

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.

Impacts of Colonization of First Nations and Parallels with Experiences of Disability

The denial by the West of humanity to Indigenous peoples, the denial of citizenship and human rights, the denial of the right to self-determination – all these demonstrate palpably the enormous lack of respect which has marked the relations of indigenous and non-indigenous peoples. (Tuhiwai-Smith, 2002, p.120)

The discourse around First Nations disability issues must be examined within the context of understanding the cultural oppression experienced by Indigenous people in Canada. Colonization of indigenous cultures results from direct, intentional abuse of power and control over First Nations. The expropriation of inherent traditional lands and resources and rights to self government, and the systemic dismantling of language, spirituality, and family structure, has resulted in crippling poverty and loss of culture and way of life for many First Nations families and confusion and conflict around self-identity. Through mandatory attendance at religious and state run residential education systems, First Nations people experienced attempts at cultural decimation. Since European contact in Canada, First Nations have been subjected to inter-generational interruption of the transmission of identity, culture and way of life.

From an historical perspective, attempts to destroy First Nations families, communities and cultures are evident throughout Canada. Still today many First Nations communities are located in remote isolated areas, often on the poorest quality of land with little long term sustainable employment opportunities. (Dickasson, 2002, p. 342-354)

The systemic intergenerational impacts of colonial oppression may be seen no more clearly than within the First Nation disability community living in

First Nations communities in Manitoba. Multiple overlapping layers of marginalization exist within this particularly oppressed segment of First Nations communities. Using the “discourse of colonization” as a key theoretical framework can promote enhanced understanding of past and contemporary relationships between First Nations persons with disabilities and “the other(s)”, which can help to dismantle negative or unequal power relationships which prevent the right to self determination. Secondly, using such a post colonialist framework can promote healing from the numerous and at times continuing impacts of colonization and oppression of First Nation individuals persons with disabilities and their families and communities.

Analysis of the impacts of colonization, the term “Ethnostress” has been used to describe the confusion and stress related to the intergenerational disruption of Aboriginal culture and identity. The denial of the access to basic services and supports for persons with disabilities and their families and communities create additional stress often leading to greater internalized conflicts within First Nations communities. The lack of options for resolution or barrier reduction leads to further stress and tension. As Hill, (1992, p.6) states, “Lastly, Ethnostress is at its highest when the feelings of powerlessness and hopelessness pervades our community existence.”

Within this project, the key analytic tools used originate from understanding the processes of colonization and equally, or more importantly, decolonization (the liberation of First Nations). They include the following;

1. assessing the impact of past and contemporary forms of oppression and/or marginalization of First Nations people such as the denial of the right for self determination,
2. exploring direct and indirect forms of oppression such as mandatory attendance at state run boarding schools and the extent of systemic poverty which exists today in First Nations communities,
3. understanding past and current structures of power and control, such as Federal Government practices and programs, which continue to negatively impact First Nations in Canada,
4. recognizing the need to value First Nations perspective and the existing cultural knowledge of First Nations individuals, families and communities, and
5. focusing on the critical importance of self determination and seeking community based, consumer defined solutions to issues impacting First Nations communities, such as the provision of disability supports and services.

History as experienced by both First Nations people and persons with disabilities, in many ways, is remarkably similar. As is with many First Nations people, persons with disabilities have also been segregated and excluded from society through mandatory attendance at “specialized” schools and institutions run by state, church and charitable organizations. These institutions were aimed at removing persons with disabilities from the general public. Prejudicial attitudes of others, including ableism, which is a belief of superiority by those who do not

have functional impairments, are the most formidable opponents for people with disabilities.

Both First Nations people and people with disabilities are often defined by “the other”. Examples include oppressive legalization such as the Indian Act which defined who, and who was not “Indian”. The Federal Departments of Health and Indian Affairs continue to wield sweeping power over First Nations communities and people with disabilities often interfering with their right to self determination. Mirrored experiences are reported by people with disabilities as they continue to be defined by and controlled by the medical community. Gatekeepers of publicly funded “benefit” programs, and in some cases, systems of classification, such as the DSM (Diagnostic and Statistical Manual of Psychiatric Disorders), continue to define, leveraging sweeping power over the lives of people with disabilities. Government defined programs and policies, based on these external forms of classification, often determine who receives support within a community and who does not.

Many First Nations people, particularly those with disabilities, define past government practices as latent and manifest attempts at racial and ableist genocide. The lasting effect of colonization, internalized colonization and the degree of lateral violence (violence directly laterally towards others directly within your family and/or culture) which exist within the First Nations populations are direct results of the legacy of the devastation of the effects of this systemic oppression. Members of the disability community report similar experiences with

direct and obvious attempts at genocide such as the eugenics movement and the forced sterilization of people with disabilities. (Shakespeare, 1999, 669-688)

Prior to and throughout the entire past century, both the First Nations and persons with disabilities have been subject to public, medical and religious “interventions” aimed at fixing “inherent flaws”. Whether it be to convert to a more “civilized” form of religion, which has been the case with First Nations spirituality, or to attempt to change or fix a person with a disability through medical rehabilitation or psychological and behavioral modification intervention techniques, all are forms and processes of human devaluation.

First Nations communities have experienced mass removal of children from their care through residential schools, child welfare agencies, and denial of access to community based services and supports. In many instances this has resulted in a loss of language and culture, and devaluation of the human spirit resulting in the formation of negative self identity. People with disabilities have also been denied access to their children and/or their right to become parents. They too experienced family disruption and exclusion from public spaces through ongoing processes of institutionalization and geographic segregation.

The colonization and decolonization processes provide a central frame of reference and analysis for the process of the project.

Rights-based analysis

Quinn and Degener (2002) in *Human Rights and Disability* note that,

A dramatic shift in perspective has taken place over the past two decades from an approach motivated by charity towards the disabled to one based

on rights. In essence, the human rights perspective on disability means viewing people with disability as subjects not objects. It entails moving away from viewing people with disabilities as problems towards viewing them as holders of rights. (p.2)

By definition, a rights based model involves addressing exclusion and discrimination of persons with disabilities through non-discrimination and equal opportunity legislation. In short, "it involves using formal laws to breakdown barriers into the mainstream." (Quinn and Degener, 2002, p.5)

The analytic tools used within this approach can include;

1. accessing and reviewing relevant legislation such as the Canadian Charter of Rights and Freedoms, and in some cases, the Canada Health Act, which guarantees equal access to services and supports for all Canadian residents, regardless of residency,
2. considering the use of laws and statutes to promote fair and equal treatment of oppressed groups in society,
3. addressing discrimination and exclusion through formal avenues such as policy and legislation, and
4. raising consciousness and promoting collective action through class action approaches.

A rights based approach can be used as a tool by persons with disabilities to gain access to equitable services and supports, and for First Nations to demand the right to sovereignty, to self government, and for full recognition of inherent treaty rights such as the right to education and health and social services.

The challenge of proceeding legally within a rights based approach to addressing discrimination and inequality, although in some situations may be the only course of action, is that it can be costly, can take a long period of time and can be very taxing on individuals and community organizations of people with disabilities and their allies.

The denial of the right to self determination and self government is still one of the most significant barriers impacting First Nations and people with disabilities in Canada. Within a social-political rights based model, processes and publicly funded supports and services are community based, culturally owned, culturally defined, and focus on the preservation of culture, language and way of life. A rights based model supports initiatives which are locally defined. One of the goals of a rights based analysis may be to invest the time and energy into ensuring that human rights for equality and non discrimination are grounded in laws and policies at the local, provincial and federal level. A rights based model can promote pride, honour, respect and facilitate positive self identity through individual and collective action. The guarantee of rights and freedoms are protected through ever evolving legislation, based on the self defined goals and needs. "Those of us who happen to have a disability are fed up with being treated by the society and our fellow citizens as if we were aliens from outer space. We are human beings with equal value, claiming equal rights." (Bengt Lindqvist in Quinn and Degener, 2002, p.13)

The integration of two world views of First Nations and persons with disabilities, can create powerful constructs to change, reshape and reform

society so that all persons can live with dignity, respect and a guarantee of human rights and freedoms with equality of opportunity for all.

Many have suggested that providing equitable service delivery for people with disabilities in First Nations communities may likely require a rights based legal strategy to mobilize any sort of significant change, or resolution of, the issues of the lack of community based resources in First Nations communities.

Access to disability related goods and services, educational opportunities, employment, housing and income supports are basic human rights to which everyone should be entitled to. The ***Canadian Charter of Rights and Freedoms*** and the ***Canadian Human Rights Code*** are the tools that protect and uphold these fundamental rights and should ensure non-discrimination and the provision of equal access to services, regardless of race, geography and disability. For First Nations persons with disabilities living in First Nations communities these rights are not being protected or upheld. It should be noted that applying a rights based approach within the context of Aboriginal issues requires consideration of the potential conflict between rights based tools. For example, the Indian Act in some situations may supersede or be in conflict with the Humans Rights Codes.

As Canadian and Manitoban governments, at every level, remain steadfastly deadlocked in denial of any fiscal responsibility, it may require a class action legal strategy to change existing situations. Ultimately it may take a Supreme Court decision to force governments to address the lack of resource for this population which is clearly rooted in ableist and racist systemic

discrimination. Some are calling for “status blind services”, meaning that the “status” of First Nation “status” should never be used to deny the right to equitable access to publically funded services or supports, which is the reality at this time in our collective history.

In summary, the theoretical tools used in this project include multi-level analysis based on a social model of disability, understanding the colonization of First Nations, and promotion of a strategy of decolonization throughout the process of this research. In addition this research has adopted a rights based approach to improving access to disability services and supports within First Nations communities.

Existing Literature

The literature on First Nations peoples with disabilities living in First Nations communities is sparse and focuses primarily on government commissioned reports outlining the lack of access to community based supports and services. Extensive literature reviews and journal searches reveal few published materials regarding the experiences with service provision from the perspective of First Nations people with disabilities.

This lack of written reference may be due to the following factors; first, the experiences of First Nations persons with disabilities have not been of great interest to past or current academic researchers. Historically, research has tended to originate from within a medicalized context, thus the thoughts, opinions and community based experiences of First Nations people with disabilities have

not been highlighted. Neither disability, nor First Nations related research has prioritized issues of First Nations disability. Issues of First Nations people with disabilities, particularly those living in First Nations communities, have been ignored.

Second, there seems to be reluctance and a lack of trust by First Nations towards academic researchers, which has resulted in a lack of information on this subject. Third, influences within Indigenous communities such as a lack of written references on disability may be due to the cultural norm of passing on and sharing information through oral traditions. Academic institutions, until recently have largely ignored and/or dismissed the cultural practice of oral traditions due to the prevalence of positivist, western dominated research methods. If it was not observed, written down and/or experienced such information was discounted as “inferior to”. Many people simply do not understand, or seem to want to understand the reality of conditions in First Nations communities, particularly for those with disabilities, who have not had a voice or space in many of the decision making processes which have affected, and continue to affect their lives on a daily basis.

First Nations Reports

There is a significant lack of information on the community based experiences of First Nations people with disabilities, however a limited number reports on First Nations persons with disabilities in Manitoba have emerged over the past decade. In 1996, Manitoba physiotherapist, Moni Fricke completed her

graduate work in medical rehabilitation on the experiences of First Nations people with disabilities in Manitoba. She notes, "Whether the responsibility for Aboriginal health care falls under federal jurisdiction for health is the source of much confusion and debate. Service delivery and availability for Aboriginal people with disabilities can differ markedly from that provided to other Canadians. (p.721)"

In addition, over the past 8 years the Assembly of Manitoba Chiefs released the following four documents on the subject of disability services and supports in First Nations communities:

- First Nations People with Disabilities; Dismantling the Roadblocks (1997),
- Mino Pimatisiwn Mikano (2005),
- Addressing Gaps in Services for on reserve First Nations People with Disabilities (2006), and
- First Nations, Provincial, Federal Joint Briefing Note on First Nations Disability Related Issues (2007).

The above listed reports outline issues affecting First Nations people with disabilities in First Nations communities in Manitoba. They conclude not only the significant prevalence of disability in First Nations communities, but the critical need for a comprehensive, community based service and support infrastructure for people with disabilities.

Although there is a significant lack of reference to First Nations experience with services and supports within this literature, one has to search for a deeper reflection of cultural beliefs in order to begin to understand the response to

community members who may experience disability. Fluent Cree speakers report there is no word in the Cree language for “disability”. Does this speak to the fact that differences or variations from normalcy are more accepted in Indigenous communities? Does this mean that there is less attention paid towards the differences of other people? Does it point to different ways that things are understood in different cultures? One bilingual participant (Cree and English) noted, “For disability some of the words in Cree are just literal translations with no negative or positive value. The word in our language for disability just describes something. In our culture we practice kindness, caring and sharing. You share your belongings. If the person is in need you can give him money to buy stuff. A lot of our people are very kind. When something happens everyone is there for support. They will give whatever they have.”

It is often said by First Nations people that persons with “differences” within the Aboriginal community hold special gifts and are here to teach us how to honor and respect all living things. Many First Nations families, organizations and communities foster belonging and as Anderson (2002) states in *A Recognition of Being, Reconstructing Native Womanhood*, “This book has grown out of my need to help the balance come home to our communities. It is about creating a vision of a society where every member has a place, a sense of value, a gift to bring (p.13).”

The literature on disability from the Indigenous community is often presented within a context of polarized diametrically opposing positions, presenting disability as an extreme sin or seeing a person with a disability as

gifted or sacred. In relation to Pacific (Native North American) people, as expressed within the following quote from a community elder, there are different views about disability which at times either complement or contradict each other.

For example, there is a view held by some Pacific people that Pacific parents who have a disabled child are cursed because (supposedly) they have sinned against God. However this contrasts with the opposite view of total acceptance of Pacific people with disabilities by their community. It is important to remember that the concept of disability not only varies between cultures, but within cultures as well." (Huakau, 2000, p. 25)

Indigenous value systems tend to focus on the collective, and value sharing and collaboration of resources and goods. Thinking styles tend to be holistic in nature with a focus on interdependence within the group. There is particular emphasis not to over-generalize or speak on someone else's behalf. For example, one will often hear First Nation elders make the following comments after answering your question, "this is only what I know for me", meaning that this is only my truth, and "you will have to speak to her/him about that if you want their opinion."

In Cree the word ***kakanatisichek*** means "the gifted ones, the special people". According to a traditional Cree woman disability is understood in a unique way within her culture,

There is no word in our language for disability, impairment or abnormality, but again this is only what I know for my community. The Creator put these people here for a purpose so that we will learn from them; they are our teachers. No one is considered abnormal in our culture. (J. Tait, personal communication, September 21st, 2004)

A traditional Oji-Cree woman suggests that, the word for disability on her language is a,

general term, never used to refer to another person. Rather the term is used to refer to a generalized condition needing acceptance, rather than needing further defining, classification or treatment. (J. Flett, personal communication, September 28th, 2004)

Rather than relying on the experiences of people with disabilities and their families, documentation, if presented from the perspective of “the other”, lacks authenticity. If presented from the perspective of “the other” assumptions about Indigenous cultures and Aboriginal practices must be deconstructed with knowledge of processes of colonization, internalized colonization, oppression and positions of power of both the researcher and those being observed or researched.

History and identity are inextricably linked. Recording history from the perspective of the First Nations person with a disability is a strategy towards decolonization. As representatives from the Indigenous community so eloquently state,

Part of the exercise (of decolonization) is about recovering our own stories of the past. This is inextricably bound to a recovery of our language and epistemological foundations. It is also about reconciling and reprioritization about what is really important about the past with what is important about the present. (Tuhiwai-Smith, 2002, p.390)

Much of the recent literature on this topic focuses on the lack of publicly funded services and supports for Aboriginal people with disabilities living on reserve. In First Nations communities, disability related services, are often still seen and if provided, are often seen within a medicalized context. This is particularly problematic in First Nations communities due to the jurisdictional offloading of all levels of government proposing that health care services are the responsibility of the “other” level of government. With regards to on reserve

disability related services for First Nations, Sinclair (2002), in the Royal Commission on Aboriginal people notes, “the services they (Aboriginal Canadians) do have are not community based or Aboriginal–controlled, and they have not been developed in consultation with Aboriginal people (p.140). The non community-based publicly funded services for First Nations people with disabilities are typically provided within a medical context outside of one’s community. Services tend to be assessment based and do not often translate into practical supports for daily living at the community level.

The majority of the First Nations and Inuit Health Branch budget (58 of 110 million dollar budget in 2004), is currently spent transporting people out of the community to provincially funded health services as opposed to supporting community based, community defined supports and services. (First Nations and Inuit Health Branch, (2004/05) annual report) Resources in areas of daily living continue to be lacking in First Nations communities due to the lack of specifically allocated government resources and the crippling poverty level and mass unemployment in First Nations communities. Issues such as systemic poverty continue to impact the quality of lives of most people with disabilities and First Nations people in Canada. Resources for supports in areas of environmental accommodation, training, employment, transportation, universal design and independent living are not provided as there is lack of clarity about who or which level of government should provide funding for the provision of such services.

In 1997, the Assembly of Manitoba Chiefs presented a report on First Nations people with disabilities. *Dismantling the Roadblocks* stated,

First Nations persons with disabilities are one of the groups most harshly affected by jurisdictional wrangling. Obviously, the problems encountered by First Nations person with disabilities cannot be completely solved until the service delivery chaos is finally resolved for all First Nations peoples. Nevertheless, because many of the services required by First Nations persons with disabilities to live independently fall under the umbrella of health and social services, they are particularly vulnerable to the uncertainties caused by governmental haggling. The fact that governments insist on clinging to rigid jurisdictional lines causes, on a daily basis, extreme hardships for person with disabilities. These hardships are genuine, urgent and in need of concrete action. First Nations persons with disabilities can no longer wait for politicians and bureaucrats to decide on how to resolve the jurisdictional problem, particularly when there is no sign in sight that a solution is even possible. Clearly, what is needed is a specific solution aimed at eliminating jurisdictional barriers in Canada, and resulting inequalities experience by First Nations persons with disabilities. (Demas, (1997), p.31)

In 1998 the Council on Canadians with Disabilities released *Access to the Sweet Grass Trail*, a report on Aboriginal Canadians with disabilities. In this report a First Nations person with a disability quoted the following experience;

I'm just starting to get to know my family and my reserve. I'm just starting to find my identity after all these years. I was taken away from my family at the age of six. They got my parents to sign some kind of form. I don't know what it was, but I remember seeing something in the way of a form that they had to sign and then I was taken away. That is all I remember. I was pushed into foster homes. I was in one for a couple of weeks, another for a couple of months, and then another for half a year and so on. I never had a real chance to go to school. I went to school but half of the time I didn't know what I was doing. It was all a big daze – going through this thing not knowing what was happening. Nobody told me anything. I just went along with everybody. (p. 34)

In March of 2001 the Assembly of Manitoba Chiefs and the Centre for Aboriginal Health Research conducted a survey with First Nations adults with disabilities living in Manitoba. This survey provided the initial glimpse of the estimated numbers of people with disabilities and helps us begin to understand some of the expressed needs of this population. This report, which is one of the

primary reasons for this project, suggested, "Studies are required to understand the social, cultural, economic and geographic context of disability in Manitoba First Nation communities" (Elias and Demas, 2001, p 38). As well the authors also state;

We also know very little about the actual delivery of disability related services to First Nations people with disability, either on or off reserve. More research is required to understand what, where, when, why and how services are provided in the home, workplace and the community. We also need to know what services are needed, but not provided. We also do not have a good grasp of all the transportation barriers that exist for First Nation people with disabilities (p. 39).

O'Brien in (2003) reports the experience of another family dealing with disability in a First Nations community in Manitoba.

Shirley Wood lives on Nelson House First Nation with her six children, including one who suffers from spina bifida, a debilitating birth defect. Wood said the Society for Manitobans with Disabilities, funded by the Province, told her she would have to move to Thompson if she wanted services for her son. "I like my community," Wood said, "Why should I have to leave home when other people don't have to leave where they live to get what they need?" Other families told similar stories (p. 4).

Families and individuals with disabilities who participated in the Assembly of Manitoba Chiefs Needs Assessment Survey (2001), cite lack of coordination of services to be one of their greatest challenges.

Since families with children with disabilities often require intervention from different and inter-related services and programs, assistance with case management would help coordinate needed services and provide much needed support to the family. Parents struggle to navigate the waters of the service delivery system that is often not user friendly or culturally appropriate. Furthermore respite care is non existent, placing a greater strain on family relationships. (Demas, Fontaine and Shackel, 2007)

Leaving a community means separation from family, as well as cultural and language loss. Connections to the community are also severed, sometimes

permanently. By choosing to remain in the community, parents of children with disabilities must let go of needed services, or limit their access to these services. There is much discussion and writing on the negative effects of the residential schools on First Nations. The negative impact on Aboriginal people of leaving a community on a long-term basis for health-related services (such as a school for the deaf)—away from family, home and culture—can be equated to that of the residential school experience. (Demas, Fontaine and Shackel, 2007)

Government Reports, Jurisdictional Analysis and Impacts on Service and Support Provision in First Nations Communities

Since the early 1980's, there have been numerous publicly funded reports written by every level of government touching on issues affecting First Nations people with disabilities living in First Nations communities. These reports all call attention to jurisdictional conflicts and offloading of responsibility by every level of government and for the need to provide funding for community based supports and services. The result of this jurisdictional wrangling of those who control delivery of publicly funded services has meant that First Nations people with disabilities who have remained in their home communities continue to live largely without a formal system of services and supports.

These reports speak to an acknowledgment of the problem, and a clear awareness by national, provincial, territorial and First Nations governments that this problem does exist. In these reports there is an absence of any concrete solutions to rectify this problem. Recommendations remain vague at best and little has been acted upon over the past 25 years.

Jurisdictional wrangling between levels of governments and departments, coupled with a lack of specific services and policies for First Nations communities, impedes children with disabilities from accessing similar services and programs at the community level. Services that are available to those with disabilities off reserve are not available on reserve, as the provincial government believes that First Nations are a federal responsibility. Accordingly, programs such as the Labour Market Agreement for Persons with Disabilities (LMAPD) is a cost shared agreement between both levels of government; in Manitoba, however, this program is not available to First Nations residing on reserve. Hearing assessments provided by the Society of Manitobans with Disabilities Inc. (SMD), are only available if the First Nations community is willing to pay for the assessment for the deaf child or adult. If the same child or adult were off reserve, SMD would provide the assessment.

(Fontaine, 2007)

Current and past bureaucrats and governments are aware of the many reports and subsequent recommendations however barriers towards implementation of change still exist.

The first government commissioned report on disability service and support provision in First Nations communities published by the Government of Canada (1981), called the *Obstacles Report*, states;

under the British North America Act, the Federal Government has direct responsibility for the affairs of Status Indians. In the matter of rehabilitation and vocational services for Status Indians who are disabled, however Ottawa has relied upon the Province to provide the necessary services. There have been considerable disagreements and legal debates regarding the jurisdiction of the Federal and Provincial Governments, and in the payment of services. As a result, the Status Indians have not received the services that they need. Two problems must therefore be solved, 1. the Status Indians must be assured of rehabilitation and vocational services, regardless of legal responsibility and 2. the ultimate responsibility and administration of these services should be decided by consulting all parties. (p.37)

It is clear that the authors of this report begin their analysis from a medical perspective outlining that supports for people with disabilities are largely situated

within the medical or vocational area. This neglects the importance of supports in areas of daily living which people with disabilities value and identify as critical for community inclusion.

Due to overwhelming concerns about issues raised in this report specific to Aboriginal Canadians with disabilities the Federal Government of Canada commissioned a second report dedicated completely to Aboriginal disability related issues. In this report the authors note;

First Nations is a sector which is frequently misunderstood by Non Native Canadians, and one which is isolated from many of the resources which disabled Canadians who are not Native, can utilize on a regular basis. (Obstacles Follow-up Report on Aboriginal Issues, 1984, p. 5)

Over the ensuing 2 decades numerous government reports repeatedly published virtually the same finding. The 1996 *Federal Scott Task Force on Disability*, and the 1997, *In Unison* report, which was a joint federal, provincial and territorial study continue to report a jurisdictional conflict and offloading, a lack of community based supports and services and the end result which is for Aboriginal people with disabilities to leave their community in order to access disability related supports and services.

The Province of Manitoba released their *Full Citizenship* report (2001) on disability related issues within Manitoba. Regarding the experiences of First Nations people with disabilities and service and support provision in First Nations communities this report acknowledges non existent or inferior disability support programs on reserve leading many families to leave their communities but does not take any responsibility for the Province of Manitoba's role in the lack of resolution of this issue. The issue of the lack of services and the need to leave

families community and culture, compares with the historic experiences of removal of First Nations children through the residential school system. The historic lack of acceptance of responsibility by Canadian governments could explain why there is such apathy and lack of concern about these issues within the general Canadian public.

In 2003, the Council of Canadians with Disabilities noted jurisdictional debates and recommended transfer of funding to First Nations,

“Aboriginals with disabilities are continually being caught in debates and battles over jurisdiction and responsibilities. Clearly Aboriginal people with disabilities are not able to access timely and appropriate services. Direct transfer of funding to First Nations for investment in disability related supports is critical.” (Council of Canadians with Disabilities, 2003, p.1)

The larger Canadian society remains largely unaware of the conditions affecting First Nations people with disabilities in First Nations communities. Individuals and families at the community level remain isolated with the majority of their energy spent surviving amidst great challenges and barriers. There are few, if any publicly funded organized efforts to highlight the current conditions and First Nations historically have not had opportunity to express a collective voice on these issues.

In June of 2007 a joint task force of First Nations, Provincial and Federal governments was established to provide key information on First Nations disability issues to the Manitoba Chiefs, the Provincial Interdepartmental Ministers and the Federal Cabinet Ministers. After considerable discussion in consultation, the tripartite working group decided on the following key points to include in the briefing note:

Legislation for delivery of health and support services on reserve does not exist. Existing policies and practices for on reserve service by Health Canada, Indian and Northern Affairs Canada (INAC), Manitoba Health and Manitoba Family Services and Housing are inconsistent and in conflict. Service gaps on reserve result from such ambiguities. (Intergovernmental Briefing Note, October 2007)

The final recommendations, as agreed upon by representatives of First Nations, Provincial and Federal governments are:

1. That governments (First Nations, Canada and Manitoba) seek the authorities to enter into a tripartite arrangement with First Nations for a **new single delivery service model** for individuals with disabilities, meeting needs first (see Appendix 6) and funding under First Nation management and control. Such a tripartite arrangement needs to be consistent with other First Nations/Canada/P/T processes underway in Manitoba.
2. That governments (First Nations, Canada, and Manitoba) develop mechanisms to incorporate the **Jordan's Principle** into their respective policies and practices to achieve a **normative standard of care** for services.

(Intergovernmental Briefing Note, October 2007)

According to the First Nations Child and Family CARING Society of Canada, Jordan's Principle refers to,

“a principle where a jurisdictional dispute arises between two levels of government (provincial/territorial or federal) or between two departments of the same government regarding the payment of services for a status Indian child which are otherwise available to other Canadian children, the government or ministry /department of first contact must pay for the services without delay or disruption.”

(accessed on January 26, 2008 from <http://www.fncfcs.com/jordansPrinciples/php>)

To date Jordan's Principle has not been adopted by any level of government and departmental offloading and jurisdictional disputes are frequent and ongoing.

Gaps in Literature

Gaps in the literature on the subject of First Nations persons with disabilities can be categorized in the following areas;

1. The neglect of First Nations voices in the literature. Most reports on this subject are written from the perspective of “the other”, typically by government and/or service professional driven processes, largely lacking direct evidence on the day to day experiences of people with disabilities. For example, most government commissioned reports are often authored and presented from the perspective of non First Nations; non disabled people, usually considered “experts” on the topic.

2. Within the existing literature there is little or no development of community based solutions or alternatives to existing models of service and supports that currently ignore this population. For example, what types of culturally and community based supports would enhance and compliment existing supports within First Nations communities? The existing literature lacks recommendations on First Nations service delivery models which would be successful in First Nations communities. Thus the problems and the limited solutions tend to be defined by government or government funded initiatives within existing services and support structures rather than from community identified ideas and representatives.

3. There is little analysis from a social model of disability which may include asking the following questions: How do First Nations promote inclusion?

Do experiences of strong extended family networks support community involvement and independent living?

4. There seems to be minimal to no recognition of culturally specific or unique responses to disability. As with other marginalized groups, issues are often presented and contextualized from the dominant Eurocentric perspective without appreciation for diversity of cultural perspective. For example, there is little regard for, or appreciation of existing First Nations and how First Nations are dealing positively with disability and impairment through humour, resilience and extended family and community based supports.

From the perspective of First Nations people with disabilities this research offers recommendations and solutions for local, provincial and federal governments which are practical in nature and defined by potential consumer of such supports and services.

In summary, a social model of disability, and a post colonial and rights based analysis provide the theoretical foundation for this study. The existing literature from both First Nation generated reports and reports from with existing Federal and Provincial governments cite both on going jurisdictional wrangling and offloading resulting in very little change in the situations for First Nation persons with disabilities. The gaps in the literature are many and this study has attempted to begin the process of addressing those gaps previously outlined in this chapter.

The next chapter will report on the processes and methodologies used and how these methods have been implemented within the context of this specific study.

Chapter 3 – Telling Their Stories – A Qualitative Approach

In this chapter, the guiding principles of the research methodology, the location or “position” of the researcher, along with a description of how the process and methodology was actually implemented for this specific research project will be presented.

Guiding principles

In order to answer the question, “What are the experiences of First Nations people with disabilities and their families in receiving services and supports in First Nations communities in Manitoba?”, the following three methodological approaches have been used as a foundation and guide. From the perspective of a rights based social model of disability, while understanding the colonization of First Nations, the methodological approaches used include participatory action research; Indigenous story telling; and research as a decolonization strategy. The methodological approaches will now be described in more detail.

Participatory Action Research (PAR)

Participatory action research is the primary methodological approach used for this project. Research, if designed and implemented without community and

consumer input and direction, can be disempowering and ultimately destructive to Indigenous and disability culture and way of life. Research framed by western paternalist constructs further contributes to the on-going effects of oppression of Indigenous peoples, particularly those with disabilities. The participants in this research project are the true experts. "If we believe people are able to think for themselves we need to talk in a real life way that reflects their individuality and experience" (McNiff, 2002, p.10).

Historically, research with First Nations people and persons with disabilities has been disempowering for First Nations individuals, families and communities. The research has been done "on" them (First Nations and persons with disabilities), with little appreciation of culture, worldview, perspectives, practices and way of life. Largely centered within a medical model, research with persons with disabilities has tended to focus on some aspect of rehabilitation, amelioration or management of sickness or cure of the disability.

In distinct contrast, participatory action research, a form of emancipatory research, focuses on the relationships that emerge throughout the process of conducting research. Equality between the researcher and the participants, the sharing of power, and the empowerment of the participants in the research are all important (and key objects of this specific project). (Herr and Anderson, 2005). Active and meaningful participation of those involved throughout the process of the research, including the participants, advisory committee members, community leaders and members of the community has been central to all aspects of this research.

“[A]ction research is inquiry that is done *by* or *with* insiders to an organization or community, but never *to* or *on* them... Action research is oriented to some action ...that organizational or community members...wish to take to address a particular problematic situation.” (Herr and Anderson, 2005: pp.3,4).

Key aspects used in this research methodology include:

1. valuing the opinion, beliefs and desires of peoples with disabilities;
2. ensuring the research has a positive impact for the community involved;
3. ensuring the key role of First Nations and people with disabilities within the research process;
4. sharing power with, and the maintenance of on going positive relationships based on respect and tolerance of diversity and difference;
5. on-going reflexivity of the position of the researcher; and
6. the ability of the research to challenge, change and influence power differentiation and revise marginalization and oppression.

Research is an on going process of building relationships and learning from one another. Research methodology must be well thought out, yet flexible enough to adapt to the changing agendas of the people and communities involved in the research. This means that over the course of the design and implementation of this project, strategies have had to shift and adapt to accommodate the needs and desires of the participants who consented to be involved in the research process. “I come to see action research not as a set of concrete steps but as a process of learning from experience, a dialectical interplay between practice, reflection and learning.” (McNiff, 2002, p.13)

Indigenous Story Telling

The second methodology used in this project can be described as Indigenous story telling. The use of oral histories and story telling is a well documented practice within First Nations Indigenous cultures. Through telling of their stories, and by defining and documenting their own history, First Nations people with disabilities and their families are participating in the documentation of the written record on the subject First Nations disability experiences. Interviews conducted for this project were guided by the participants' telling of their stories. Telling one's story, expressing one's feelings and having the opportunity to speak and be heard is a strongly valued expectation and individual right within First Nations culture. Elders use story telling as a primary method of teaching requiring the listener to develop sophisticated analytical aptitude and exceptional listening skills.

According to Tuhiwai-Smith (2002), "while non-indigenous research has been intent on documenting the demise and cultural assimilation of indigenous peoples, celebrating survival accentuates not so much our demise but the degree to which indigenous peoples and communities have successfully retained cultural and spiritual values and authenticity" (p.145) As Julie Crookshank (1990) in *Life Lived Like a Story*, illustrates this approach when collecting life stories of three Anishnabee elders.

Instead of working from the conventional formula in which an outside investigator initiates and controls the research, this model depends on collaboration between the interviewer and the interviewee. Such a model begins by taking seriously what people say about their lives rather than treating their words simply as an illustration of some other process" (p.1).

Atkinson (1993) suggests, "life stories can act as a counterbalance to other (often negative) accounts (of the experience of disability)." (p.9) Often these other accounts have focused on pathological differences, on deficits/defects or, through case records, have given a very limited view of people's lives. The life story or autobiography allows for a richer and more contextualized account of experiences. Williams also notes that "life stories act as a counterbalance in other directions too, tempering the professional orientation of normalization, for example and the victim approach of the well intentioned revelation of the worst aspects of institutional life." (Atkinson, 1993, p.10)

The use of collecting stories and documenting life narratives is an opportunity to achieve the stated goals of this project. Many studies of enquiry including Native Studies, Women's Studies, Disability Studies, Peace and Conflict Resolution Studies and Education studies recognize story telling as a very effective method of data collection with groups who have been oppressed. In Fitznor (2002), McLaren (1994) further acknowledges the transforming importance of storying,

The act of telling our stories, of speaking our narratives, inserts us as active agents in history. And not just any history but a history that matters, a history that is informed by critical practice. And knowing that history matters, we simultaneously open up a space for the telling and retelling of our stories in ways that no longer require us to ask permission to narrate the sensuous specificity of our lives (p.160)

Bishop (2002) also suggests that "the indigenous community becomes a story that is a collection of individual stories ever unfolding through the lives of people who share the life of that community." (p.145)

Research as a de-colonization/de-marginalization strategy

Research with marginalized groups can, and should be used as a tool or strategy towards decolonization. The intent of this research project is to investigate, write about and expose systems of oppression within existing public service frameworks and to examine subsequent impacts on the lives of indigenous peoples with disabilities and their families.

For decades little attention has been paid to the voices of disabled First Nations people and their relatives. Giving attention to their story, their testimony can be an opportunity for healing.

Indigenous testimonies are a way of talking about an extremely painful event. The formality of the testimony provides a structure within which events can be related and feelings expressed. The structure of the testimony itself is the sense of immediacy which appeals to many indigenous participants, particularly elders. While the listener may ask questions, testimonies structure the responses, silencing certain types of questions and formalizing others. (Tuhiwai-Smith,2002, p.144)

Tuhiwai-Smith (2002), in *Decolonizing Methodologies* describes 25 Indigenous research projects and categorized their impacts on a movement to promote “the survival of peoples, cultures and languages, the struggle to become self determining, and the need to take back control of our destinies.” Framed in this way research then can become an integral link and an important element of the process of de colonization and the struggle for self determination”(p. 142). “They showed us that our teachings today must include both a decolonizing (where we critique and stand up against colonialism) and Aboriginalizing/ Indigenizing of knowing and processes - rekindling and asserting our ways” (Fitznor, 2002, p.64).

Location/Position of Researcher within the Context of First Nations Disability

Acknowledging that power relationships shape feminist and social justice research. Feminist and social justice organizations are also embedded in relations of power and privilege so that it is necessary to always remain self-reflective about our own positioning in relations of power.

(Canadian Research Institute for the Advancement of Women, (CRIAOW), 2006, p.6)

An important aspect of any research partnership, particularly with any marginalized group, is to consider and reflect upon “position” in relation to power and privilege. This includes understanding historic position of power and privilege held by both the researcher, and those who are participating in the project. It is extremely important to reflect upon these issues in order to position the research process in a manner which contributes to the empowerment of the group participating in the research process.

Validating alternative world views and knowledge that have historically been marginalized; and understanding that varying groups of women (or any other marginalized group including First Nations person with disabilities) experience diverse histories that position them differently in hierarchical social relations of power and give rise to different social identities.

(Canadian Research Institute for the Advancement of Women, (CRIAOW), 2006, p.6)

As a non Aboriginal, non disabled male, who has never experienced poverty, to any degree, I must be self reflective about the perspective and approach with which I approach the issue of First Nations disability. I have been raised and socialized from a largely western, Eurocentric education system and have been taught through formal health, social service and education systems that the pervasive response to disability is that persons with disabilities are to be “rehabilitated”. These belief systems are situated within a medical model

approach to disability. How does this affect my assumptions about disability and what is an acceptable response to these issues of disability; particularly within a cross cultural context? Am I fully aware of the historical marginalization of First Nations and of persons with disabilities, and do I fully understand and appreciate the intergenerational implications of this oppression? How can I use my position of privilege as both a researcher and as a service provider to enhance the lives of First Nation persons with disabilities and their families? Finally what is my role within the context of research on this issue?

These are the questions that have been central to my process of realigning my “perspective and practice” towards disability and in better understanding my role as an ally within the First Nation disability issue.

An “ally” might be described as a person who is committed to fighting the oppression of a particular group of people; a group whom one does not readily identify as member of. Anne Bishop (2002), in *Becoming an Ally*, identifies six steps towards becoming an effective ally with oppressed groups. They are:

1. understanding oppression, how it is held in place and how it stamps patterns on the individual and institutions that continually create it,
2. understanding different oppressions, how they are similar, how they differ and how they reinforce one another,
3. consciousness and healing;
4. becoming a worker for your own liberation;
5. becoming an ally;
6. and maintaining hope.(p.22)

This process of self reflection and realignment of belief and perspective has taught me that, as an advocate or ally for others, the “real” change does not have to happen with the First Nations people or people with the disabilities,

rather with those around them, *including myself*. This lesson is the hardest to learn, yet the most important action we can all take if barriers to a full and inclusive society are to be removed.

As a researcher and service provider, with many opportunities to influence other people, I have realized the importance of becoming an effective ally for both the First Nations and disability communities. Rather than perpetuating the prevalent medical or charity model and hegemonic beliefs, which further accentuates power imbalances in society, the power that I do have can be used to promote a rights based social model of disability and the de-colonization of First Nations people in Manitoba. The position that I do occupy can be used, as others such as Anne Bishop state, to build relationships, to increase consciousness and promote healing, and to maintain the hope that community based services can and will improve in First Nations communities.

One of the most important roles I can play is to use this thesis as a tool to tell these important stories in order to draw attention to the injustice of this issue. Through this project, I can also promote the self representation and individual and collective advocacy now and in the future. All of these actions will ultimately contribute to validating alternative worldviews which may be different from my own and will better position First Nations persons with disabilities in the hierarchy of social relations in Canada. "Clearly we are attempting to reclaim and rekindle what was almost lost through a process that speaks to, "self – determination, decolonization and social justice." ((Smith, 1999, p.4) in Fitznor, 2002, p. 60). In the face of multiple levels of continued marginalization I can

persist with advancing this issue, which in turn can provide hope First Nations persons with disabilities and their families.

Finally, this project has encouraged active participation of First Nations people with disabilities and their families. As a First Nations colleague and disability positive advocate once advised me, "We as First Nations have always practiced inclusion long before it was identified as a "best practice" within non First Nations communities and culture." (J. Tait, personal communication, February 14, 2007)

The experiences and the process towards internalized self reflection has been, and continues to be, a tremendous learning opportunity for me as I journey towards understanding the true meaning of an ally. It is a process of being very conscious of the power within and between relationships at the individual, group, and institutional levels which eventually shapes the relationships and positions we all find ourselves within.

As Anne Bishop (2002) states,

Many allies still drive themselves too hard and try to do too much, but they do understand that they are part of something much larger than they are. They take responsibility for helping to solve problems of historical injustice without taking on individual guilt. Most look for what they can do, with others, in a strategic way, and to try to accept their limitation beyond that. (p. 110)

This journey I am on and my growth as an effective ally has only just begun. I will never be done understanding oppression, but am thankful for the opportunity and position that I am in. "Unlearning oppression is a never ending process, particularly for all of us in Western societies." (Bishop, 2002, p.115)

As I continue to study and reflect more upon the role of the ally, and how I define and position myself in relation to the issue of disability with a First Nation context, my responses to this issue shift. I have moved from feeling the need to be in front championing the cause and have taken on a different set of roles. They include organizing and arranging opportunities for self representation so that ideas and solutions come directly from the community. In addition, I now see one of my primary roles as needing to expose the pervasive dismissal of the voices of members of the First Nations disability community. In addition, I now spend much more time building linkages, coalitions and facilitating the development of support systems for persons with disabilities and their families.

As this shift occurred, the community has begun to see me, and even publicly define and recognize me using terms such as “freedom fighter” and “an effective ally.” Most recently, in January of 2008, I was presented with the “Honouring the Ally” award for “the most positive contribution as an ally to the field of Aboriginal education in Manitoba.” Once again this is proof of the need for, and appreciation of good, effective allies working with and for community.

The process of implementing the identified methodology will now follow.

Research Design and Process of Implementation of the Methodology

The purpose of this study has been to examine, within the broad theoretical frameworks of a social and rights based model, the experiences of First Nations people with disabilities and to collect the stories of their lives in First Nations communities in Manitoba. The intent is to document the availability of services at the community level, to determine the impacts on families of

impairment and to seek the direction and solutions from persons with disabilities and their families about what they would like put in place to make their lives more livable.

My initial hypotheses, based on the existing literature and my experience as a service provider in First Nations communities, include;

1. there are extremely limited services and supports in First Nations communities for people with disabilities and their families;
2. the voices of First Nations persons with disabilities and their families have been marginalized with little opportunity for self or collective representation or advocacy;
3. First Nations persons with disabilities demonstrate resilience in the face of multiple layers of oppression and marginalization;
4. families living in northern remote isolated communities have fewer services compared to those living in non isolated First Nations communities in the south, closer to urban centers;
5. the values and beliefs of inclusion, respect, generosity and belonging within First Nations ensure that there is a high level of community inclusion, and active participation, despite the apparent lack of services;
6. extended family support is the primary form of support for persons with disabilities and their families in First Nations in Manitoba; and;
7. all project participants and their families, with appropriate First Nations language translation and with the provision of alternate forms of

communication such as Braille, American Sign Language, would be able to express their realities and indicate the programs and services they would like put in place within their community.

In order to further investigate the above listed hypotheses, the following processes were implemented:

To begin, Chiefs and Councils from three First Nations communities were approached for their consent for their communities' involvement in the research project. All aspects of the project were explained in detail to community leaders, either in the form of initial face to face meetings, by telephone calls, or through presentations provided about the project and related issues. Ongoing communication occurred through emails and by faxing information to the various communities. All community leaders were given copies of the consent forms and the ethics application and approval from the University of Manitoba. Ongoing communication has occurred with community leadership throughout the project and will continue in the future. All three community leaders, and/or their representatives, immediately provided consent for their communities' participation in the research process. The three communities include one northern non-isolated community, one southern community and one remote isolated northern First Nation community only accessible by air or winter road (only open once the lakes freeze solid).

The point of entry to access project participants was through the local education system, therefore the next step of the process was to contact the local Resource Teachers from each of the three communities. At this time the

Education Directors, Principals and Resource Teachers from the participating communities were approached and the project was explained in detail in order to gain their support of the process. Again, full disclosure of the intent of the project was provided. All those who were approached gave their consent and have given their full support of and blessing for the project. The school staff, all members of professional disciplines, who were involved in identifying potential family members and in passing along information to the families all signed an oath of confidentiality to ensure the confidentiality of the families was protected.

Resource Teachers in the three communities then identified three families and approached these families to determine if they would like to participate with in the project. All of the families who agreed to participate have children/adult children with disabilities and had been, or are currently involved in the local Special Education/Student Support Programs within the school. The nine children/young adults with disabilities ranged in age from 6 to 23 years of age. At the time of the interviews, five of the nine students were attending their local school; one was attending school in Winnipeg, as his parents recently decided to move to access services and; one participant was 23 years old, but had attended her local school until graduation. Two of the nine students were school aged, but were not in school due the lack of disability related supports available within their school system at this time. Every parent/caregiver of the nine identified participants readily agreed to participate in this research project. Many more participants would have liked to participate in the project, however, in order to complete the selected methodology within one trip per community, only three

families from the three communities were selected for the project. The existing relationships between myself, the local resource teachers and the families were used to help explain the process and make families feel more comfortable sharing their stories.

Following the interviews with the parents, they were given the opportunity to provide consent to participate in an interview along with their child who has a disability. Of the nine families interviewed, all families gave their consent, however semi-structured meetings/visits were only possible with five children/young adults with disabilities. It was important to note that all of the families that I met with asked me to spend time with their children, even if verbal communication was not possible. Although a great deal of information was gathered through these observations and meetings with the children/young adults with disabilities, the majority of the information in this project has been gained from the stories and recommendations of the parents/caregivers of the children/young adults with the disability.

Complete interviews, as I had planned, were not possible with four of the children for a number of reasons. Firstly, three of the children/young adults with disabilities were non verbal. Alternative communication skills had not been developed by these persons, despite being enrolled in schools within their home community. This again speaks to the limited degree of alternative and specific programming available in First Nations. Another significant factor impeding any form of communication was for the deaf children. Both children with this type of disability were not able to communicate in any alternate form as opportunities to

learn American Sign Language have never been available to these children while living in First Nations communities. The children were six and eleven years old and had yet to learn any formal method of communication. They could not read, write, or communicate in alternative formats such as American Sign Language. This is one of the most important findings of this research and speaks to the diminished quality of life for First Nations children and adults with disabilities in Manitoba.

Families chose the location for the interviews. All interviews took place in their home communities, with the exception of one family's interviews which occurred in Winnipeg. Most of the interviews occurred in the homes of the families, however some participants felt more comfortable meeting at the local restaurant or at the local school. Most families felt that they could tell their stories at one sitting typically lasting from one to three hours in duration, During most sessions there were numerous immediate and extended family members present offering their ideas and perspectives as families shared their experiences. Some families used more than one sitting to tell their stories, while other asked me to come back and talk to different members of their family at different times.

Consistent with the social model the questions asked focused on discussing various aspects of community living and inclusion including transportation, employment, education, barrier reduction, participation in community events and access to programs supports and services which affect daily living. Consistent with participatory action research, families were asked

their opinion about what should be done with the recommendations and suggestions provided by the participants. Although an interview guide with sample questions was prepared, the interviews seemed to “take on a life of their own”, and uninterrupted story telling was encouraged in order to remain consistent with the story telling approach as the preferred method of data collection. Little prompting was needed as the stories and experiences were shared by the participants.

Following the completed collection of the stories, the transcribed stories were sent back to the families for their review, with the opportunity to note any changes or modifications to the documentation of their stories.

As is customary in many indigenous cultures, a small gift or token of appreciation was given to all families and participants of the project, thanking them for their contribution. In addition, all participants will be given a copy of the final thesis and will be involved in ongoing efforts to disseminate the findings to wider targeted audiences, including local, provincial and federal political governments and service organizations.

Throughout the process of implementing this methodology, a number of themes emerged. They include;

1. issues related to the researcher as advocate;
2. participant expectations for systemic change; and,
3. emotional trauma.

All three will now be discussed in greater detail.

Researcher as Advocate

First Nations families impacted by disabilities shared that they typically live in extreme poverty and are isolated even within their home communities. Due to the present lack of service unmet needs are great. Reciprocity and helping others is not only a part of First Nations culture, but is also an important aspect of building and maintaining any relationship. During the data collection phase I was placed in positions of advocate for and assistant to the families involved in the project. Although I found myself explaining the limitations of my involvement and clarifying the parameters of the project, the overwhelming needs of the families often resulted in the role of the researcher assuming the role of the advocate as well. I had to quickly realize that the most important aspect of the entire project was the collection and dissemination of these stories. During this process I found myself becoming overwhelmed, exhausted and feeling powerless in the midst of the alarming need that exists.

As the participants were sharing their time and ideas, I was grateful for their cooperation, therefore I felt obliged to provide help or assistance in various capacities. Such services ranged from providing rides, to sending information packages to providing information on alternative educational options for parents and their children. In one situation, I accompanied a mother to explore her educational options at a local college which was related to her ultimate goal to help support her son. In another situation I was asked to assist a family to cope with the emotional crisis of one of their other children.

With some families their involvement in this project was simply a continuation of a relationship, and for others it is the beginning of an ongoing relationship which may well continue as long as I am providing services for their local school system.

Expectations for Systemic Change

Following one of my first set of interviews in one of the Northern communities, I was about to board the airplane to fly home when I met the father of one of the families who consented to participate in the project. As I greeted him he turned to one of his friends from the community and introduced me to him. In English combined with Cree, his first language, he informed his friend that I was the guy who came “to help to get things in place for a better life for his son.” I gently smiled at him and silently hoped that through my introductions and my explanations of the project that he fully understood that, even though they participated in this project, things may not get better for his son. I wondered if I had created false hope within his family. I later called them to request that one of the local teachers meet with him and clarify that although the intent of the project is to advocate for change, this may not happen. The dissemination of the stories might have some influence, however it will be up to much larger factors outside the influence of this small project for systemic change to occur.

I believe that this story speaks to how strongly families impacted by disability want services and support at the local level. It also speaks to the need to ensure false hope is not created with families participating in such projects.

Some families even requested that I assist them to proceed legally so that their services and supports are put in place. The inability to provide thorough advocacy work for even the small number of families involved with this project was one of the most difficult and stressful aspects of the project.

The stress resulting from the hopelessness, frustration, anger and feeling powerless began to impact me as the interviews continued. In order to cope with the stress, I spent many hours debriefing with friends, colleagues, academic advisors and family members so as not to allow the feelings of despair to overwhelm me. In addition, as I do have access to forums at the provincial and federal levels, I was able to vent my frustrations at various regional and provincial forums, opportunities often not available for families.

Emotional Trauma

Most families with children with disabilities experience varying degrees of stress, guilt and emotional trauma. The guilt and trauma seem to be exacerbated for families living in First Nations communities.

During and shortly after the interviews with the project participants, a number of individuals (mostly mothers) indicated how emotionally draining their participation in the process had been. One mother noted that her feelings of guilt and of possibly “not doing enough to help my son” had re-surfaced through her participation in this project.

First Nations families impacted by disability often face the incredibly difficult decision of whether or not to move away from family and community, or

even relinquish guardianship of their children in order to access disability services and supports. The family who moved from their home community to access supports and services in Winnipeg reported feeling guilty for leaving their home and extended families. The families who stay in the community reported feeling guilty that their decision to remain in their community has denied their children of much needed supports and services. The history of the residential school systems and First Nation families make this situation increasingly complex, as many parents and grandparents are dealing with traumas they themselves endured when they were taken from their families and forced into a foreign education and child welfare system. All of the above factors make such decisions about your own children's needs more complex.

Participants expressed extreme frustration, anger and resentment towards members of their local governments, and both the Federal and Provincial governments for the denial of services and support in their communities. During the interviews, families reported that participating in the project seemed to bring up all of the angry feelings which people have had to find numerous ways to cope with. Some families noted that the experience of getting angry again was positive as they felt that this project might help to influence change. However, many indicated that they were not confident that anyone would take their recommendations seriously. Most feared for the future if supports were not put in place. "If the government does not listen I don't see a very hopeful future for my son. He will end up in the justice system and then the government will be spending a lot of money to house another criminal, meanwhile you could put a

mentor in place and he might not go into the criminal justice system.” (project participant)

In order to ethically respond to the families’ varying strong emotions, I ensured the following: First, I spent a considerable amount of time with families following the interviews validating their feelings and providing supportive empathetic responses. My background and experience in mental health counseling was tremendously beneficial. Second, I offered to make referrals to outside counseling and/or disability support programs located outside of their community, however no families requested this. In addition, for a number of families, I made follow up contact to ensure that families were all doing well following the process. The families contacted seemed to appreciate the follow up and concern. Most of all, the families wanted assurance that the information and recommendations they provided would be sent to all levels of government so that decision makers might make changes which would have positive impact on their lives.

To summarize, the process of making connections and building relationships with the families was not only difficult and painful for the families, but also for myself as the researcher. Although issues of anger, resentment and guilt persisted throughout the project, and complex expectations emerged, this provided opportunities for healing and expression of unresolved grief.

The data collection phase, using a qualitative approach and aspects of both participatory action research methods and Indigenous story telling has

started a process which will continue long beyond the duration of this specific project.

The next chapter will provide a rich description of the project participants and their families and will provide analysis of the data collected of the stories.

Chapter 4 – Project Participants

The first program participant was a 16 year young man who lives with his grandmother and has a pervasive developmental disorder. Due to his limited oral communication skills, he has a full time educational assistant at school to help him manage his daily routine. His grandmother reports that he loves to go to school and is very good with computers. He enjoys spending time with his family, listening to music and watching television. He likes “jigging” and very much enjoys being around his large extended family. His grandmother indicated that he would soon like to meet a young girl and when he is finished high school, she thinks he would like to work at a local place of business in his community.

The next two participants were brothers aged 12 and 14, both with a pervasive form of autism with global developmental delays. They live with their mother and younger brother. They are receiving special education support from their local school and can not wait to get to school in the morning. They are both non verbal and have excellent computer and technology skills. They are well liked within their school and are leaders in their life skills program. One brother loves to cook, while the other brother likes to look after animals. Their mom has aspirations of having a restaurant where her sons can work. She hopes that independent and supportive living options are available for them in their community when they are older.

The next participant was 7 years old, lives with her grandmother and has Fetal Alcohol Syndrome(FAS). Prior to her placement with her grandmother, this child had been in five homes before the age of four. Although she is funded for

full time support in her local school, she has only had sporadic attendance. Both the school and home have found that she is not able to cope in a high stimulus environment with other children around her. She has profound articulation challenges and is easily frustrated. She is full of energy and keeps her grandmother always on the go. She likes puzzles, does her school work in very quiet surroundings and has made great progress over the past year. She likes any and every sport and enjoys spending time playing sports with her cousins and other members of her extended family. Her grandmother reports being exhausted, as there is no respite available for her in her community. They are living far below the poverty line, as she has had to sell her local business in order to provide full time care for her.

The fourth participant was 6 years old. He lost his hearing when he was 2 years old and has had a difficult time since then. Although he has seen numerous specialists over the past 4 years, he has not had the opportunity to learn American Sign Language. He was in school last year full time and was funded for one on one assistance, but no one in the school or community could teach him or communicate with him in American Sign Language. He, like the other students in the project, loves his computer and also likes to watch TV. He hangs around with his two brothers, and likes to be with his family. His family recently moved away from their First Nation, so that he could attend a school with supports and services for deaf students.

The next participant was 23 years old. He is non verbal and has a combination of FAS and autism. He has lived with his adoptive family since birth

and has never left his remote isolated community. He attended the local school where an alternative program was developed for him. He struggled throughout his school years due to his difficulty with communication and he was often very easily frustrated. Sadly, since he has transitioned out of the school when he was 19 years old, he has been at home without opportunity for social interaction outside of the home or opportunity to develop independent life skills. This participant is a gifted artist and expresses himself through his art however has not had access to art supplies since he left high school. His mother reports that she does not have enough money to feed him properly. He would like more opportunity to be involved in his community. One day he would like to take a trip outside of his community to either Thompson or Winnipeg. His family lives without running water in a small overcrowded house and indicate that he would like more space and privacy.

The sixth participant was 21 years old and lived with his adoptive parents. He has had a long struggle achieving academic success, however he is still taking courses and working hard at school. He is very good at math and drafting, but says he still struggles with reading and writing. He is very close to his adoptive parents and siblings and would like to move to his own house some day. Over the past years, with the help of his adoptive parents, he has started his healing journey by reconnecting with his birth family and putting his life back in order. He says that he struggles with anger and has at times had difficulty with mental health issues. He would like to get a job in his community and likes to spent time with his many friends.

The next participant was born deaf and is now 11 years old. He lives with his mother and brother and sister and attends his local school. He has many gifts and talents and has spent a great deal of time with his grandfather learning the traditional ways of life. He has a wide range of bush survival skills and can hunt, fish and trap, which are all skills he learned from his grandfather. Unfortunately, he has never been given the opportunity to learn American Sign Language and neither has his mother. He does have a teaching assistant full time, but again no one in the school has skills in American Sign Language. His mother had to advocate for him to be able to attend the local school, but since he has attended, he has not been given the support he needs to keep up with his classmates. He can not communicate using American Sign Language and can not read or write or express himself in any language. He has a good sense of humor and has a number of good friends he "hangs around with". He likes watching TV and his mother has strong hopes that eventually Sign Language instruction will come to their community. She has been waiting 11 years for this, but has yet to see her dream come true. She knows her son is smart and is determined to keep him with his immediate and extended family in their community.

The eighth participant spent the first two years of his life in a hospital in Winnipeg. He is now 10 years old and has profound Cerebral Palsy and another rare genetic disorder, leaving him with profound mobility impairments and unable to communicate verbally. His mother reported that the Federal and Provincial governments continue to argue over who is responsible to pay for the medication

he requires to digest his food. This has left his mother with no option but to become an exotic dancer in order to pay for her son's medications. He lives in a very small house without running water with his mother and four siblings. His mother has to carry him up the hill to her mother's house in order to bath him. He does not have access to mobility aids and devises and is currently not in school.

The final participant was a 13 year old girl with cerebral palsy. She has profound mobility and cognitive impairments and lives with her extended family of 14 people in a house with 2 bedrooms and no running water. She attends school, but again there have been times of extended absences due to her school not being physically accessible. In addition, she has to travel by plane to access her numerous medical appointments outside of the community. She likes to use the computer the school purchased for her, which is now in her home. Her mother notes that the entire community is not wheelchair accessible, therefore much of the time she spends lying on the floor in her home. Her mother reports that she and the entire family are tired and they would like to see much needed physiotherapy services provided in her home and in other community settings, such as the school. Her mother would also like to see an alternative communication system developed for her daughter.

Three of the nine children/adult children reside with their biological families, three live with adoptive parents and three live with their biological grandparents. Five of the nine families reported living in houses without running

water, and five reported living in extremely small overcrowded houses in multiple family settings.

The three communities involved in this project all have locally controlled education systems. All three communities have developed Special Education programs in their schools with Resource Teachers and Education Assistants and have completed a locally developed special education plan. All of the communities have their own local Child and Family Services organizations and have operating nursing stations or local health centers. Home care was at differing stages of development in all three communities. Other than one small supportive living program for three young adults with disabilities, and the local special education program located in the school, I found no evidence of any disability specific service or program in any of the three communities.

The following chapter will present the stories shared by the families listed above. This chapter will also include analysis of the stories, including what needs to be in place to enhance the quality of lives for the project participants.

Chapter 5 – Analysis of the Stories

The analysis of the data collected through the story telling process will now be shared. The presentation of the stories will contribute to addressing gaps in the existing literature, as outlined in an earlier chapter, including the neglect of First Nations voices in the literature and the absence of a set of consumer based recommendations for the provision of a continuum of support and services within First Nations communities. Participants in this project provided information and shared experiences and insights in three distinct areas. They include first, providing information about what disability related supports and services exist in their communities; second, giving commentary about the subsequent consequences for persons with disabilities and their families, and; finally, participants shared recommendations about what families need in place to make their lives more livable.

What services and supports do First Nations persons with disabilities and their families have in place?

From the social model of disability, and the inclusion and participation in all aspects of family and community life, families were asked what types of disability related supports and services were currently available in their communities. The immediate response from all participating families was in every case “nothing, nothing at all.” One family reported, “Many times we asked for that support, but it was not around. The only thing we knew to do was to ask our parents. We had no supports, just family. There is family support, but no funded service.” (project participant). Another participant reported, “There are

no supports. I asked the health authority and they said they do not have any money. That is what they always say. For the past seven years since he finished school he has just been sitting at home with no activities and no one to help out.”

The situation in southern First Nations seems to be equally bleak, one mother noting, “There is really nothing for disability kids to do out here other than school. In the city there are lots of services and out here there is nothing. It makes me angry because the kids with disabilities can’t get the help they need out here.”

After some reflection, some families reported that disability related services had been established within their education system. Five of the nine families reported some degree of satisfaction with the disability related services offered through their local education system. Some examples of support from the local education system included the availability of teaching assistants, some of whom were family members, and the provision of computers for children with disabilities. Some families indicated that the Resource Teacher was very helpful to children with disabilities and their families. “We have good schooling for disability here and the T.A’s are good here.” (project participant)

Other families however reported extreme dissatisfaction with the local education system, as the specific types of support for their children have never been available within the school system. “Since he was four years old, people said he does not belong in this school. I think he deserves to be there. There is no one in the school who can sign fluently. A number of years ago, they put all

the special need kids in one class. This was not good.” (project participant) One reason for the dissatisfaction with the education system could be the lack of awareness of the types of support for specific children with specific impairments such as hearing and visual impairments, First Nations schools have never had access to consultants in the areas of sensory impairments as all other schools throughout the province of Manitoba do.

These kids are getting T.A's, but they don't know any sign language. The Resource Teacher can not even communicate with my daughter. My daughter was funded, but nothing happened in school. We would like American Sign Language classes offered at the community level. We would like a specialist to come and develop curriculum for the deaf students. If there is a TA who works with a deaf child then they should have the necessary training so a proper curriculum could be set up.
(project participant)

Most families indicated that they had repeatedly asked for assistance from health, community services and housing departments, with no success or response. Many families indicated that their Chiefs and Councils were very much aware of their needs, but for reasons they did not understand, community leaders did not seem able to provide any type of support to the families.

I live in a house with 5 children with no running water. There is only one room and we do not have a bathroom. I have to carry my son up 2 steps to get in. We also do not have any plumbing. I have to take my son to my mom's house for a bath and have to lift him up. He is over 80 pounds now and I am not much more than that myself. I have nothing at all in place. I have tried to get housing. I have 5 children and one with a disability. When I tried to advocate for myself at the band office I was told that if I kept calling I would be put at the bottom of the waiting list. I have been told that if I can not look after my kids with what I have, they will phone Child and Family Services on me.
(project participant)

One issue frequently reported was the great need for, and the lack of access to community based respite services, particularly for families with high needs children. Although all families indicated that this was one of their most pressing needs, only extended family members were available to provide respite. During their sharing, another participant noted;

I am a single mom with three disability kids. I have always done it by myself and there is nothing for them out in our reserve. I get tired and need respite really bad. I just need a break sometimes.

Another mother commented,

My son is non stop and rarely sleeps. My family gives me 2 hours of respite and if this was not in place I would lose him. My little boy is hyper and can only sleep about four hours at a time. This has affected my health because we have no services. I have to take him everywhere with me and I never get a break.

Although most of the participants in this project had children under the age of 18, one common concern expressed by most of the families was their worry about the future in the absence of any type of adult community based support system for their family members with disability.

Most all child and family support services in First Nations communities are provided within the context of mandated child protection services. First Nations child welfare agencies are often called upon to deal with all child and family services issues far beyond those situations when a child is at risk of neglect or abuse. This has resulted in the development of very tenuous relationships between child welfare agencies and families of children with disabilities. Many families assert that their children are not in need of protection and having to open a child protection file in order to access disability related services is unfair and

unjust. Families do not want to have to approach a mandated agency in order to receive services like respite, home support or therapeutic services for their children. Families feel judged by child and family services workers and they are scared that they will lose guardianship of their children. Ample evidence was provided by the families as they shared their stories. Some examples of the testimonies of the parent/guardians show the degree of distrust and anger towards child and family service organizations in their communities;

The only way I can get respite is if I put my kids in care with CFS. If I had to put my kids with CFS it would destroy our family. It would rip us apart. I don't believe in CFS and that is why I will never use them. This CFS is ridiculous. Down here you have to give up your kids just to get them help. And that is the way it is out here. It terrorizes families.
(project participant)

When my family is sick I have to ask for respite. CFS asked me if I needed it from them but do not want it from them. I will use it from the care home but not from them. You know I have some grandchildren who were raised by CFS. Those kids do not listen now. My grandchildren who were raised by CFS are always in and out of jail. All of a sudden CFS opened a file. I did not want this file opened. They said they wanted to make sure he was in a good home. He is in a good home.
(project participant)

In addition, the families who adopted children with disabilities also expressed anger and resentment toward former and existing child welfare agencies regarding some of the past practices and the subsequent impacts on their lives.

Before Child and Family Services places children in adoptive or foster homes they should tell the families about the background of the children and what disabilities they might have. This did not happen to us.
(project participant)

I never knew where my son came from or where his mom or dad are from. They just sent me the papers. They told me he is the way he is. I heard his mom was drinking when she had him. The Child and Family Service

agency has never done anything since we adopted him. They have done nothing.

(project participant)

The systemic impacts of poverty such as living in overcrowded houses without running water seem to exaggerate the hardships experienced by persons with disabilities and their families. One family from a First Nation reported that they did not have enough money for food for their son and yet another states, "I can not go to work because I can not leave him anywhere alone. I have gone from being a business owner to a welfare recipient. I am way below the poverty line. I can not go to work because I do not have childcare." Another family from the north said, "I do not have the funding to get the equipment that she needs. She goes without it and it does not make me feel good."

The families involved with this project noted the economic impacts of disability on their families. Along with the systemic poverty at the community level, the high cost of living, especially in the northern isolated communities, the majority of families who participated in this project are living on social assistance, far below the poverty level. Of the nine families interviewed, seven reported that the primary caregivers in the household are unemployed. The primary reason for being unemployed was the need to be at home to provide care for their children in the absence of any form of programming at the community level. Four caregivers reported they had quit full time jobs or businesses in order to provide care for their children with disabilities.

In the absence of formal services families reported the additional financial burden on their families as they are often forced to purchase services, equipment and supplies from their already limited incomes.

Financially, it is a big burden. We have to go out for medical appointments. Because my wife had to quit her job, a good stable job, this impacted us. We have to pay for all of the material on our own even for the school. We had to pay for DVD's, computers and sign language materials. Because we live in a fly in community, we could not just drive out we have to fly and that is an enormous cost. It made dealing with the disability that much harder.

(project participant)

The extra costs of having to purchase disability related services, aids, devices and supplies has led some families to exceptional acts of sacrifice.

It has been hard getting him the things he needs like his food and pampers. His medication is not covered and that is why I had to become an exotic dancer. I became an exotic dancer to cover the things he needs. I also traded paintings to get the things he needs. I had to leave him at night. I can not think of what should be in place for parent of kids like this. I never put myself first. I always have to just focus on what my son needs.

(project participant)

Renowned Lakota psychologist and spiritual leader Dr. Martin Brokenleg, asserts that along with mastery and independence, belonging and generosity are two of the four components necessary for the healthy growth and development of all individuals in society. (Van Bockern, S., Brendtro, L., and Brokenleg, M., (2000) When commenting about what supports are in place, families repeatedly commented on the degree of support and generosity within their immediate and extended families. This is often one of the central reason families choose to

remain in their community and is how families continue to cope and support their children.

In our culture we practice kindness, caring and sharing. You share your belongings. If the person is in need you can give him money to buy stuff. A lot of our people are very kind. When something happens everyone is there for support. They will give whatever they have.
(project participant)

While I am living on the reserve I have a lot more access to family support. Although the services may be better in the city, a quiet rural setting is better for him.
(project participant)

The support for my grandson will always come from our family.
(project participant)

It is clear for many participants that family is everything and that connectedness with extended family members is central to their decision to remain in their home communities. It is within their communities that they often report feeling safe, nurtured and “connected” to others, which they describe as central to their well being and well being of their children.

It is a unique situation living in a First Nations community where you can bring up your child in your own home. Families do not want to move to the city. In the long run the family unit disintegrates. It is breaking up families. They know the extended family is not there when they get to the outside.
(project participant)

They said we should send him out to that school (the Manitoba School for the Deaf). We have been there twice. It is hard to send your child into the outside by himself especially when he has a medical problem. He belongs with his people, his family. We will lose him if he is over there. He belongs in his community. I want him here. When my dad was sick he said “do not sent him out. Let him stay here and learn the traditional way of our people. Do not let him go to the city or he will get killed”.
(project participant)

Throughout my visits with families it is apparent that the 7 First Nations teachings of respect, love, honesty, humility, generosity, kindness and courage along with their spirituality provide First Nations people with guidance and direction in relation to their experiences with disability. One project participant stated, "There are the seven teachings you can learn and this applies to disability. Some of the medicine people themselves have a disability. My kids are my teachers and they can be the ones to teach the others." During her sharing another participant noted,

There are teachings that these are special children and are a gift to the community. He is a chance for the community to learn how to deal with a difficult situation. Our Elders say that a child with a disability has gifts in other areas. My son is a peer tutor. He is a leader. With his disability he leads the other children. He is a gift and that is part of the paradigm shift.
(program participant)

Another participant stated, "Every child is a gift from the Creator. I have always tried to seek that spiritual help from my dad. You need to show respect and warmth to that person and you can not look down on him."

The next portion of this chapter will share reflections from the families about the consequences of the above noted situations in First Nations in Manitoba.

Consequences of the existing service and support system for children and families

The results of the existing support systems in First Nations often leave families impacted by impairment with three options. They include:

1. to stay in the community and live without the necessary services often resulting in poorer quality of life, isolation and deterioration of health;

2. to leave the community and live away from community and extended supports which results in further social isolation, loneliness and isolation; or;
3. involuntarily placing your child in the care of a child welfare agency hoping that services will be provided by the mandated agency of care.

The existing immediate and extended family support and cultural and linguistic ties results in First Nation families wanting to remain in their home communities. All nine families felt that the preferred option for service is the establishment of a community based system of support and service to compliment or enhance the existing support within their families. This is particularly important for persons with disabilities whose first language is not English, but a First Nations language. The one family who relocated to Winnipeg plans to return home as soon as possible. They indicate,

Well, it is easier back home than in the city. I don't like my kids running on the streets there is just too much danger. But we need to be here because there are lots more services. If services do not come to our community the next family will have the same struggles as us. If I had my choice I would rather stay up North. Home is home. That will always be my home. Once I have received what I have come for, I will move back and hopefully by the time we move back, I hope services will be in place.
(program participant)

Although immediate and extended family support is strong, caregivers are angry and emotionally and physically exhausted. In frustration, one father notes, "We are very frustrated, hopeless and obviously sad as parents. You are looking out for the best interests of your child and your hands are tied. You don't even know where to go to get help." Another mother says in frustration, "Our leaders, Chief and Council, INAC (Indian and Northern Affairs Canada) and the education

system should all get a copy of this report. It will pull our parents together and show them that we are burning out around here and something needs to be done.” When asked what could be said to government, another mother responded, “All of those political assholes that are just sitting up there doing nothing anyway.”

The long term effects of the on going stress and frustration are resulting in the deterioration of the health and well being of individuals and families in First Nations communities. This will result in increased costs for public health care, child welfare and the criminal justice system in dealing with the increased involvement with child welfare and drug and alcohol addiction services and treating the physical complications of stress and caregiver burnout.

From a social model of disability, active participation, inclusion and accessibility are all important aspects of life for person with disabilities. A disappointing finding is that despite cultural teaching about inclusion and the importance of belonging in First Nations communities, participants repeatedly report how inaccessible First Nation communities are for people with disability. In addition, participants report that people with disabilities in their communities are very isolated. One participant stated,

There are no wheelchair ramps at the band office or church. Aren't these the two places people should get together with the disabled? Why isn't there a wheelchair access there? These are the two most important places in our community. I do not see people with disabilities around in our community.

Another project participant reported, “In our community we do not give people with disabilities jobs. We need to open the doors and give them the

opportunity. The organizations and businesses need to take them in for four hours a day to explore the jobs. You can not even get into the band office if you are in wheelchair. They do not have any accessibility.”

The non-visibility, lack of inclusion and decrease in community participation of community members with disabilities in First Nations communities may be due to a number of factors. Firstly, the lack of community-based supports does not promote community participation of persons with disabilities in First Nations. Secondly, many participants commented on how inaccessible community spaces such as band halls, band offices and churches are in their communities. Thirdly, many families note the number of persons with disabilities and their families who have had to move off of the reserve, thus community members have simply moved away from the First Nations community. Fourthly, participants noted that community roads are non accessible. Many suspect that there are more people with disabilities in their community, isolated in their own homes, particularly those who are older whose mobility may be restricted. A one project participant states, “We have very bad roads. If you are in a wheelchair you can not go very far.”

The lack of support and services for adults with developmental impairments was another theme outlined by the participants.

My son needs things right here in the community. He needs things to do in the day and some things for his artwork. He needs someone to take him out in the community and someone to take him to the city. He has never been out of our community in his life. Something has to be in place for his future right here in the community. We are getting older and will not be here forever.

(project participant)

Lastly, one observable and unfortunate consequence of the lack of service in First Nation's communities is the conflict which arises when individual, families and existing organizations and services providers seek answers and solutions when trying to determine who is responsible for providing disability related services in First Nations communities. Families blame local governments as well as local programs and agencies. First Nations blame outside governments. The Federal government blames the Provincial government and the Provincial governments blame both the Federal government and local authorities. At a time when individuals, families and organizations should concentrate on building collective approaches towards resolution of the issues, such on going unresolved conflict only perpetuates the isolation and continued marginalization of First Nations peoples with disabilities.

The solutions and recommendations about what would make their lives more livable as outlined by the participants of the project will now be shared.

What do First Nations persons with disabilities need to have in place to make their lives more livable?

The most frequent recommendation from all families who participated in the project was the need to develop community based disability related services and supports. Ranked in order according to the number of times recommended by different participants, the following supports are needed at the community level:

First, universal design accommodations such as elevators in schools, visual alarms for people with hearing impairments and adaptations for the

physical environment, such as ramps and washroom lifts, in home and public places was the most frequent suggestion. Second, families requested adult supports services, such as supported/ independent living services including supportive employment programs for adults with developmental disabilities.

Next, families asked that respite services be available for all families who have children with disabilities. A number of parents suggested the need for a centre in their community for persons with disabilities and their families.

We need a place where we can go, like a centre. We need the funding to do that. In the centre would be places for all of the senses, for the blind person, for the deaf person with sign language classes, and rooms for the physically disabled, maybe even a pool for them. In this centre we need a place for families to get together and maybe just talk.
(project participant)

Families also suggested enhanced supports within the education system, such as specialized training for TA's, tutors and the provision of deaf educators. Many families noted that technical aids, equipment and devices are not available to them in their community and need to be. Some families requested that a disability worker be hired for their community, to both enhance awareness of disability related issues and to support families at the local level.

Other families suggested that their community should develop a form of accessible transportation. Still others would like to see access to community therapy services, including physiotherapy, speech and language therapists and occupational therapists.

Some families identified the need for opportunities for peer support for both PWD and for family members. The Independent Living Resource Centers

(ILRC), already operating in Manitoba, may well serve as a model of development to meet the identified needs of the families.

The parents of the deaf children identified the critical need for community based American Sign Language training and for a deaf consultant to come to their community. The parents of the children with FAS noted the need for FAS mentorship programs.

Resoundingly, the families suggested that these services be offered in their community, but separate from and outside of the mandate of Child Welfare/Child Protection agencies. Of the nine families interviewed, only one family had current involvement with child and family services. Many families talked about a negative history with child and family services such as when CFS had approached them. Families noted they would not voluntarily seek out the support of child protection agencies at any time. Some families reported that at times the threat of CFS had been used against them as they advocated for their needs and the needs of their children. In summary, families contend that access to disability service and support should not be considered as a child protection issue and that the distinction between the two areas be clearly understood within First Nations communities.

Further analysis of the data reveals that services and support recommendations seem to be consistent with those from a social model of disability. Although a relatively small number of families did request community based therapy services, the vast majority of suggestions for support and service focused on services needed to enhance the participation, access and inclusion

for persons with disabilities in all aspects of daily living. This finding has tremendous significance for existing agencies, service organizations and local, provincial and federal government departments. As groups proceed to consider funding community based services, they must be aware of the historic response to disability which has originated from within a western medical model approach. Families do not want more medical services, rather they want a system of social supports such as independent living, access to aids and devices, and support which will facilitate access to greater participation both inside and outside of their communities.

One example of a service from a social model could be a tripartite agreement between all three levels of government to create a community centre for person with disabilities and their families, which could include a wide range of services as requested by families impacted by disability. If governments proceed to focus only on a “professionally driven, rehabilitation based model”, services will not meet the needs of the families who told their stories for this project.

The next chapter will provide final comments and reflections about the research question and the initial hypotheses set out for this project.

Chapter 6 – Final Reflections

In this section, the initial hypotheses will be revisited, including unexpected results. Final recommendations from participants will be shared regarding their advice to decision makers and the dissemination of the data. New questions related to the topic will be posed.

Asking the question, What are the experiences of First Nations persons with disabilities and their families?, a number of hypotheses seem to be proven true. First, families did report that, with the exception of some school based programs and one small isolated community based program, there is a remarkable lack of services and supports in First Nations communities for persons with disabilities and their families. In addition, the voices of First Nations persons with disabilities and their families have been marginalized and the families have had little opportunity for self or collective representation or advocacy. First Nations persons with disabilities do demonstrate resilience in the face of multiple layers of oppression and marginalization and the fact that they are continuing to survive in the face of such difficulties is a testament to this resiliency. As one mother noted, “I have three special needs kids and I have been involved with the school ever since they have been going. It has always been a good relationship. I see disability kids as very smart. They are smarter than you and me in certain ways, you know. I am the only support I have. I just do it myself.”

Based on my knowledge of First Nations, I suspected that extended family support would be the primary form of support for persons with disabilities and

their families in First Nations in Manitoba, which has been echoed by all of the project participants.

Prior to meeting with families, I suspected that families living in remote and isolated communities would have fewer services than those living in non isolated southern First Nations communities located close to urban centers. Much to my surprise, despite the location of the First Nation (either northern or southern), and the degree of remoteness from urban settings, families reported that services and support are no more accessible in First Nations communities located close to Winnipeg than the community located in the northern isolated First Nations in Manitoba. The lack of services seems to be due more to jurisdictional divisions and to poverty rather than to location or to remoteness of the First Nation community. Resulting from maintained jurisdictional disputes, the services stop at the “reserve line” and it is First Nation residency which impacts access to service more than isolation and remoteness of the community. Services provided in Manitoba are not in fact “status blind”, meaning that services are denied based on residency in a First Nations community. Having First Nation status and residence in a First Nations community are the factors which markedly affect one’s ability to access services and support.

I also anticipated that due to the values and beliefs within First Nations, there would be a high degree of community inclusion, despite the apparent lack of services. Unfortunately, the reports from families reveal that persons with disabilities are not included in many aspects of life within their community and in fact all families reported that persons with disabilities are very isolated within their

communities. One participant noted, "I do not see people with disabilities in the community. They are very isolated in our community because there are no supports for them." Another participant stated, "I do not see anyone like my grandson in the community at work or anything." In frustration another mother said,

I have a daughter with a severe disability, but there is nothing being done but what is in place in school. I would like to get things started. We talk and then there is no action. People with disabilities do not have housing, equipment or anything. There are just no services that would meet our standards.

In the planning phase of the project, I had anticipated that with appropriate First Nations language translation and with the provision of alternate forms of communication such as Braille or American Sign Language, that all project participants (persons with disabilities aged 6 years- 23), and their parents/caregivers would be able to express their ideas and fully participate in the data collection phase of the project. Much to my disappointment, only one of the persons with disabilities was able to fully express his perspectives and interests on this subject. Due to lack of developed program services and supports, the remaining children/young adults with disabilities were not able to fully communicate, even in alternative format, to provide their own perspective. This again is symptomatic of the current reality of persons with disabilities in First Nations communities.

Participating families provided a number of recommendations for the changes which need to occur. Two themes emerge with resounding frequency. First, families feel that decision makers and the general public are not aware of

their current reality living with a disability in a First Nations community. They are tired, frustrated and angry, and often feel hopeless. They believe that awareness of disability related issues starts at the local level. Many families commented that decision makers and leaders at the local level are so busy with the other community issues that disability is just not a priority. Families are aware of the lack of funding provided for First Nation communities to address these issues, but also feel that local leaders must take a more active role in advocating for change. Instead of blaming families, local leaders and department heads in First Nations communities must listen and actively support the families currently caring for children with disabilities.

Participants feel that at the local, provincial and federal level the needs of children and adults with disabilities have never been a priority for policy makers and program developers. They feel “lip service” is paid to their requests and they are very frustrated in their attempts to access the services of provincial and federal government programs. Typically they give up and settle with what can be done themselves and their extended family members.

Throughout the process, families have made numerous offers for both provincial, and federal government representatives to come to their homes and communities and experience their reality and barriers they face on a regular and on going basis. Many families felt that decision makers would better understand their needs if they would come to their communities and experience aspects of their daily life.

The parents' desire for broader understanding is illustrated in the following quotes,

I don't think the government will ever put things in place. The government does not have to live with these kids. May be 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)

I do not think the people in Winnipeg would be able to walk a mile in my shoes. If they did they would probably take them right off and give them back to me.

(project participant)

I do not think people really know about this. They need to be in my shoes and experience it first hand.

(project participant)

There should not be a difference between what is available (for on and off reserve residents) because we are all equal. People need to learn how to share what they have. We should all be as one. We want everything we need and we are entitled to this. We want equipment and workers willing to come in and help out. Why is it that they don't come and experience our lifestyle and what we have to deal with? How would you like it if I gave you my daughter to look after in our community? What would you do with her? Do they understand the meaning of my child's disability? Are they just sitting there making the show look good? The funding is there and the services should be available to our children.

(project participant)

Second, when asked about the dissemination of the recommendations, project participants suggested that copies of this document be shared with program participants, existing disability programs and services in Manitoba, local

governments and First Nation programs of health, education and child and family services, and provincial and federal government departments. “They (the recommendations) should go to parents, Directors in First Nations, to Indian and Northern Affairs Canada, First Nation and Inuit Health Branch, the department of Justice and to provincial levels disability services.” (project participant). The dissemination of the recommendations will be done in accordance to the wishes of the project participants and through existing First Nations service organizations such as the Assembly of Manitoba Chiefs and the Manitoba First Nations Education Resource Centre. In addition, I anticipate that the collection and dissemination of the stories will result in multiple venues for families to advocate for change at regional, provincial and national levels. Families would also like First Nation leadership and organizations to facilitate changes at the local level.

From this project further areas of enquiry have emerged. They include:

1. How do First Nations, provincial and federal governments and organizations understand issues impacting First Nation persons with disabilities?
2. What are the long term impacts of the current reality in First Nations on the health and wellness of persons with disabilities and their families?
3. What are the experiences of First Nations persons with disabilities and their families in other provinces in Canada as compared to those in Manitoba?

4. Are the experiences of Indigenous persons with disabilities in Canada similar to the experiences of Indigenous persons with disabilities in other countries?
5. What are the experiences of persons with disabilities and their families who live in First Nation communities compared to those who live with similar impairments in non First Nations communities in comparable geographic locations in Manitoba?
6. Finally, what are the experiences of First Nations persons with disabilities in accessing services and supports when residing in non First Nations communities in Manitoba?

As is readily apparent, many of the initial hypotheses of the project were proven correct. However, a number of findings were not anticipated. The participants recommended that their reality be appreciated and fully understood and that their suggestions for improvements be forwarded to all three levels of government.

Chapter 7- Conclusion

This project posed the question: What are the experiences of First Nations persons with disabilities in accessing services and supports within First Nations communities in Manitoba? Theoretical frameworks and the methodology were formed from a rights based, social model of disability, paying particular attention to the historical aspects of colonization of First Nations people. Qualitative analysis used methods of participatory action research and the story telling approach consistent with First Nations oral traditions and practices.

Participating families played a key role in not only determining the process of telling their story, but in identifying a dissemination strategy so that community members and leaders better understand their concerns and on going struggles. In addition to sharing their experiences in accessing services and supports, the families provided a detailed picture of the consequences resulting from the lack of supports, as well as a clear and concise blueprint for decision makers to move forward to provide supports from a social model of disability within First Nations communities in Manitoba. Families want to be heard and want greater understanding from other Manitobans and Canadians, particularly those in positions within First Nations, Provincial and Federal governments.

The caregivers of children and young adults with disabilities in First Nations communities are exhausted and shared that the lack of support within their communities has resulted in drastic effects and impacts on their health and on the health and well being of their family members. The children and the young adults continue to live in isolation, even within their home First Nations

communities. Some children are not able to communicate with others as opportunities to learn alternative methods of communication such as American Sign Language are still not available to them. Some of the young adults with disabilities who have finished school in their communities are at home with little to do day after day. Many of the children and young adults, and their parents, continue to be very isolated from others who are going through similar experiences. The impacts of poverty magnify the barriers and struggles faced daily and as one mother commented, “my son has never been out of our community, we just can not afford it.” Still other families continue to have to leave their communities, some temporarily, others permanently in order to access necessary services or supports, and report feeling the deep disconnect and isolation of being away from extended family members and culturally and linguistically relevant supports within their home communities. Since collecting these stories some individuals report that their families have “fallen apart” and their children have once again been placed in the care of a child welfare agency. This adds additional stress and deteriorates their children’s attachment to their natural families.

How has this experience changed me? What are the next steps for me as an ally and for the participants in their project? For myself, I continue to feel stronger and more confident in my role as an ally. I see increased opportunities to influence or change the Canadian landscape both politically and in the area of services and support provision. I find myself more motivated with the frequent praise and support from both the disability and First Nations communities. The

newly labeled “freedom fighter ally” and my recent First Nations education “Ally” award feeds my soul and lifts my spirit.

Most recently the organization I work for has agreed to sponsor a gathering in Winnipeg for the participants of this project and other children and young adults with disabilities, and their parents from First Nations communities in Manitoba. This gathering will take place on March 27, and 28, 2008 in Winnipeg, Manitoba. At this event the families will come together to share their stories, to build supports and to express their frustration with existing conditions in their communities.

For some participants this will be the first time they have left their First Nations community. They will share their hopes and dreams for their future and will provide recommendations for policy and program change for all three levels of government. First Nations leadership, and Federal and Provincial governments have been invited to attend; not to present, but to sit in the back of the gathering and listen and learn. This will be the first time for many to share their experiences and their strong feelings with all three levels of government and to connect with other families going through similar experiences. This event will also provide the opportunity for participants to tell their stories to the broader community through the members of the media who have also been invited to attend this gathering.

In conclusion, I am confident that the outcomes of this gathering will be many and that through our continued collective efforts, this situation will change.

Meaningful services and supports will eventually become a reality so that lives of the participants will truly become more livable.

Taking direction from one of the participants, we all must continue until justice is achieved. As she so eloquently and bravely states,

“I will do it. I keep on going with my kids, because that is just a mother’s love. I do not know where I would be without my kids. That is all I have is my kids.” (program participant)

All we all have for our collective future is the children.

Appendix 1 – Summary of Community Based Disability Supports and Services as defined by program participants

Global Community Based Supports:

- Improve accessibility to public spaces
- Provide a targeted fund for improving universal design for community housing
- Establish Locally run First Nations Disability Resource Centers
- Improve transportation and recreation for persons with disabilities at the community level
- Develop a community defined disability strategy for community participation and inclusion

0-18 Population:

- Continue with Special Education funding –expand to include 0-5 population
- Provide more technical supports, ASL(American Sign Language, Orientation and Mobility, Communication devises, Technology, and mobile therapy teams)
- Create access to centers, with recreation and cultural activities fully accessible for citizens with disabilities

Adult Population:

- Provide Independent Living Supports
- Provide Supportive Living Options for adults with Intellectual disabilities
- Establish an adolescent/adult mentorship programming for community members with FASD
- Provide employment opportunities with support for people with disabilities

Supports for Families:

- Provide a respite program with well trained staff
- Promote information exchange and training at the community level for parents and other caregivers
- Create a place to go for families of children with disabilities
- Provide education and awareness about disability related issues at the family and community levels

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