually J. would phone and ask to be picked up, but often he would simply not return. Several days later I would be called by the hospital to pick him up. The reasons for admission were alcohol or drug abuse, causing seizures or physical injury from falling, and overdose of medication. On other occasions I would be called by relatives and informed of J.'s whereabouts, usually in an abandoned house or just lying on the ground somewhere. During this period, J. suffered numerous physical injuries and constant ear infections.

J. received \$200.00 per month from oil royalties and this money was often taken away either by persuasion of relatives or by physical force by others. An application was submitted by the Public Guardian Representative to Inuit and Indian Affairs to have a trustee appointed, and by the Personal Support Group for Assured Income for the Severely Handicapped (AISH). Despite numerous follow-ups the trusteeship application was not acted upon, and the AISH application was denied.

A Catalyst Grant was received from

The Alberta Institute on Mental Retardation to employ a support worker to help J. find employment on the reserve and support him in the job. The support worker position began in June, 1990 and by mid-June J. began work at the reserve Health Centre as a janitor. Two days later the Health Centre terminated the position citing community pressure to provide the position to an able-bodied individual. The support worker resigned immediately afterwards.

The residential situation deteriorated from this point. In mid-July J. returned to the reserve. Funding from provincial social services was cut off as J. was once again residing on the reserve.

July 1990 to November 1990:

Although I no longer had any direct responsibility for J., I remained in contact with him. Although J. was supposed to be living with his sister he was actually drifting from home to home on the reserve. He was seen several times sleeping overnight in ditches and to a great extent survived by eating junk food purchased from whatever oil royalty monies he was able to keep for himself.

While discussing J.'s difficulties with assorted service providers on the reserve, I was able to identify eight other disabled adults who were either lacking services or had been institutionalized but wished to return to the reserve. It was felt that there were probably many more disabled who had not been identified. No coordinated effort had ever been made to determine how many disabled there were and what services they required on the reserve. The prevalent attitude was that handicapped individuals who could not meet their own needs should be removed to institutions, although at the same time it was felt that disabled natives should remain within their culture.

J. clearly wished to remain within his culture. However, no individuals could be found on the reserve with the skills and resources to provide an independent living situation for him. I suggested that a residential facility staffed by natives on the reserve or immediately adjacent to the reserve be considered. Although the concept of a residence was found acceptable by the community services and a proposal was written up and presented, no funding could be accessed from either the federal or provincial governments.

November 1990 to February 1991:

In November 1990 funding resumed from the Alberta Institute on Mental Retardation to employ a support worker to assist J. on the

reserve. I was appointed as monitor. In the following three months the support worker quickly re-established regular medical treatment and adequate nutrition for J.

Accommodation for J. continued to be difficult. He was residing with his sister who had stated that as of mid-January J. would have to find alternative accommodation. The reserve social services attempted to find a home for J. but were unsuccessful. The reserve social services found and allocated \$150.00 per month to J.'s sister and she agreed to keep J. in her home until April.

J. continued to be abused financially, his money being taken away by relatives and others by persuasion or force. The support worker documented several instances of physical abuse toward J., including bruising on his legs and cigarette burns on his arm.

... Indians have consistently received ... inferior welfare services to those provided to non-Indians.

In December, 1990 a letter-writing and phone campaign to the Department of Inuit and Indian Affairs was organized to expedite the trusteeship which had been applied for in April, 1990. In January, 1991 an account was opened for J. and the reserve social services agreed to act as a trustee and disburse J.'s money in small allotments.

A new proposal for an additional three months of funding was submitted to The Alberta Institute on Mental Retardation. J. subsequently returned to his nomadic way of life on the reserve, at serious risk of death from exposure, abuse and medical complications, as permanent funding could not be obtained.

Discussion

Natives are at a greater-than-average risk for the development of physical and mental disabilities, and the most significant obstacle for adult disabled Natives is the lack of services and programs on reserves. There is a gaping hole in the social safety net for the population of disabled natives on reserves. The federal government does not provide programs or funding to the

disabled on reserves, and provincial government departments, although willing to be flexible in trying to provide funding to Native clients, will not do so on reserves.

In 1967, the Hawthorn Report stated: "The fact remains that Indians have consistently received different and in most cases inferior welfare services to those provided to non-Indians" (Hawthorn, 1967, p. 315). According to the report, the assumption that Natives are "wards" of the federal government, and that reserves are federal islands in the midst of provincial territory, has had the unfortunate effect of causing provincial welfare authorities to ignore Natives living on reserves. Provincial and municipal governments have been unwilling to provide services or extend monies to a group regarded as the exclusive responsibility of the federal government (Hawthorn, 1967).

Twenty-two years later, Alan Pratt writes:

Generally, the governments of the provinces have argued that aboriginal people have a special relationship with the Crown in right of Canada, and that this relationship is now expressed in unwritten constitutional conventions which create a political role of guardian or fiduciary. In the view of the province, this relationship gives rise to a federal obligation to pay for most or all programs and services for on-reserve status Indians (1989, p. 22).

Most Native governments are unequivocal in their stance that the federal government has legal and fiduciary obligations to provide for the care and well-being of Natives on reserves, obligations which have evolved through a complex mixture of treaties, legislation, and court decisions. The responsibility of provincial governments, however, must also not be overlooked. A clear line of policy to meet the needs of Native disabled individuals on reserves is urgently needed.

Reserves desperately require support services, including residential and vocational facilities for the disabled. The establishment of small residential and vocational facilities on the reserves would help to ensure the safety needs of the disabled and at the same time educate the community about the particular needs of their disabled members. In time, as the communities become more aware of the needs and rights of the disabled,

independent living programs could be introduced.

Those currently working as service providers with Native disabled adults across Canada continue to encounter either Native disabled adults institutionalized against their wishes and wishing to return to the reserve, or Native disabled living on the reserve in less than adequate conditions at constant risk of physical, financial and emotional abuse, and receiving no support services.

A needs assessment is needed to gain more precise data on the size of the population of disabled Native adults and the types of services required for this population. An accurate count of disabled Natives on reserves and those who have been institutionalized is needed to determine the type of culturally-appropriate services required. The rights and needs of the disabled, including community integration and normalization concepts, are not being operationalized by the Department of Indian Affairs, despite the suitability of native culture to accept and care for its disabled, and the desire of Native disabled adults to remain socially and culturally integrated.

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