BARRIERS TO RECOVERY IN A FIRST NATIONS COMMUNITY

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ABSTRACT

The practice of psychiatric rehabilitation is a concept and method that developed in urban-based settings. It has become a widely used guiding principle in mental health practice. This research examines how psychiatric rehabilitation fits within a remote First Nations community. Ten people—service providers, consumers, and family members—were interviewed to gather information about their perceptions of and experiences within the mental health system. The interview material was examined using content analysis. The results suggest that geographic and economic factors create serious barriers to application of the psychiatric rehabilitation method in a remote First Nations community.

INTRODUCTION

Health care can be thought of as a social process in which the providers and recipients negotiate an understanding of the problem and a plan for intervention (Waxler-Morrison, 1990). When the provider and the recipient are both members of the same cultural group and the same environmental context, understanding is more likely to be shared. However, cultural and environmental differences can lead both to misunderstanding and to the application of intervention strategies which may not be effective or appropriate within a particular milieu. Mental health service to Aboriginal people in Canada reflects this difficulty.

There is a fairly large body of mental health research regarding Aboriginal people, much of it produced since the early 1970s. Material written prior to this time is not abundant, and what is available often tends to have an anthropological focus. Non-Aboriginal mental health professionals and cultural anthropologists studied what seemed to them unusual occurrences such as "windigo psychosis" and "pibloktoq" (Teicher, 1960; Parker, 1962). More recent research concentrates on suicide and various associated intervention and prevention strategies. This focus is not surprising given the rates of suicide within Aboriginal communities (Royal Commission on Aboriginal Peoples, 1995). Other research has begun to look at service provision and ways in which traditional healing might be used to deal with the broad issues of mental health which have their genesis in the colonization process (Waldram, 1997; Lederman, 1999). However, the context of mental health service to Aboriginal people who have severe and persistent mental illnesses such as schizophrenia is not well documented. A few studies suggest that psychiatric hospitalization rates are higher for Aboriginal people (Dalyrymple, O'Doherty, &

Nietschei, 1995; Health Status Research Unit, 1989), but overall material is fairly limited.

Part of the difficulty in documenting the experiences of Aboriginal people within the mental health service system relates to the fact that the system does not consistently identify them as Aboriginal (Waldram, Herring, & Young, 1995). Further, Aboriginal people are a marginalized group who tend to live in more remote parts of the country, where they often remain invisible to the general population. Their particular needs have not been closely considered and, by and large, treatment has followed predominant mainstream models. Institutionalization was the operative model through more than half of the last century; however, since the shift to deinstitutionalization in the 1960s, community-based programs have become increasingly important. In the context of the community mental health system, psychiatric rehabilitation is an important and widely used approach. The intent of this paper is to examine the concept of psychiatric rehabilitation and its application to Aboriginal people with severe mental illness.

Psychiatric Rehabilitation

The concept of psychiatric rehabilitation and the models which developed out of it have redefined traditional approaches to psychiatric disability. William Anthony (1979) described psychiatric rehabilitation as a process of ensuring that people who experience a psychiatric disability have every opportunity to learn and perform the physical, emotional, social, and intellectual skills needed for them to live and work in their community with the minimal amount of professional help. More recently, Anthony (1998) has said that psychiatric rehabilitation helps people to identify goals and to develop the skills and supports necessary to achieve those goals. Rehabilitation approaches concentrate on developing an individual's strengths (Anthony, Howell, & Danley, 1984). Despite often divisive arguments about etiology, most service providers, family members, and consumers agree that rehabilitation should be an optimal goal. People who experience a serious mental illness such as schizophrenia have the possibility of gaining renewed hope through psychiatric rehabilitation programs which are increasingly respectful of their needs and wishes.

Examples of ideas and programs which emphasize the values of choice and citizenship are numerous. In 1984, Trainor and Church constructed a framework for support in which community and services were available as wanted and needed. Sullivan (1994) described the elements of a strengths-based approach in which supported employment and housing, along with consumer programming and self-help, could create an "enabling niche" which would lead to normalization. Carling (1995) proposed a process for achieving community integration which included revamping and reforming existing mental health support systems, improving and developing access to housing, creating employment opportunities, and promoting social integration.

Within the context of this thinking, it is clear that psychiatric rehabilitation models are community based and rely upon particular components to ensure their success. Cohen and Anthony (1988) described six critical components: (a) values which maximize choice within a framework of unconditional support that increases

competency; (b) a focus on consumer goals rather than service-system goals; (c) a focus on consumers' perceived need for assistance; (d) a focus on the consumers' preferred level of intervention rather than an all-or-nothing approach; (e) emphasis on substance in service delivery rather than on configuring service structures; and (f) a process of encouraging, supporting, and involving consumers in the community as active contributing members in order to establish a sense of acceptance. These components have been an important part of mental health initiatives in Canada throughout the 1990s. Macnaughton's (1991) "snapshot" of provincial policies and initiatives suggested that provincial governments have, at the very least, included the rhetoric of psychiatric rehabilitation in their planning and policy documents.

Assumptions of Psychiatric Rehabilitation

Psychiatric rehabilitation ideas and programs are an important part of community mental health in Canada. Like most mental health approaches, psychiatric rehabilitation originated within urban centres. These origins have led to a number of particular beliefs or assumptions: (a) that communities have a range of housing options available for consumers (Carling, 1995; Trainor, Morrell-Bellai, Ballantyne, & Boydell, 1993); (b) that the employment market is diverse and reflects multiple opportunities for work (Chandler, Levin, & Barry, 1999); and (c) that various services—such as psychiatry, hospitals, social work, and nursing—are readily available within the community, or at least are available within close proximity (Anthony, Cohen, & Farkas, 1990).

While it might be argued that psychiatric rehabilitation represents a progressive approach, difficulties associated with its application must also be acknowledged. Such difficulties are especially acute for northern and remote First Nations communities which face additional structural problems related to poverty, lack of economic opportunity, and systemic racism.

The Context of Service Organization

Health and social services for northern and remote communities have been organized in a manner that can be described as vertical, meaning that programs and funding arrangements are controlled from a central point (i.e., a provincial capital in the case of provincially funded services or Ottawa in the case of federally funded services). Vertical control creates problems for northern people in that programs are often designed with a southern, urban population in mind. Urban service delivery tends to be highly specialized, whereas health and social services in small northern communities typically have employed workers and offered programs which are less specialized in their function (Collier, 1993; Lee, 1998). Even in the more densely populated rural United States, health care services, such as mental health, are delivered primarily by non-specialty providers (Merwin, Goldsmith, & Manderscheid, 1995).

This tendency towards providing generalist services, in which agencies and workers must attempt to be all things to all people, occurs for several reasons. Most importantly, small, widely dispersed populations make it difficult to support highly specialized services which are only used by a handful of people. It is

difficult, for example, to justify and fund a drop-in centre for people with severe mental illness in a small community where only two or three people might make use of it. Further, it often is impossible to recruit specialized workers for employment in the northern environment; thus, generalist services are the only available option.

In small, isolated communities, the use of mental health services may prove to be difficult. Some community members, whether they reside in cities or small northern villages and reserves, stigmatize mental health service organizations and the people who need them. The problem for residents in small northern communities is that their activities are highly visible to friends and neighbours, and accessing a service in a way which is discrete and confidential may present challenges (Delaney, 1995). As a result, it is not uncommon for those people who are able to spend time and money travelling great distances to use services in another community.

Various structural elements further complicate matters for northern residents. The cyclical nature of resource-based economies places northern people at periodic risk for unemployment. This difficulty is even greater within Aboriginal communities where unemployment and poverty are at unacceptably high levels.

Service provision for Aboriginal people is also limited by jurisdictional disputes and funding arrangements. The British North America Act (BNA Act) divided power between the federal and provincial governments. Jurisdiction over hospitals, asylums, charities, and charitable institutions was assigned to the provinces, while the federal government retained power over marine hospitals, quarantine facilities, and Indians and their lands. Extended health services such as adult residential services, community mental health, home care, and ambulatory health care service are not insured and generally have not been covered by the federal government. This situation has led to service disparity between Aboriginal and non-Aboriginal people. Provincial governments, for example, have developed community mental health programs, but these services normally are not available to Aboriginal people living on a Reserve (Awasis Agency, 1994). In short, the movement to community mental health has resulted in people receiving different levels of service based on race. There are further differences in health service entitlement among Aboriginal people depending upon their status under the Indian Act (First Nations Health Commission, 1994).

These various considerations also must be understood within the broader context of application. Urban-based models and ideas come to be applied to remote Aboriginal communities for several reasons:

(1) Since educational facilities and training institutions for service providers are almost all urban-based, research funding is more readily available to those urban-based professionals and researchers who are situated within institutions which are capable of competing for scarce resources;

(2) The entrenchment of community mental health education, research, and administration within urban settings contributes to the introduction and management of urban-based ideas within remote Aboriginal settings;

(3) When specialized services are provided to remote settings, the provision generally is on an itinerant basis and the providers are professionals who reside in urban centres; and,

(4) Planning for service delivery to remote Aboriginal communities, until recent years, has been driven by large federal departments which have not always been able to consider clearly the particular circumstances and conditions of individual communities.

Some of the specific difficulties associated with the application of an urban-based model can be best understood by examining a remote First Nations community and the process of service delivery at the local level. The terms northern and remote are relative, but include a range of characteristics such as latitude, climate, lack of economic diversity, limited services, distance from major population centres, and primary dependence on a single resource-based industry. The question for consideration is: How effectively does psychiatric rehabilitation work in a northern and remote First Nations community?

METHODOLOGY

In exploring this question, ten people—consumers, family members, and service providers—were interviewed to obtain their views on service provision and opportunities for people with psychiatric disability living in a remote First Nations community in northern British Columbia. The sample of subjects was deliberately small and purposive in order to obtain detailed information representing different perspectives within the mental health system. The research proposal was first reviewed by the Chief and Council of the selected community and they provided their permission and support to proceed. The proposal also went through University of Northern British Columbia ethics procedures regarding research with human subjects. All participants in the research read or were read a letter explaining the purpose of the research. If they agreed to participate, they signed a consent form. The nature and purpose of this form was also explained. None of the participants was deemed to be illiterate, incompetent, or incapable of understanding the nature of informed consent. The results were shared with the Chief, Council, and the research participants. In addition to the ten people who were interviewed, two potential participants—one family member and one consumer—chose not to participate. They indicated that they did not have time for the interview.

Each interview was conducted using a semi-structured interview guide. The interviews were tape recorded and transcribed using a code to identify participants. The transcriptions were analyzed using content analysis (Krippendorff, 1980). The specific approach used was what Janis (1965) has referred to as assertions analysis or thematic analysis. The transcripts were read and colour coded to identify specific themes. These themes were grouped into five categories: (a) service delivery, (b) housing barriers, (c) employment and education barriers, (d) community attitudes, and (e) identified needs.

The ten interviewees included three reserve-based service providers, one itinerant service provider who lived in Prince George, two family members, two persons with a psychiatric disability (one having schizophrenia and one having

bipolar disorder), and two Prince George-based service providers. Persons with psychiatric disability and family members were identified through discussion with the reserve-based service providers. Service providers from Prince George were interviewed because Prince George is the location to which people from the community would travel for specialized mental health services, including psychiatric in-patient services. The hospital and attached programs function as a central regional resource, which means that the hospital deals with people from various communities throughout the northern interior of British Columbia. The education and professional background of all the service providers included two social workers (one MSW and one BSW), one social service worker (two year community college diploma), two registered nurses, and one licensed practical nurse. Two service providers and one family member were interviewed in Prince George. The other participants were interviewed in the reserve community.

RESULTS

Service Delivery

The respondents suggested that major gaps in the service-delivery system create large obstacles to recovery. One area which was addressed by all of the service providers related to referrals among resources or services. The comments and concerns raised by respondents describe a picture of a very disconnected service system. This disconnectedness is due to a number of factors. One service provider suggested that clients who are dealt with in Prince George don't seem to connect with resources back in their home community, perhaps because of problems with transportation and a lack of knowledge about where to go for help.

Another service provider indicated that, because of higher rates of staff turnover in remote areas, it is difficult to develop and maintain reliable, up-to-date, and knowledgable referral resources in those communities. This person also suggested that the turnover rates result in staff shortages, extremely high caseloads, and the hiring of inexperienced staff:

> Quite often we have new people who are in their first position—they're right out of school. And sometimes I even wonder if they know anything about mental illness. Again we have some very experienced people and we're happy with the level of service they provide.

Lack of knowledge about local resources is best exemplified by the comments of one service provider, who reported:

> I've never received a referral from a psychiatrist. In my experience I've found that the referral process is usually the other way. The majority of people I see have never been diagnosed, so I'm making the referral to the GP and then the psychiatrist.

Knowledge of mental illness among service providers also appears to be an issue. Some persons with a psychiatric disability may have a dual diagnosis of substance misuse and mental illness. In most First Nations reserve communities, National Native Alcohol and Drug Abuse Program (NNADAP) workers are available. However, the NNADAP workers generally have very limited training in recognizing mental illness. As one service provider recalled:

> I met a young woman from a First Nations community and it was clear that something was going on. She had spoken to two counsellors—one was a community counsellor and one was a NNADAP worker—and they didn't know what to do with her. The idea of a mental illness was remote, so she'd never had a referral to a GP to explore that further.

Another service provider indicated that, because resources are either non-existent or difficult to connect to, most referrals go to the local General Practitioner because, "at least I know then they connect up with somebody." When people are ready for discharge from a treatment resource in Prince George, it is difficult to know whether or not the situations to which they are returning are appropriate because discharge planning assessments are not always reliable. This problem is exacerbated by the fact that it is very difficult for family members to travel to visit a hospitalized family member and to participate in discharge planning. One community-based service provider said that financial and transportation difficulties restrict interaction with a mentally ill family member:

> Family normally don't go to Prince George to visit because there's nowhere to stay. There's no funding for compassionate travel so, especially if an adult family member is on income assistance, they won't have a vehicle, they won't have money for meals, and they won't have money for accommodation.

Follow-up resources often are located in an adjacent community rather than in the reserve community itself. For example, one service user reported using a community mental health resource which was located in a larger community 50 kilometres away. This person's family did not have a vehicle; thus, accessing the service was very difficult.

Housing Barriers

Besides the poor connections among resources, it is clear that key material resources which might facilitate rehabilitation are virtually non-existent. The primary difficulty relates to the availability of any kind of housing. The community in this study had a population of just over 600 inhabitants. One of the service providers reported that 90 people are presently on the community's waiting list for housing. A service provider noted:

> It is fair to say that the housing shortage makes it difficult for healthy individuals to get housing. If you have a disability, like a psychiatric disability it is even more difficult.

This difficulty creates further obstacles for a person with mental illness, in that choices related to the type of housing are severely limited. Psychiatric rehabilitation uses a range of housing options including group homes, adult care homes, supported independent living, cooperative living arrangements, independent living, and other variations. This range of options simply is not available in most First Nations reserve communities. The reality is that housing is in short supply and people live in overcrowded conditions, often with two or more families sharing the same dwelling. One service provider noted that people end up being discharged from hospital into a household where there are often a lot of children and limited privacy. This service provider stated that "people might be discharged into very crowded living conditions with associated higher levels of stress and concerns

about safety." One of the consumers in this study stated that crowds created discomfort and this person reported a need for privacy and quiet.

Employment and Education Barriers

The situation regarding employment, vocational rehabilitation, and education options is similarly bleak. The Chief and Council have actively and strategically developed and promoted employment options for the residents. However, like many northern communities, employment options are confined primarily to the single resource industry or the service sector. The relatively small size of the community limits the latter option, while the former is restricted by fluctuation in market demands for raw wood and wood products. The downturn in the forest industry has resulted in an unemployment rate that community officials estimate at 55% of the employable population. Like the housing situation, high rates of unemployment restrict options for persons with a psychiatric disability. One service provider stated:

> There's nothing. We have to find a position for them [mentally ill people] that would be a job shadowing model, with a structured growth pattern and there's nobody who is willing to take that on. We have one person who is developmentally delayed, not a specific disorder, just a very slow person [who works] as a janitor alongside another person and that is as far as people are prepared to go.

Funding for employment options is severely limited, or even non-existent in many cases. As a precursor to supportive employment or independent employment, life-skills training is an important component. However, all of the service providers as well as the family members and consumers described a total lack of life-skills training. While there are regional funds attached to an independent living skills program, most of these funds remain in Prince George.

One Prince George-based service provider indicated that life-skills training is critically important for many people with persistent and severe mental illness. If there was a base for life-skills training, this provider believed that it would make a tremendous difference for many people with serious mental illness from remote First Nations communities. However, the provider noted that life skills often are taught within the context of things such as day programs and, in smaller more remote communities, there is a concern around economies of scale. If there are only two people in a community in need of life-skills training, then an approach other than a day program is required. Two reserve-based service providers also talked about the importance of life-skills training, which they noted is totally lacking. Life-skills training is based on assumptions about available opportunities and supports, without which the suitability of the approach can be questioned—especially as it relates to an isolated Aboriginal community.

Community Attitudes

The recovery process is based in part upon community support and acceptance. One respondent reported discomfort at having a family member who experienced mental illness. This person stated that many people don't understand and don't seem to want to understand what is involved with a mental illness. The family member said, "They're either afraid or confused." Several service pro-

viders agreed that, among some community members, mental illness has the stigma of bad medicine or a curse attached to it. One local service provider said:

> Some people believe in curses or bad medicine. It depends a lot on what's going on. If a person becomes violent and then suddenly changes, there are those in the community who think that this is some kind of witchcraft or something.

A family member said,

> The community reaction to mental illness is very negative, even cold. People don't want to have anything to do with you, or it's always your fault and you're just a bad actor. It's a very poor attitude.

Consumers as well as service providers all spoke of the need for community education about mental illness. One service provider observed that mental illness generally is seen as the same thing as mental retardation. There is no differentiation in the minds of many community members. This service provider stated, "mental illness, brain injury, and mental retardation are all placed in the same pot and viewed as the same thing."

Identified Needs

The respondents in this study suggested a number of specific resources and activities that would be helpful for persons with severe and persistent mental illness. One suggestion related to community education. Consumers of service as well as service providers described a need for more community and public education about mental illness. The health centre and the school were seen as the most appropriate places to provide public education and information.

Service providers on the reserve also talked about the need for supportive housing options. However, they noted concerns related to economy of scale and thought that a supportive housing project would have to include people with a range of disabilities besides a psychiatric disability. Clearly there is a danger of creating a "mini-institution" within the community; but, given the small numbers and the intense pressure on housing resources, this appeared to service providers as the only option as far as supportive housing was concerned.

Service providers saw life-skills training as being critically important in developing skills for independent living. There is a lack of knowledge about mental illness, and life-skills trainers are also seen as people who can begin to address this need.

Finally, as one service provider stated, "There's a real need for information—to know what services are available." This need is apparent in Prince George as well as in the remote communities. The system is far from being seamless and there is an alarming disconnection between specialized resources in the urban centre and the communities on the periphery.

DISCUSSION: IMPLICATIONS FOR PSYCHIATRIC REHABILITATION

Models of psychiatric rehabilitation assume a reality that is urban-based. They rely on employment, housing, education, and access to a range of mental health

resources which are economic as well as social, and which—in order to provide optimum conditions for recovery—need to be configured in a way that promotes consumer choice and empowerment. However, there is a clear schism between urban-based services and people in remote First Nations communities. This schism is produced by jurisdictional issues and the reality of barriers produced by geography and the economy of small isolated populations. The reality is, though, that northern communities, particularly those which are First Nation communities, experience a disconnectedness from the services and information which are available through urban-based resources. Models of psychiatric rehabilitation assume a reality that is urban-based.

Perhaps the only reasons why this situation has not been identified as a serious problem are the massive challenges faced by First Nations communities. Within the context of those challenges, the needs of First Nations people with serious and persistent mental illness are often subsumed by broader concerns. People with a serious mental illness who live in remote First Nations communities experience a significantly poorer quality of health and social-service care. They face numerous barriers that can be described as structural—that is economic, social, and geographic blockage to an acceptable quality of life. These barriers preclude the application of mainstream psychiatric rehabilitation models which operate from the perspective of metropolitan assumptions.

CONCLUSIONS

Clearly, there are no easy solutions to this problem. There are, however, a number of initiatives which can be taken to address the blockage to psychiatric rehabilitation as applied to remote First Nations communities.

Such initiatives must begin with a reflection on the concept of citizenship. Citizenship refers to membership in a society and the entitlements that membership provides. The history of jurisdictional disputes between the federal and provincial governments has produced a situation wherein First Nations people have been denied some of the services normally available to other Canadian citizens. This situation is compounded by what might be called the two-tiered system of mental health services which exists between urban-dwelling Canadians and those who reside in remote northern communities. The possibility of realizing full citizenship is further diminished by the experience of serious mental illness and the oppression and social prejudice associated with this experience.

The extension of full citizenship is not an easy process; however, a beginning can be made by eliminating the jurisdictional disputes and concentrating on the development of a seamless system of service. Bridges, Huxley, and Oliver (1994) have noted that psychiatric rehabilitation depends upon an integrated and coordinated system of services. Such a system will never exist in remote First Nations communities until federal and provincial governments unite to identify and provide service based on need as opposed to jurisdictional responsibility. First Nations self-government may go some distance toward addressing this issue, but indigenous resources will not be sufficient and there will be a continued need to link with the resources available through provincial health care and social service systems.

A second consideration must be housing. The lack of housing and the access to housing within First Nations communities is a national disgrace. As the federal government contemplates its large budget surplus, it is clear that money from this surplus needs to be directed toward a major housing initiative within First Nations communities. The nature and form of housing construction also has to change to represent diverse community needs.

Respondents in this research suggested that specialized housing for persons with a mental illness may need to include other people who face disabilities of a different nature, whether these are persons who are differently abled physically or persons who may be mentally challenged. This suggestion tends to fly in the face of conventional wisdom, as the construction of facilities which group together persons with disabilities may be seen to create a ghetto for people who are already marginalized within the community. Nonetheless, economies of scale make it very difficult to provide the types of housing options which occur within urban settings. A possible way around this problem would be to provide variety in the existing housing stock, so that persons with a psychiatric disability would be better able to exercise choice. Multiple dwelling units as well as larger single dwelling units need to be considered more fully in housing construction plans.

Education and employment present particular challenges. Unemployment rates are high in First Nations communities and, as an overall problem, this factor has to be addressed. In the interim, provisions need to be made for persons with serious mental illness. Several respondents talked about job shadowing and the problems associated with this practice. Employed community members who might have provided a work experience were reluctant to do so because of misunderstanding and misgivings about mental illness.

This reluctance leads to the possibility of broad-based community education programs around mental illness and mental health. Such programs could be developed for the whole community. They might, however, more specifically be developed for people in employment situations who could serve as models and mentors for people with psychiatric disability. The concept of mentorship is not alien for First Nations people; it is the role of elders and a highly valued activity.

Community education/awareness initiatives also must be considered. Provincial campaigns do not always reflect cultural sensitivities and attributes, such as the centrality of spirituality in the First Nations' worldview. Such considerations can be better addressed by local initiatives which can be undertaken for a relatively low cost. Organizations such as the Canadian Mental Health Association and Health Canada need to give serious consideration to distributing money for public education at the local level.

Finally, there needs to be a major initiative relating to resource information. Central resources which provide specialized care do not know what is available for people who are moving back to their remote community settings. At the same time, service providers in the remote community settings are not aware of how to access the resources which may be available in the urban setting. Resource inventories which are updated regularly need to be provided to both urban and northern service providers. Having computer technology accessible to both remote First Nations communities and the urban centres would make such inventories a real and

distinct possibility. Without this kind of information, coherent and integrated plans for psychiatric rehabilitation will not develop and remote First Nations communities will continue to be marginalized from mainstream service delivery.

RÉSUMÉ

La pratique de la réadaptation psychosociale est un concept et un méthode d'origine urbaine. Elle est devenue un principe très utilisé dans la pratique de la santé mentale. Notre recherche examine la réadaptation psychosociale dans une communauté autochtone isolée. Des entrevues on été faites avec 10 personnes—praticiens et praticiennes, consommateurs et consommatrices, membres des familles—pour documenter leurs expériences vis-à-vis du système de santé mentale. Les entrevues ont été examines par l'analyse de contenu. Les résultats suggèrent que les facteurs géographiques et économiques créent des obstacles sérieux pour la pratique de la réadaptation psychosociale dans les communautés autochtones isolées.

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