

The Experience of First Nations People with Disabilities and Their Families
in Receiving Services and Supports in First Nations Communities in
Manitoba – Honouring the Stories

By

Donald W. Shackel

A Thesis Submitted to the Faculty of Graduate Studies
in Partial Fulfillment of the Requirements for the
Degree of Master of Arts

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MASTER OF ARTS

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Abstract

First Nations people with disabilities and their families living in First Nations communities are caught in a complex web of government based jurisdictional and departmental wrangling and offloading, directly impacting the lives of many First Nations families and the types of services and supports they receive at the community level. Families and caregivers are disempowered and persons with disabilities have been denied access to supports to enable their full participation and involvement in their communities.

Using a story telling approach, the purpose of this qualitative research was to collect stories of the experiences of First Nations people with disabilities and their families. In addition, using a social model of disability and a rights based analysis, this project asked families to reflect upon what services and supports do exist within their communities and then to share about the consequences of the existing conditions for both children and families. Project participants reported that three undesirable options exist for persons with disabilities and their families. These options include; staying in the community without the necessary services and supports, leaving the community, living away from community and extended supports or involuntarily placing your child in the care of a child welfare agency hoping that services will be provided by the mandated agency of care.

In this project, participants also provided recommendations for local, provincial and federal governments for a continuum of community based services and supports in First Nations communities which would make the lives of persons with disabilities and their families more livable.

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Dedication

This thesis is dedicated to the families who so graciously welcomed me into their homes and lives and so freely shared their perspectives and experiences. It is my hope that this project in some way shapes a future in which services and supports will never be withheld based on the race of the person with a disability.

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Chapter 1- Introduction

The colonization, oppression and marginalization of First Nations people with disabilities is deeply rooted in attitudes of ableism and racism prevalent within Federal, and Provincial governments, and in medical, social and educational institutions in Canada. First Nations people with disabilities and their families are tired and angry because of the neglect of their support needs within their communities. "We feel very frustrated, hopeless and obviously very sad as parents. You are looking out for your child's best interest and your hands are tied. You don't know what to do or where to go for help." (project participant)

Families are frustrated with local, Provincial and Federal governments and health, social service and educational organizations they feel should provide them with support and assistance in order to live full and meaningful lives. "There is nothing for disability in our community and that is very hard. There is no support from the Education Authority or from anyone at the local level. We did not know if there was help or not. I do not think disability is understood. Disability means someone on crutches. They do not see someone who is blind or deaf as disabled. Disability is not a priority." (project participant)

One participant who had to leave her community to access supports for her daughter expressed her anger towards both Federal and Provincial governments by stating, "I should not have to move my family to the city. Instead of me going to the service they should come to me. What if it was turned around and all the governments were Native and they did not let the non-Native people have any services? How would they feel if we had all of the services on the

reserve and they had to come to the reserve or move away from their communities in order to get services?" (project participant)

Consistently, the participants in the project said that governments and many existing service providers do not understand their reality.

I don't think the government will ever put things in place. The government does not have to live with these kids. Maybe the government should look after my kids for at least 24 hours. They probably would not want to and would run away. They should see what the mothers have to go through. They should come and live a day out here and see what a mother of children with disabilities has to go through. Come and see how we live. Do not feel sorry or pity for us because that will make it worse. Do not judge us either. If I could I would give the government an earful.
(project participant)

The families who participated in this project also displayed resilience, using cultural values and beliefs as well as strong community and extended family ties and supports to cope with the lack of formal supports at the community level. "I have been helping other families with children with disabilities. We have a support group and it really helps. A lot of community supports we have build ourselves as neighbors. We trade babysitting and our peer support is very good." (project participant)

Within the disability community in First Nations in Manitoba attitudinal barriers, prejudice and systemic discrimination seem to be counteracted by a deep inner resilience, a strong belief in the importance of all children and the belief that community is paramount. Immediate and extended family support is evident as a prevailing practice in First Nations communities. "There is always someone there from the family to provide support; if not your immediate family, then your uncle or grandfather. That is the uniqueness of First Nations to be

open to share whatever you have. That is one of the strong values our people have.” (project participant)

A predominant western, Eurocentric medical model of disability, which sees disability as a weakness or ailment in need of change or amelioration, has prevailed over much of the mainstream’s approach to disability. The perspective of disability within First Nations families and communities seems to be more consistent with the social model of disability, which sees limitations not within the individual with the impairment, but rather in conditions outside of the person. First Nations perspectives seem to be more accepting of difference with less desire to change the individual. Thus the onus for change, accommodation or accommodation is at the environmental, community and societal level, not on the individual with a physical, psychological, sensory or cognitive impairment.

My interest and passion, as a researcher and service provider, is to further understand issues concerning disability service and support provision in First Nations communities arose out of a long standing interest and appreciation of First Nations people, and the historic and contemporary issues they face. This regard, coupled with my work at the Manitoba First Nations Education Resource Centre, deepened my interest in this issue.

In this project the existing literature on the subject of First Nations disability including First Nation reports and existing government documents reveal a complex system of government offloading and a distressing lack of community based services within First Nations communities. In this thesis the existing literature will be summarized exposing the gaps in the existing literature

including the lack of analysis from a social model of disability; as well as the disregard of First Nations perspectives.

By inviting families to tell their story, which is consistent with First Nations cultural perspective and practice, this project explores the experiences of First Nations people with different disabilities in various aspects of community life, and in particular, in receiving services and supports at the First Nations community level. It provides critical analyses of the subsequent impacts of government driven policy and practice on the lives of First Nations people with disabilities and their families who live in First Nations communities in Manitoba.

Story telling and oral teaching methods have been used as the primary data collection methodology, as story telling is an integral component of First Nations cultural practices. “It is time I felt as if these researchers were giving voice to our Ancestors (Kirkness, 1992) through their work of oral story telling of their work and of the people that co-participated in their research.” (Fitznor, 2002, p.64) Reflexivity, or sharing my own story as a part of this process highlights the importance of self reflection and the need to examine one’s own “position” and my response to issues of both disability and impairment and the approaches used in a cross-cultural setting.

Through methods of participatory action research, and by using this process as a strategy towards de-colonization and de-marginalization, the goal of this project is to empower First Nations people with disabilities to influence the enhancement of a community-based continuum of service and support which will build upon existing strengths of First Nations practices and way of life.

Using a rights-based approach, the project celebrates strengths of First Nations citizens, families and communities, and honours First Nations perspectives. Inclusive of this paradigm is a fundamental belief in the right to self determination of First Nations people with disabilities. The project calls specific attention to impacts of colonization of First Nations in Canada, citing historical and contemporary government (Federal, Provincial and local) related policies, practices and the subsequent conditions experienced by First Nations people with disabilities in First Nations communities, such as the impacts of the legacy of residential schools. “Every child given to us is a gift from the Creator. I have always tried to seek spiritual help from my dad. You need to show respect and warmth to that person with a disability and you do not look down upon him. Because of the residential school some of those teachings are gone.” (project participant) Another project participant stated, “I don’t want my daughter to go out of the community and experience the issues of the residential school. We have always been here. This is my home and where I want to live.”

It is my intention to use this project, and my position as a researcher, to try to shift the inequitable power structures which impact the lives of First Nations people with disabilities living in First Nations communities in Manitoba.

First Nations people with disabilities, perhaps more than others, have been significantly affected by government imposed and maintained jurisdictional barriers and conflicts which continue to affect access to community based, publicly funded disability related supports and services. Although a wide range of similar issues exist for many people with disabilities, such as systemic barriers

to inclusion, First Nations people with disabilities often face additional barriers such as the lack of culturally and linguistically relevant services and supports. This is particularly the case when families have to relocate in order to access services and supports which exist within the broader society. “It is very hard when our people have to move to the city if you do not speak the second language (English). A lot of times the person does not know where to go. Being away from home is very difficult. It is like culture shock. People ignore you and there is lots of discrimination.” (project participant)

During the data collection phase, families reflected about the degree of inclusion for people with disabilities in their communities. Many families noted the lack of accessibility, inclusion and participation for people with disabilities in their communities. For example one participant from a northern First Nation noted, “I do not see anyone like my son out in the community at all.” A mother from a different First Nation stated, “I do not see anyone with a disability working at any place on our reserve.”

Taking direction from the participants, recommendations for change at the policy and service delivery level have been collected as well as suggestions from the participants as to how, and to whom, these recommendations should be disseminated. The ultimate goal of the process is to work towards dismantling the systemic barriers First Nations citizens and their families face in various aspects of daily living.

Finally, this project is an opportunity to learn about First Nations cultural and traditional teachings, beliefs and practices related to people with varying

physical, sensory, cognitive and psychological differences. These differences have always, and will always exist, as normal components of the diverse range of the human condition. By viewing disability through this specific cultural lens, this process is an example of the documentation of First Nations epistemology with respect to “difference from the norm.”

In the final reflections and conclusions of this report there will be sharing of some unexpected results such as the remarkable similarity of the lack of services despite the degree of remoteness of the First Nation. The conclusion will also present new questions and raise issues requiring further discussion and research inquiry on the topic of First Nations disability.

Statement of Purpose

The purpose of this project is to document the experiences of First Nations people with disabilities and their families in receiving services and supports in First Nations communities in Manitoba. The research question which began this quest was, What are the experiences of First Nations people with disabilities and their families who live in First Nation communities in Manitoba? The analysis of the data included the following three subcategories;

1. What services and supports do First Nations people with disabilities and their families have in place;
2. What are the consequences of this existing system of services and supports; and

3. What do First Nations people with disabilities and their families need to make their lives more livable?

In telling their stories, families provided valuable feedback about the education, social services and health care systems that exist within their community. From this feedback, families indicated almost unanimously that support from extended family members is the most important, and often the only form of support available to them. “The support for my grandson will always come from our family.” (project participant)

During the interviews, families revealed the consequences they have experienced from the lack of service system and described how they continue to cope and survive in the absence of a more formal system of public support and services. Sadly, many caregivers shared incredibly painful and difficult experiences resulting from their children’s impairments not being accommodated in their community and the fact that there is often not any level of publicly funded services accessible to them in their home communities. As one mother from a First Nation community states, “My son is 23 years old and never does anything. He just sits around all day and colors.”

In addition, almost all families spoke about negative experiences with child protection services and their strong desire to avoid child welfare agencies for accessing disability services and supports at any cost. “I only use CFS because I have to. If I had it any other way I would have the services in the community from another agency. My (disabled) son has attachment issues as

well. Before I got him he had been in four different home placements in the first 30 months of his life.” (project participant)

This qualitative research explores the experiences of people with disabilities and their families in First Nations communities with various aspects of daily living. By replacing the medical model of disability with the social model, paying particular attention towards colonization/de-colonization processes impacting First Nations people, analysis and reflection from a rights based perspective has been a central theme.

Inquiry into First Nations experiences with disability related service and support provision requires an appreciation of the diversity within different First Nations individuals, families and First Nations communities. This project explores how disability is conceptualized in First Nations communities and how First Nations communities deal with diversity.

Not found within existing written literature, rather based on more than 20 years of experience working with First Nations people, in both disciplines of mental health and education, I observe that reaction to disability and “difference from the norm” in First Nations communities tends to be grounded in the following beliefs;

- 1) a high tolerance of difference;
- 2) the equality of community members;
- 3) the importance of seeing the gifts rather than the deficits;
- 4) the collective responsibility for children within First Nations; and

5) the need to see the experience of disability within the context of healing from the intergenerational effects of colonization.

First Nations persons with disabilities deserve the opportunity to develop appropriate community based systems that they identify are needed to meet their needs. In contrast, existing federal government services are often constructed in a manner which is based on fragmentation, isolation and a lack of coordination, often resulting in a “siloing effect” whereby departments and jurisdictions work independently from one another. Programs and services are often developed without input from the potential consumers of these services and supports. Because supports and services are so limited, this is the perfect opportunity to seek input, guidance and direction from families who may use these services in the future.

Unlike government reports and the other limited projects on the topic of disability within First Nation communities, taking direction from First Nations families is a central theme throughout the research. This project has investigated community based solutions including for families living in remote and isolated communities only accessible by air travel or on winter roads, who are often forgotten, and further isolated. Opportunity to meet with these families is possible due to the present travel schedule of the principal researcher currently working with the schools in these remote communities throughout Manitoba.

This project has been a process of building relationships by sharing the pains and concerns of the participating families and discussing the impacts of impairment of their lives. The project has been an opportunity to listen with an

open heart and mind with dignity, honour and respect. In this process families have reflected upon the actions and inactions of other community members and of local provincial and federal governments and programs regarding the needs of people with disabilities within their communities.

Most importantly, this project is a call to acknowledge the reality and experiences of a subgroup within a particularly marginalized culture in Canada. “At the base of such problems lies a definition of service obligations and funding levels for both Canada and Manitoba. Manitoba’s Full Citizenship: A Manitoba Strategy on Disability (2001) summarized such problems, noting that First Nation persons with disabilities on reserve have often found that their rights to government service have been ignored as a result of ongoing disputes between the federal and provincial government over which level of government is responsible for such services.” (Intergovernmental briefing note, AMC, 2007)

Due to the socio economic conditions in First Nations communities in Manitoba many individuals and families experience poverty and the related negative impacts on health. Poverty and health conditions interact to generate greater vulnerability for persons with disabilities and their families living in First Nations communities in Manitoba. This project will explore the impacts of disability on the economic status of families living in First Nations and conversely the impacts of poverty on the families of children with disabilities who participate in this project.

The participants in this project include people with a range of impairments, reflecting this study’s commitment to a cross-disability rather than a uni-disability

perspective. The families include children with disabilities ranging in age from 6-26 years of age and family members have graciously shared their experiences, perspectives and desires for their future, the future of their children and of their communities.

Delimitations

Although broad-based analytical tools have been used, this study has a number of limitations in terms of its scope and objectives. Although this project focuses on disability related service and support issues of families living in First Nations communities, it does not explore the social, systemic and structural issues experienced by First Nations peoples with disabilities who do not live in First Nations communities.

Second, this research, although interested in exploring the commonalities and similarities in perspective and experience of all First Nation people with disabilities, does not attempt to definitively define a specific First Nations cultural perspective on disability.

Third, this research includes a cross-disability approach with participation from people experiencing different physical, sensory and psychological impairments. Thus, another limitation of this study will be that it may not provide a complete and thorough analysis of one specific disability in relation to all of the services and support needs for that particular disability at the community level. It does however appear that the experiences reported by families, regardless of the

impairment, are quite similar including systemic barriers such as limited opportunity for participation in the various aspects of daily community life.

Along with a review of the theoretical frameworks used for analysis of this topic, including the social model of disability, the impacts of colonization and a rights based analysis, and the relevant existing literature and government reports on the subject, the next section includes an analysis of the jurisdictional issues impacting the delivery of disability services and support in First Nations. The data collection methods used for this project will then be reviewed including: participatory action research (PAR); Indigenous story telling; and research as a de-colonization strategy. A description of the methodology of the project and how it was implemented, along with a review of the analysis of the data, will then follow.

Chapter 2 – Theoretical Frameworks and Existing Literature

Within the context of this project, the experiences of First Nations persons with disabilities in accessing services and supports are examined within three broad based theoretical frameworks. They include the social model of disability, which is a broad theoretical understanding of disability, and a post colonial framework, which sees broad based analysis of the impact of colonization and oppression of First Nations people. The third framework, a rights-based analysis, sees First Nations people and persons with disabilities as holders of rights, including the inherent right to self determination and equal right to access services and supports.

Social Model of Disability

The social model was developed to counter the prevalent medical model of disability. In this section, we will examine the medical model as well as the definition, goals and key analytic tools of the social model.

With the medical model of disability, impairment, or more specifically, deviation from “normal” functioning, is viewed “in a negative context as a handicap and government interventions involve a medical model treating and fixing the impairment.” (Henteleff, 2002, p.5) Disability is often responded to as a “problem” which needs to be controlled, counted, classified, defined, and/ or corrected. As Linton (1998) suggests,

the medicalization of disability casts human variation as deviance from the norm, as a pathological condition, as deficit, and significantly, as an individual burden and personal tragedy. Society, in agreeing to assign medical meaning to disability, colludes to keep the issue within the

purview of the medical establishment, to keep it a personal matter and “treat” the condition and the person with the condition rather than “treating” the social processes and policies that constrict disabled peoples lives (p.11).

Publicly funded services and supports for First Nations people with disabilities in First Nations communities, if they exist at all, are still often provided within a medical model context. Within society there is continued discomfort with difference from what is perceived as “normal”.

By contrast, the social model of disability shifts focus of change away from the individual who may be different from “the norm”, towards society accommodating and including others and removing barriers so that all people can fully participate in all aspects of society. The social model seeks to understand the experience of disability addressing issues such as inaccessibility recognizing the importance of full and equal participation in all aspects of human functioning and social interaction. The social model involves understanding various aspects of human interaction, including the positions of power we all occupy, and working towards creating a just and fair society for all.

Persons with disabilities worldwide have adopted a social model as a much more effective way of working towards inclusion at all levels of society. One of the most significant barriers which the social model attempts to address is the negative or prejudicial attitudes towards individuals in society who have sensory, cognitive or physical impairments. This model promotes an appreciation of and tolerance for difference and sees these differences as a way of creating a rich and diverse community and society.

The social model is an approach which sees “dis-ability” as a socially constructed phenomena resulting from existing societal barriers preventing full inclusion and equal participation for persons with sensory, physical, cognitive or psychological impairments. (Stienstra et al, 2002) As Wolbring (2004) states, “disability is a variation of human diversity” (p.2). Every human in some way experiences impairment and related disability, to some degree or another, at some time in their life. Accepting these variations as normal ranges of the spectrum of the human condition has the potential to create more inclusive, diverse and vibrant families and communities.

The evolution of a social model of disability, as defined by the Roeher Institute, (2003) broadens this definition stating,

Disability is the status of having: *limitations* in carrying out daily activities of daily living and in participating in the social, economic, political and cultural life of the community arising from:

- Personal conditions (such as physical, sensory, psychological, intellectual)
- Stereotypes of such conditions that lead to exclusion within society
- Physical barriers that prevent participation and full citizenship (and)
- Recognizes that accommodation may be required for carrying out activities of daily living, participation and full citizenship regardless of the severity of the disability.

The Roeher Institute (as cited in Henteleff, 2003, p.6)

Along with seeing “disablement”, or barriers to full inclusion, as a set of factors existing outside of the individual, the social model provides an effective framework for political and social action at the individual, family and community level. Promotion of self representation, advocacy, social inclusion and equal participation are components of a social model of disability. “First, it (the social model) enabled the identification of a political strategy, namely barrier removal. If

people with impairments are disabled by society, then the priority is to dismantle these disabling barriers, in order to promote the inclusion of people with impairment.” (Shakespeare and Watson, 2002, p.5)

The social model holds as its goals full inclusion, equal participation and access within all aspects of individual, family and community functioning.

Inclusion measures how people with disabilities are taken into account in the design, implementation and evaluation of strategies, policies, programs and projects. **Participation** measures the extent to which people with disabilities and their chosen representative organizations are given and able to use a voice in decisions that are made affecting their lives and the lives of their communities. **Access** measures how people with disabilities are able to use the built and natural environments well as information and communication systems.

(Stienstra et al, (2002), p.X1, XV1,X1X)

Within the social model of disability, the key analytical tools used can include;

1. assessing for self representation/determination for full and equal participation,
2. the need for examination of positionality (one's position and social situation) in relation to the experience of disability, (or any marginalized group),
3. recognition and valuing diversity and inclusion of all, and
4. the importance of dismantling structural and systemic barriers in society.

Similar to the social model of disability within the field of multicultural education Dr. James Banks, renowned multicultural scholar, identifies four key stages of multicultural education including the contributions approach, the ethnic

additive approach, the transformation approach and the social actions approach. Using a social actions approach, "actions and decisions are made relating to the concepts, issues, and problems being studied to make the world a better place." (Pinoy Teach, 2004, p. 2) The ultimate goal, aimed not at the individual level, but at intervening at the societal level is to, "put theory into practice such as service learning projects for students, campaigning and writing letters to the editor, resulting in empowering students to be the social agents of change." (Pinoy Teach, 2004, p. 1-2) Both the social model of disability, and the social actions approach in multicultural education, places responsibility for acceptance and inclusion of diversity from Eurocentric and ableist perspective and practice. These concepts and practices are now clearly articulated across disciplines and in various academic and community based settings. James Banks (2003, p.5) indicates that within the social actions approach, "that schools should help students acquire multicultural literacy, which will enable them to develop a delicate balance of cultural, national, and global identifications and a commitment to act to change the world to make it more just and humane." The end result of both approaches is the creation of a more just and fair society for all.

Analysis using these tools is valuable as it promotes self reflection of past and current practice and also provides a framework for future action and development.