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Intellectual Disability and Aboriginal People:

An Overview of Current Practise and Process in Institutionalization

by

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Submitted in partial fulfilment of the requirements for the degree of Master of Education

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Abstract

Currently in Manitoba, Aboriginal people with intellectual disabilities are more highly represented in institutional placements than they are in community based services. At a time when citizens with intellectual disabilities are demanding to be included as full participants in society, it appears that the institutional experience continues to be the norm for people who are Aboriginal. The purpose of this thesis is to determine the reason for this. Qualitative research was the method of inquiry used in this study. Interviews were conducted with people from federal and provincial governments, community service agencies. Aboriginal service agencies, advocacy groups, and perhaps most importantly, people with intellectual disabilities and their families. These participants identified several themes that help to explain why Aboriginal people with intellectual disabilities have been institutionalized. These themes include: a lack of services in reserve communities, a lack of clear legislation and policy about which branch of government is responsible, and consequently a lack of funding from which to draw. Issues such as poverty, racism, and a history of off-reserve service provision further compound the problems. Even in off-reserve communities Aboriginal people are not highly involved in community based services. In spite of the array of difficulties that exist participants also identified several reasons for optimism.

ACKNOWLEDGMENTS

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Chapter 1: Defining the Problem

In this study I examine the institutional experience of people who are Aboriginal and have an intellectual disability. I interviewed a number of participants who were asked to address the key questions of the study: namely, what is the experience of people who are Aboriginal and have intellectual disabilities and why do these individuals seems to be over-represented in institutional settings. Currently, in Manitoba, Aboriginal individuals are more highly represented in the provinces large, hospital-like settings than in community agencies or services. A source in one institution estimates that between 20% and 25% of the centre's population is Aboriginal. This is quite high in light of the fact that Aboriginal people comprise only 10% of Manitoba's population.

At a time when many advocates are demanding that citizens with intellectual disabilities take their rightful place as full participants in society, it appears that the institutional experience continues to be the norm for people who are Aboriginal. There are a variety of reasons for this, ranging from the concrete problems of access to services in remote communities, to the more subtle systemic issues of poverty, racism, and jurisdictional responsibility.

There are two components to this study. On the one hand I explore the possible reasons for high rates of institutionalization of people who are Aboriginal and have intellectual disabilities. This was done through the use of key informant interviews, where people with professional expertise were asked to give their perspective. On the other hand I have attempted to make this the story of individuals. Through interviews with Aboriginal people who have intellectual disabilities or their families, there was an opportunity to understand the struggles and problems that led to institutionalization. Data

were collected from both people in key decision making roles and those who live with the resulting policies and decisions.

It was difficult through out this study to determine how much of my personal interpretation should be included and how much the data should be allowed to speak for itself. At times it was tempting to look at the information and impose a personal perspective or adopt a particular theoretical viewpoint. Authors with personal perspectives on issues such as colonization, marginalization, or oppression would no doubt have recognized threads of these issues in the words of participants. However, this is an initial study in this area and I felt it was important to give a voice to the struggles of families and the opinions of people who have thought about this issue. I wanted to reflect on the actual words and thoughts of participants.

My desire to explore this topic comes from three main sources. The first has to do with where I live. For the past six and a half years I have lived in an area where many of my neighbours are Aboriginal people. This has lead to an increased awareness of the issues that Aboriginal people face. I think I have become more attuned to news items, reports, issue statements, and social commentary that relate to Aboriginal people because of this closer proximity. I am developing a growing understanding of the historical and current injustice that many Aboriginal people experience.

I also teach in the Developmental Services Worker program at Red River College. This program prepares students to work as care-givers for individuals with intellectual disabilities in school, work, and home settings. For the past few years we have had Aboriginal women as students. They began asking questions about how services were provided to Aboriginal people with intellectual disabilities. They indicated that they saw

many Aboriginal people receiving services in institutional settings but very few in the community agencies they visited.

The comments of these students corroborated my own work experience. For about twelve years I worked in community-based services for people with intellectual disabilities. During this time I worked in both residential and day programs and was a member of several committees and coalitions that reviewed issues relevant to people with intellectual disabilities. In all of these contexts I can recall only two individuals out of perhaps three hundred and fifty people with intellectual disabilities who were of Aboriginal background. All of these factors have lead to a growing interest in finding out more about the experience of people who are Aboriginal and have an intellectual disability.

Defining Key Terms

To begin, it is important to identify who is being referred to as 'Aboriginal' and what is meant by 'intellectual disability'. In defining 'Aboriginal', Frideres (1998) points out that there is a "plethora of terms now used in identifying the original inhabitants of North America and that these are not 'universally accepted' - either by the indigenous population or the non-indigenous peoples" (p. 21). In Canada, many non-Aboriginal people are currently quite confused about terminology, aware that using the term 'Indian' is not quite acceptable but not knowing what to substitute. While Aboriginal people may refer to one another with humour and affection, as 'Indian' this is a way of reclaiming terminology that has often been used in an oppressive way.

The Royal Commission on Aboriginal Peoples uses the term Aboriginal to refer to "the indigenous inhabitants of Canada . . . to Inuit and to First Nations and Metis people" (Vol. 1, Terminology, XV). For this study, it is this group of people who will be referred

to as Aboriginal. Within each of these groups there is the possibility of further delineation.

For example, First Nations people may be Registered (Status) or Non-Registered (Non-

Status) which means that they either are or are not "on the 'roll' in Ottawa" (Frideres,

1998, p. 26). Being on the roll typically means that individuals are descendants of people

who were registered with the federal government after the Indian Act of 1876. Status

individuals are usually connected with a particular band or reserve community. In 1997

there were 95,113 registered or status individuals, and 61 reserve communities in

Manitoba (Government of Canada, Department of Indian and Northern Affairs). Some

people may prefer to be recogized by the names of the original nations or tribal groups.

Others may describe themselves as coming from a particular band and others identify with

a particular reserve. Often members of one nation were divided when the bands or reserve

communities were formed. (Internet, 1995, First Nation Confederacy of Cultural

Education Centres.)

Definitions become increasingly complex because a term such as Aboriginal is

open to various interpretations. For example, Status Indians can either have Band

membership or not, Band members can be either Treaty or Non-Treaty, depending on

whether or not their forefathers signed a treaty. Both Treaty and Non-Treaty people may

live on or off the reserve, and so on. The complicating factor is that each of the possible

combinations may indicate a different kind of relationship with the federal government.

The nomenclature often defines a legal relationship with related obligations and benefits.

For this study, it is important to determine funding and responsibility patterns for people

who have intellectual disabilities and are Aboriginal.

The definition above is useful and sufficient for this study. However, with this

definition, problems may exist in trying to determine specifically how many Aboriginal

people are in institutions. Records that have been kept may not describe all Aboriginal

people. For example, Metis and Non-Status individuals may be very hard to find in

records or documentation. Attempts will be made to apply a definition that is as inclusive

as possible.

Defining 'intellectual disability' is also a complicated process. Over the years

people with intellectual disabilities have been referred to in a variety of ways. Historically,

terms such as 'imbecile', 'idiot', and 'feeble-minded' (Wolfensberger, 1975, p. 3) have

been used, and in their time may not have had the stigma that they currently carry.

Presently there appear to be a variety of terms that could be used, including: mental

disability, intellectual impairment, intellectual disability, mental handicap, and so on. Each

of these terms may have slightly different meanings depending on the context and

experience of the user. The term 'mental retardation' is defined by the American

Association On Mental Retardation (AAMR) as:

> ... substantial limitations in present functioning. It is characterized by significant
>
> subaverage intellectual functioning, existing concurrently with related limitations in
>
> two or more of the following applicable adaptive skill areas: communication, self-
>
> care, home living, social skills, community use, self-direction, health and safety,
>
> functional academics, leisure, and work. Mental retardation manifests before age
>
> 18. (9th Edition, 1992, p. 5)

The AAMR goes on to broaden its perspective by saying that in addition to this

description of a condition that resides within the individual, there is also a social aspect to

understanding disability. Authors describe an initial phase of services that focused on

"institutionalization and segregation" (p. 135). This period began with the first North American institution in 1848 (Wolfensberger, 1975, p. 26). Though institutions still exist, the AAMR goes on to characterize the following period from 1976 - 1986, as a time of "deinstitutionalization and community development," leading to a present new era of "community membership" (Mental Retardation, 1992, p. 135). Intellectual disability must be understood from a social perspective because often it is the lack of social acceptance that contributes to the disabling quality of intellectual disability.

I am reluctant to use the term mental retardation because members of People First, a self-advocacy organization for people with intellectual disabilities, have frequently stated that they find it offensive and demeaning (Lovett, 1996, p. 33; Dybwad & Bersani, 1996). Consequently, I will be using the term intellectual disability. In instances where study participants use the term 'mental retardation' I will reflect their usage. The Roeher Institute, which is the research branch of the Canadian Association for Community Living, has used the term intellectual disability since 1992 (conversation with Roslyn Ward, September 1999).

Both Aboriginal people and people with intellectual disabilities have been labelled in ways that have had powerfully negative effects on their lives. Lovett, (1996), points out that "Liberation movements justifiably pay attention to terminology because language is not just empty symbolism" (p. 33). Those struggling for liberation know that present terminology is laden with a history of abused power, political manipulation, oppression, and efforts to maintain a status of inferiority (Wolfensberger, 1992; Dybwad & Bersani, 1996). Terminology has contributed to the devaluation of both people who are Aboriginal and people who are intellectually disabled. The terminology I have chosen is intended to

relay both respect, and recognition of the struggle for equality.

<u>The Institution and the Residential School</u>

Of particular interest to me is the experience of institutionalization for Aboriginal people with intellectual disabilities. For many non-aboriginal people with intellectual disabilities the experience of institutionalization has been life defining. The challenges and hardships of life within the institution, the efforts for deinstitutionalization, and finally the ongoing struggles for rights, status, power, equality and inclusion within the community have all had the effect of making the institution an ominous reality in their lives (Dybwad & Bersani, 1996; Scheerenberger, 1987, pp. 241-248). It is important to understand the experience of institutionalization for Aboriginal people with intellectual disabilities so that their voices can be heard as well.

While little has been written about the institutional experience of Aboriginal people with intellectual disabilities, there is a wealth of information about the residential school experience for Aboriginal people. Perley (1993) describes the residential school as an instrument for European 'colonization' of North American Aboriginal people and identifies the following as qualities of residential schools: (a) geographical separation of schools and communities from which students came, (b) the 'colonized' were not consulted in the planning process, (c) parents performed no role in the determination of educational content, (d) the language utilized in schools was that of the 'colonizer', and (e) the culture of the 'colonized' was negatively evaluated (p. 121).

There are many similarities between the residential school and the institution. Goffman (1961), in his examination of the nature of all institutional settings, defines a total institution, "as a place of residence and work where a large number of like-situated

individuals, cut off from the wider society for an appreciable period of time, together lead

an enclosed, formally administered round of life" (Introduction). This description is

echoed in the following reference to residential schools. "Residential schools were almost

all built in the country, far from White settlements. Contact between Aboriginal children

and their parents was minimized. The schools were highly regimented and insisted on

strict conformity" (Royal Commission on Aboriginal Peoples, p. 151).

Likewise institutions for people with intellectual disabilities are described by

Wolfensberger as places where, "the retarded were congregated into huge groups,

sequestrated from society, segregated from other retarded persons of the opposite sex,

asexualized, and dehumanized" (1975, p. 62). He goes on to say that the institutions

were: poorly supported, inhumanely run, and highly regimented. Both residential schools

and institutions for people with intellectual disabilities have left behind a legacy of abuse as

well as residents who feel ill prepared to face life outside of the institution (York, 1990;

Wolfensberger, 1975).

It is interesting to note that in the last century there were even suggestions that the

link between conditions for people who are Aboriginal and people with a intellectual

disability be even greater. Wolfensberger, (1975) illustrates this in the following, "The

extreme in segregation was advocated by Barr who proposed the establishment of one or

more national institutions or reservations (Barr, 1897; 1988; 1902; Dunlap, 1899) similar

to the management of another large deviant group in America, viz., the Indians" (p. 43).

There are indeed many similarities in the response society has made to people with

intellectual disabilities and people who are Aboriginal. One key difference, however, is

that while as a society we accept the harmful effects of the residential school, (Mennonite

Central Committee, 1992; Government of Canada, Statement of Reconciliation, 1998) we continue to support the institution as an appropriate placement for people with mental disabilities.

Aboriginal individuals who were placed in institutions for the intellectually disabled would no doubt have experienced the same things that other residents report however their loneliness, loss, and separation would have been compounded by a loss of culture and language. O'Connor (1993) also points out that at the point where two cultures meet there are increased opportunities for stereotypical attitudes and negative connotations (Racino, Walker, O'Connor & Taylor). So in addition to the stresses of institutionalization Aboriginal people with intellectual disabilities may also have had an additional burden of racial prejudice. As Traustadottir, Lutfiyya and Shoultz observe, "members of racial minority groups with disabilities experience a double dose of discrimination" (1994, p. 415, in Hayden & Abery). It is the experience of Aboriginal people living in institutions for people with intellectual disabilities that will be explored in this study.

Chapter 2: A Review of the Literature

In doing a literature review I hoped to discover published information on the institutional experience of Aboriginal people who have intellectual disabilities. This specific information proved very difficult to come by. Using terms such as "Native," "Native American," "Aboriginal," "Indian," "First Nations," coupled in various permutations with "intellectual disability," "intellectual impairment," "mental disability," "mental retardation," "mental handicap," and "institutional" I was unable to get a single response. I searched the ERIC, PsychLit, and Sociofile databases and again was unable to find any articles. On three or four occasions in 1997, 1998, 1999, and 2000 I did Internet searches of the same terms and again there were no responses. At one point I physically paged through seven years (1992 - 1999) of nineteen different disability or Aboriginal education journals. These are in Appendix A. In doing this I found five distantly related articles having primarily to do with teaching different ethnic groups or with cultural bias in testing. One article was called, "Communication Versus compliance: African-American parents' involvement in special education". Another was titled, "Professional Services in a Cree Native Community". While articles such as these may shed some light on the topic, there was no information related directly to the institutional experience of Aboriginal people with intellectual disabilities.

The Native American Research and Training Centre has published a series of monographs related to disability, but these focus primarily on physical disabilities and/or perspectives on the nature of disability. They provide, for example, the definition of unwellness in Hopi communities. Traditional Hopi beliefs say that disabilities (though there is no specific word for disability) can be caused by both natural and unnatural

unwellness, that the description of the disability serves as a name for the handicap, and that disabilities are only considered to be handicapping when they render an individual unable to contribute to his or her society (n.d., Locust).

When I broadened the search to include PsycINFO, Dissertation Abstracts Online, Ageline, and Sociological Abstracts and extended the search period back to the mid-sixties, I found six articles that seemed somewhat relevant in that they dealt with the experience of Aboriginal people with disabilities. Only one dealt with an institutional experience. Interestingly, this article was written in 1985 and is titled, "A study of institutionalized mentally retarded patients in Manitoba: Over-representation by Canadian Indian children." These authors concluded that while Aboriginal children made up 6.8% of the Manitoba population of people aged 0 - 19, they formed 18% of the population in the institutional settings. The authors further concluded that this over-representation by Aboriginal children was not "due to an increased propensity of Indian families to institutionalize their children," but that "Indian children were primarily over-represented in the groups with acquired retardation" (Evans, Hunter, Thompson, Ramsey, 1985, p. 163). This one article, which is somewhat limited in that it deals only with statistical and diagnostic issues, was the only directly related article I could find on this topic.

I was able to find some information on programs that have been implemented on reserve communities in the United States. Titles such as "Early Intervention in Rural Northern Arizona," "Pueblo Infant Parent Education Project," or "A Path to Peace of Mind: Providing Exemplary Services to Navajo Children with Intellectual disabilities and Their Families" reflect an American trend to provide support to children with disabilities and their families in reserve communities. These articles are relevant in terms of clarifying

alternatives to institutionalization however, they do not shed light on the institutional experience of people who are Aboriginal.

On the Internet I was able to access a number of web-sites that provided general information on disability issues for people who are Aboriginal. A key web-site that linked many of these sites was developed by the National Aboriginal Network on Disability (http:www.schoolnet.ca/aboriginal/disable). I found articles such as 'Completing the Circle: A report on Aboriginal people with disabilities', or 'Facing a Life of Barriers: Aboriginal people with disabilities'. These provided Canadian information including, statistics on disabilities, and current trends for addressing disability issues. In some instances the sites have been established by provincial organizations comprised of Aboriginal people with disabilities. Examples of these oganizations are the Saskatchewan First Nations Network on Disabilities and the BC Aboriginal Network on Disability Society. These sites are effective in providing a forum for Aboriginal people with disabilities to describe their issues, learn about developments in other parts of the country, become familiar with federal government initiatives and access information about various conferences.

There are a few source documents referred to on several of the web-sites indicated above. These include the 1991 Canadian Census, which provides key statistical information. Likewise the Royal Commission on Aboriginal Peoples which published their findings in 1996 provides a thorough overview of present circumstances for Aboriginal people. Prior to this, a major publication on disability issues called Obstacles (1981) was presented by the federal government through the Special Committee on the Disabled and the Handicapped.

Drawing from these sources, various sites say that 31% of Aboriginal people have a disability. This rate of disability is almost twice that of the remaining population in Canada at 16.8% (Facing a Life of Barriers . . . p. 1). These sources also indicate that at present things are not going well for Aboriginal people with disabilities. Everett Soop, in the Saskatchewan Indian, (April, 1988) says that "to be handicapped and to be Native means to be doubly pitted against the whole Canadian Establishment" (Removing Barriers: An Action Plan for Aboriginal . . . p. 1). Others affirm that though attempts have been made to further define issues faced by Aboriginal people who have disabilities fundamental problems continue:

> "System-wide problems within government bureaucracies, together with the harsh
>
> realities of poverty, unemployment, social and geographical isolation and
>
> inadequate living conditions, continue to contribute to the high incidence of
>
> disability amongst Aboriginal people. As well, these same factors make organizing
>
> and obtaining adequate services and programs more difficult." (Completing the
>
> Circle, The Current Situation, p. 1)

A recent Manitoba study by Moika Frike, (April 1999), entitled "First Nations People with Disabilities: An analysis of service delivery in Manitoba," confirms that within this province there is a huge discrepancy between service access and delivery for First Nations people with disabilities and other Manitobans with disabilities. Likewise, Bluechardt, Durst, Morin, & Rezansoff, in studying the situation of Aboriginal people in Saskatchewan, found that "persons with disabilities usually left their reserves in order to access health and social services" (p. 109). These authors describe individuals as being subject to 'triple jeopardy' because they are Aboriginal, they have a disability, and they are

off reserve or urban.

While there is information available about people who are Aboriginal and have

disabilities, it tends to by fairly broad in scope. I could not find information that focused

specifically on individuals with intellectual disabilities and their experience with

institutional settings. I feel confident in saying that there is no readily accessible, published

information on the institutional experience of people who are Aboriginal and have

intellectual disabilities.   This study will make a contribution to this specific area.

Chapter 3: Using Qualitative Research

<u>Choosing the Design of the Study</u>

In doing this study, I was faced with a choice to two primary research

methodologies, namely quantitative research or qualitative research. In quantitative

research, the student begins with an hypothesis and sets out to prove or disprove it using a

control group and a research group. Data are expressed in numerical scores, and analyzed

based on comparisons between study and control groups, there is an attempt to control

and limit extraneous variables, findings are expressed in a statistical summary of results,

and there is a willingness to manipulate aspects, situations, or conditions in studying

complex phenomena (Fraenkel & Wallen, 1996). I feel all of these quantitative

methodologies seem inappropriate in the study of a topic such as the experience of people

who are Aboriginal and have intellectual disabilities.

Qualitative research is appropriate in situations where "the whole phenomenon

under study is understood as a complex system that is more than the sum of its parts"

(Fraenkel and Wallen, 1996, p. 444). There are several characteristics of this study that

make qualitative research an appropriate method for exploration. For example, this is a

topic that requires an holistic perspective and there are potentially a variety of interrelated

perspectives and factors affecting this issue. The experience of Aboriginal people who

have intellectual disabilities has elements of culture, history, politics, wealth and poverty,

race, disability, employment, institutionalization, and resource development. It is by no

means a simple topic to address.

Qualitative research is also characterized by inductive analysis and design

flexibility. Inductive analysis means that the researcher becomes immersed in the data and

tries to gain an understanding of the "categories, dimensions, and interrelationships" (Fraenkel & Wallen, 1996, p. 444) that become evident after some thought and evaluation. The researcher begins with genuinely open questions rather than having an hypothesis that must be proved or disproved. The responses to the questions form the primary body of data used by the researcher.

Design flexibility means that decisions about how the study will proceed are made throughout the duration of the study (Bogdan & Biklen, 1992). In qualitative research there is an assumption that change is constant and ongoing whether the focus is on an individual or an entire culture. It also allows for attention to process; "Qualitative researchers are concerned with process rather than simply with outcomes or products" (Bogdan & Biklen, 1992, p. 31). For a new area of study such as this, it is important to be responsive and able to change in light of new information. Both design flexibility and inductive analysis are appropriate for a topic such as this.

Qualitative research is also characterized by context sensitivity and naturalistic inquiry. Researchers are asked to look at the real world as it unfolds naturally. It places the data or findings in a "social, historical, and temporal context" (Patton, 1990, pp. 40 - 41). The complexity of the issue of people with intellectual disabilities who are Aboriginal, requires a research methodology that embraces the richness of individual experience, the uniqueness of cultural realities, the relevance of social values, and the pressure of historical dictates. Qualitative research was very appropriate for this study.

Data Collection

This is a regional study based in Manitoba. The data are based on the experience and expertise of Manitobans. People who were knowledgeable about the experience of

Aboriginal people who have intellectual disabilities were asked to share their perspectives about this topic. In research terms, this planned selecting of participants would be called a 'purposive sample'. Bogdan and Biklen (1992, p. 32) describe how qualitative researchers are interested in the perspectives of the participants in a study. The assumptions, motives, reasons, goals, and values of the participants are all of interest and likely to be the focus of the researcher's questions. Though direct observations were not necessary in this study, participants were visited in situations where they would feel comfortable and at ease. The perspectives of these individuals provided the main source of data for this study.

Interviews were conducted during two periods: a beginning study in the spring of 1997 and the thesis study during the summer and fall of 1998. The data are comprised almost entirely of the transcriptions of these taped interviews. In the beginning study 96 pages of transcribed data were collected and 337 pages were collected for the thesis. This represents between twenty-one and twenty-two hours of taped interviews in total. Another portion of data is made up of the contextual notes and debriefing sessions for each interview. Typically the notes were about two single-spaced pages of information for each interview. A third part of the data collection occurred in February of 1999. Various direct services for people with intellectual disabilities were contacted about the number of Aboriginal people they support.

Through out the process of data collection I kept track of participants, potential participants, interview dates and times, research assistants, and other contacts on a white board in my work-space. This provided a visual image of what was occurring through out the data collection process.

The Beginning Study

In the spring of 1997, I completed a course called Qualitative Research Methods

for Education. A requirement of the course was that students complete a qualitative

research project. I conducted five interviews as part of this study. A summary of the

study is in Appendix B. I focused primarily on the apparent over representation of

Aboriginal people with intellectual disabilities in institutional as opposed to community

settings. Before starting this study, I contacted an individual from an institutional setting

to see if this issue was a relevant or accurate one and it was. Without the openness of

individuals from an institutional setting it would have been very difficult to proceed with

this study. The first interview was a joint interview with two people who worked in an

institutional environment.

The second interview was with an Aboriginal woman who is currently working as

a faculty member at a local university. This individual was particularly helpful at providing

an historical perspective on issues of poverty, loss of traditional values, and the federal

government's policy of assimilation. In the third interview I was able to speak with an

Aboriginal woman who has a disability. She had a broad scope of experience working in

Aboriginal organizations and was increasingly working in more of an advocacy role for

Aboriginal women with disabilities.

The fourth interview was with the director of a local province-based advocacy

organization for people with intellectual disabilities. Because advocacy often plays a key

role in deinstitutionalization it was important to interview someone from within the

advocacy field. The final interview in the beginning study was with an Aboriginal woman

who has a vision impairment. She works for a large local Aboriginal organization in a

leadership role and has been involved in researching issues related to Aboriginal people and disabilities.

Developments from the beginning study. All of these participants were very knowledgeable and they effectively addressed the topic. During the beginning study it became apparent however, that there were additional perspectives that could shed light on the experience of Aboriginal people with intellectual disabilities. I had not, for example, been able to interview people from relevant federal and provincial government departments. Also, people who currently work providing services within the Aboriginal system, both in reserve situations and in the broader community, had not been consulted. There were also other institutions and services for people with intellectual disabilities who had not been included. Perhaps, most significantly, people who are Aboriginal and have intellectual disabilities, and their family members had not been included in the beginning study.

In order to gain a fuller perspective on the experience of Aboriginal people with intellectual disabilities I made a proposal to address this topic as an area of research for my Master's thesis in Education. The expansion of the topic was also necessary because participants clearly indicated that the issue of institutionalization was complex. I wanted to clearly document key perspectives on topics that had been identified in the beginning study, including jurisdictional issues, historical factors, poverty, racism, and the process of institutionalization and deinstitutionalization.

The Thesis

During the beginning study I was able to complete much of the foundation work that was needed for the thesis. For example, I was able to develop questions that were

useful in both studies. The consent form was developed in the beginning study and used, with a few minor changes, in the thesis. In my ethics application for the beginning study and in the consent form, I noted that the findings from the beginning study might be incorporated into the thesis.

For the thesis study, the ethics committee made a few additional requirements, namely: the preparation of a stakeholder letter which described the topic to individuals who recommended study participants, a Letter of Consent specific to parents and participants with intellectual disabilities, and questions specific to parents, to participants from Aboriginal organizations and to participants from government and institutional settings. The Ethics Application including Letters of Consent, Stakeholder letters, Parent letters and various question sheets are in Appendix C.

Larger scope of the thesis. Perhaps the most significant difference between the beginning study and the thesis was that the thesis was much larger in scope. As with the beginning study, in some instances there were two participants in one interview. This tended to happen when the person I initially contacted about the interview felt that there was someone else he/she knew who would have an opinion about the topic. In some instances I was not aware that there would be an additional person present until I arrived for the interview. For the thesis, thirteen interviews were conducted with a total of seventeen people. When added to the six participants from the beginning study there were a total of twenty-three participants in eighteen interviews.

In determining who to interview I did one of three things: I contacted people I knew who had expertise about the topic, I asked people I knew to recommend others who had expertise, or I phoned a particular office and after describing the nature of the study, I

spoke with someone they recommended. Personnel from institutional settings were instrumental in introducing three of the four family participants. The overall categories or groups of interviews were drawn from the findings of the beginning study. There is more information about how each participant was contacted in the section of this thesis on participants (see p. 33).

Typically, participants were contacted by phone and asked if they were interested in being part of the study. Usually a portion of this first call focused on what I felt the participant had to offer to the study. I also discussed the consent form during this initial phone call so that the person would not feel on the spot during the interview and I would not have wasted their time. The date and time of the interview was then set. One interview was held in my home and one interview was held at a restaurant because the participant could only find time over lunch to meet. All other interviews were held at people's workplaces or homes.

The usual pattern of an interview was to begin with introductions and small talk. The participant was then asked to sign the consent form, the tape machine was turned on, and the interview was begun. Typically interviews lasted between an hour and an hour and a half. Notes were rarely taken during the interview, unless perhaps the participant mentioned something that should be looked up or a person who should be spoken with.

Presence of Aboriginal Research Assistants. This study differed from the beginning study because of the presence of four Aboriginal research assistants. Adler and Adler (1987) refer to the nature of the relationship between the researcher and the individuals who are members of the group being studied. They say that "To study social life, it is incumbent up on researchers, whenever possible, to adopt some sort of

membership role in the scenes they study" (p. 33). I am a non-Aboriginal person, who does not at this point in life have a disability. It can be very difficult to understand from a personal perspective, what life is like for individuals who are Aboriginal and have an intellectual disability. While none of the research assistants had an intellectual disability, as Aboriginal people, they certainly held membership in the perspectives, history and on-going issues of Aboriginal people. None of the research assistants were interviewed as participants in the study. Three of the research assistants attended three interviews and one research assistant attended four interviews.

Responsibilities of the research assistants. One of the tasks of the research assistants was to assist in identifying potential participants in the study. This was particularly important in finding participants from families. Because the research assistants were more closely linked to the Aboriginal community they were more likely to have contact with an individual or family who had experience with intellectual disability and institutionalization. Several possible participants were identified.

Prior to each interview the research assistant and I would meet to talk about the upcoming interview and identify any special considerations, such as language or particular expertise that the participant might have. During the interview the research assistant was responsible for helping participants feel comfortable, helping explain cultural concepts that I might not be familiar with, translating when another language was used, helping avoid misinterpretation, and generally ensuring that I understood the context and nature of the comments made during the interview. The research assistant and I would typically alternate asking the questions so that the participant would feel that they were addressing both of us.

The research assistant and I also met to debrief. Following the interview we would review what we felt the key themes had been in the interview. I would take notes during these meetings and these notes became part of the data for this study. This debriefing usually took an hour to an hour and a half. While the research assistants were involved in the data collection portion of the study, the data analysis was my responsibility and I am solely accountable for the conclusions drawn from the data.

One research assistant also conducted the telephone survey that formed the third source of data collected for this study. This took place in January of 1999. The research assistant contacted agencies in Winnipeg that provide support to people with intellectual disabilities. The goal was to determine the level of representation of Aboriginal people with disabilities in these community based residential and day programs. The reason for collecting this information was to see if in fact the apparent over-representation in institutional settings was accurate in comparison to placements in the community. In other words, if representation was as high in community settings as it was in institutional settings, then there would simply be a higher number people with disabilities in the Aboriginal population and not an over-representation in institutional settings.

Over a three week period the research assistant contacted thirty-four services in Winnipeg. He received responses from thirty agencies. According to this simple survey about 5.09% of the people in community-based services for people with intellectual disabilities are Aboriginal. Some individuals may have been counted twice; once in the day program and again in the residential setting. This means that the percentage may actually be lower than indicated. It seemed important to have this piece of information to support the perceived reality of institutional over-representation.

Introducing the research assistants. As with all of the participants in this study, the

names of the research assistants and places of references have been changed to ensure

confidentiality.

1. Sharon Sanger: I met Sharon when she was a student in the Developmental

Services Worker Program at Red River College. She came originally from Loon Bay,

Manitoba; a Metis community of 1000 people, bordering the Cedar Creek First Nations

reserve which has a population of about 800 people. Both communities are located near

the northwestern shore of Lake Winnipeg. Sharon is one of a family of ten children.

When she was a child one of her younger brothers was involved in a home accident that

resulted in him having an intellectual disability. His needs were such that he could not

remain at home and recommendations were made that he be institutionalized. Sharon

made frequent visits to see her brother in the institution and continues to have contact

with him now that he has moved to a group home. She completed her diploma in the

Developmental Services Worker program in 1998 and currently works in the area of

supported employment in a mid-size town near Loon Bay.

2. Pete Thundercloud: I have known Pete for about four years. I initially knew

him as a fellow member of a local inner city newspaper committee. He has had what he

describes as a "three decade flirtation with the writing world" and I know him primarily as

a writer and neighbour. Pete was born in Saltsands, Saskatchewan in a log cabin built by

his father. At the age of seven he received his naturalization papers which meant that he

was a citizen of Canada, but also that he was no longer recognized as an 'Indian' by the

government of Canada. He comments that "his neighbours sometimes suspect him of

being Aboriginal". During his varied work years in North America, Pete has cleared and

burnt bush along road allowances and highways, worked on a ranch as a hired hand, been

an itinerant minister, been a public school-teacher in Manitoba, and an orderly in

Minnesota. In both the United States and Canada he has worked with children and adults

who have both physical and intellectual disabilities. He was a licensed foster parent who

often provided a home for children with disabilities and he also worked for a short period

in an institution for people with intellectual disabilities. Currently he lives in a seniors

home where he is an active member of the residents' committee.

3. **Brenda Jones:** Brenda is the individual who initially mentioned this topic as

an area of concern. She was the Developmental Services Worker student who said that

she found many Aboriginal people with disabilities in her institutional placements but very

few in her practica placements in the community. She questioned whether this was a

reality or a perception. Brenda is a Metis woman who has balanced work and raising a

family for most of her adult life. When she was in her early forties she went to college

where she graduated with her Diploma in Developmental Services in 1997. I met Brenda

when she was a student at college.

4. **Charlene Armstong:** Charlene was the only research assistant I did not know

prior to the study. Zana Lutfiyya, my advisor, passed on her name to me. Zana knew her

as a student currently working on her Masters in Education at the Faculty of Education.

She came originally from Stoney Bay and was very familiar with the kinds of issues

currently facing band leaders and communities. She was also accustomed to research

processes so was able to fit easily into the interview and debriefing sessions. She was also

instrumental in arranging one of the family interviews.

All of these individuals were skilled, knowledgeable, and concerned about the

situation of Aboriginal people with intellectual disabilities. I thank them for their insight

and able assistance.

<u>The Questions</u>

The purpose of the research question is to help give focus to the study. Strauss

and Corbin (1990) state that, "the research question begins as an open and broad one; but

not so open, of course, as to allow for the entire universe of possibilities" (p. 38).

Bogdan and Biklen (1992) also support that questions in qualitative research need to be

"open-ended and concerned with process and meaning rather than cause and effect" (p.

156).

The research question for this study is made up of two parts. One part has to do

with the over-representation of people who are Aboriginal and have intellectual disabilities

in institutional settings. The other has to do with the overall experience of Aboriginal

people with intellectual disabilities. I found these issues to be interrelated in that when I

tried to understand the high representation issues I was immediately forced to consider the

overall experience of Aboriginal people with intellectual disabilities. A research question

that addresses both of these elements is "What has the experience of Aboriginal people

with intellectual disabilities been and how has this experience resulted in over-

representation in institutional placements?" This question is the focus of the study and all

other questions supported or were probes to address this central issue.

Questions were developed for the following three groups: participants from

Aboriginal organizations, participants who work for government departments or in

institutional settings, and individuals with disabilities who are Aboriginal and/or their

families. All sets of questions included: introductory questions, content or probing

questions, and concluding questions. The introductory questions asked participants to tell who they were and what they did, what they felt typically happened for a person who was Aboriginal and had an intellectual disability. They were also asked what their ideal scenario would be for these individuals. For the family interviews participants were asked at this point to tell their story or the story of their family member. Specifically, this involved describing the nature of the disability and the life history that had lead to an institutional placement.

The content questions included a series of probes related to why Aboriginal people with intellectual disabilities might be more highly represented in institutional settings. The probes raised issues about the nature of the disability, traditional Aboriginal values, poverty and racism. Often people addressed the 'probes' in their initial answer so these were then dealt with in a more cursory way. In this section I also included questions specific to each participant group, for example, with participants from Aboriginal organizations I asked about jurisdictional issues and funding responsibilities, and with participants from government and institutions I asked about per diem rates, where funding could be applied, funding sources, and so on. The concluding questions asked if there were areas of support for Aboriginal families that were particularly needed and if there were any other issues that hadn't been addressed in the interview that people would like to talk about.

The questions remained mostly unchanged through out the interview process though there were instances when something that was mentioned in one interview became a factor in successive interviews. For example in the beginning study, the question of the

role of the new Vulnerable Persons Act[1] came up (Interview Five). The participant questioned if the planning process required in the act would be applicable to Aboriginal people and if this might lead to greater deinstitutionalization. In the first interview of the thesis study, a participant used the example of the 'medicine bag' as an illustration of how Treaty promises are often open to many interpretations. This issue then reappeared in several interviews as an example of confusing jurisdictional issues.

The presence of these issues did not really alter the list of questions that we took to each interview, but if during the interview the participant seemed to be saying something about a related issue we might ask a specific question. For example, following the mention of the Vulnerable Persons Act, we made sure that we addressed this issue to participants who would be familiar with the application of legislation, namely participants from the Department of Family Services and from the Department of Indian and Northern Affairs. The questions used proved to be effective in both the beginning study and the thesis study.

Maintaining Confidentiality

I am very concerned about maintaining the confidentiality of participants in the study. I assured participants of confidentiality when they signed the consent form. The purview of the study draws on a fairly small community and the service field within that community is even smaller. In some instances if I clearly define a role it will be fairly easy for others to figure out who the study participant is. While confidentiality is vital it is also important for the credibility of the study that participants be seen as individuals who have

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[1] The Vulnerable Persons Act is Manitoba legislation passed in 1997 that addresses the rights of people with intellectual disabilities to make their own decisions in their lives. It also outlines the need for protection from abuse and the need for regular program and placement planning.

expertise about the topic. My response to this dilemma will be to try to give a sense of the

role the individual plays without identifying the person. In the study thirteen of the

seventeen participants are Aboriginal.

Pseudonyms are used to replace the proper names of all participants, agencies and

organizations. In some instances I do refer to government departments directly if no

specific individual is being identified. I also say that this is a Manitoba study so that the

extent of the study is clear.

The Participants

In determining who to talk to about this topic I felt that there were four groups of

people who would potentially be most helpful. A summary of information about the

interviews is listed in Table 1.

Table 1.

Beginning Study
conducted in the spring of 1997
• comprised of five interviews (with six people)
• 96 pages of transcribed data generated
Thesis Study
• conducted in the summer and fall of 1998
• comprised of thirteen interviews (with eighteen people)
• 337 pages of transcribed data generated
• included a community service survey

Aboriginal people and their families. These are the individuals who would be most able to give a first hand account of the experience of having a intellectual disability and being Aboriginal. It was not until the end of the study that family members who were willing to be interviewed became available. I wondered for awhile whether I would be able to find any family members to interview. Three of the family members that were included came through recommendations by personnel working in institutional settings. The final family participant came though one of the research assistants.

All research assistants knew one and sometimes two or three individuals who would have been appropriate participants in the study, however these participants from the family group were very reluctant to talk about their experience. Research assistants attributed this reluctance to shyness about being interviewed and a desire to not recall the painfulness of the experience. For each of the family interviews indicated below, I have later provided a fuller description of the experience and history of the individual with a intellectual disability.

The first family interview was with an Aboriginal man in his thirties, who has received services for people with disabilities most of his life. His mother was also present for the interview and while she did not seem discomfited by the interview and frequently made comments, she did not wish to sign the consent form. I felt that her behaviour indicated consent in that she stayed even when she saw me turn on the tape recorder. Despite my interpretation of her actions, I have made only limited reference to the things she said on the off-chance that I was mistaken. She primarily spoke Ojibway so the research assistant frequently translated her words into English. The man in this interview, and his family, live in a town in rural Manitoba. They were relations of one of the research

assistants.

I received the names of two of the family participants from personnel at an institution for people with intellectual disabilities. Initially personnel from this institution had been very reluctant to pass on names and it took about three different approaches to finally have them feel comfortable enough to recommend participants. The first of these interviews was with an individual who has a brother and a sister who have intellectual disabilities. Her family members currently live in the institution. This individual clearly outlined her experience and that of her family members with intellectual disabilities.

The second participant from this source was a young woman who is currently attending a local college where she is working toward her nursing degree. She has a brother who currently lives in an institution. She and her brother originally came from a northern reserve community. This young woman and the participant mentioned above, are both part of a project run by the institution, which links people in institutional settings with family members in the community.

The final family interview was with the mother, and her partner, of a young man who was in an institutional setting in a large urban area. The institutional service provided her name, though they had some difficulty coming up with potential participants. They were actively trying to assist but because of delays caused by summer vacations, and general work pressures it took some time to get this name as well. This family lived in a reserve community and the interview was held in their home. Their son had extensive physical and health related complications associated with his disability and about two weeks after the interview personnel from the institution phoned to say he had passed away.

Personnel from institutional settings. In the beginning study I was able to talk with two people from one institutional setting in the province. The information they provided on this topic was extremely helpful and they wondered as well why the representation of Aboriginal people was as high as it was in institutions. For this study I had hoped to broaden contacts with institutional settings to see if the statistics were consistent across institutional placements. There are currently three institutional placements for people with intellectual disabilities in the province. I contacted personnel at both of the institutions I had not yet spoken with. Both were reluctant to meet with me; one stated this was because of extreme work loads, and the other because the files are not computerized and it would take a lot of time and staff energy to find the information.

In a telephone conversation personnel from one site confirmed that 10% of their residents have treaty numbers. This would not include Metis people or individuals who may be eligible but have not applied for registration under Bill C-31[2]. Staff at this institution pointed out that they have not broken down their statistics according to culture as they did not feel this was relevant to the care provided to the individual. The key reason for interviewing institutional personnel was to consider the apparent over-representation of Aboriginal people in institutional settings. Since the percentage cited in the conversation with staff appears to be lower it is important to assess this finding in light of other information.

It is helpful to refer again to the 1985 study that focused on children in all of Manitoba's institutions. This study found the percentage of Aboriginal children (under 20

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[2] Bill C-31 is legislation that amends the Indian Act. It was passed in 1985 and identifies four types of Indian person: 1) status with band membership; 2) status with no band membership; 3) non-status, but with band membership; and 4) non-status, non-band (Frideres, 1997, p. 30).

years of age) with intellectual disabilities at that time to be 18% (Evans, Hunter,

Thompson, & Ramsey, p. 155) of the total population of the institutions. This study

included children who had two parents who were Indian or Inuit, two parents who were

Metis, or one parent who was Indian or Inuit (p. 154). At the time of the study Aboriginal

children made up 6.8% of the total population of children in Manitoba so the 18%

figure was nearly three times higher than the community population at that time. Since

1985 the percentage of Aboriginal people in the population has increased so it is unlikely

that the percentage within institutions would have substantially declined. Also, this study

may have excluded people who would qualify as Indian under Bill C- 31. So the 18%

figure could be artificially low. I feel it is safe to say that over-representation in

institutional settings continues to be an issue and I would have very much liked to have

confirmed this by interviewing institutional personnel. Unfortunately I was unable to do

this.

Representatives from government departments. In order to address the

jurisdictional issues that were raised in the beginning study it was important to hear from

personnel in respective government departments. These participants could describe from

their perspective who would be responsible for the on-going care and support of

Aboriginal people with disabilities. I was able to speak with individuals from three

different departments in the Provincial Government and with someone from the

Department of Indian and Northern Affairs.

The first government person I spoke with was an individual who works for the

provincial government. She is in a position of responsibility for services to people with

intellectual disabilities. It was important in this study to find out what people in the provincial government feel their responsibility is for Aboriginal people with intellectual disabilities. In this interview it was clear that the province feels it is responsible for all Manitobans with intellectual disabilities except individuals living in reserve communities. Individuals on reserves are seen as clearly being the responsibility of the federal government. It was very important to have someone outline the provincial government's perspective on this issue.

The second participant's name initially came through a contact at a city planning organization. In 1996 this organization had published a report on Aboriginal persons with disabilities that was primarily focused on physical disability and employment. I contacted the project manager and she suggested that I interview this individual for the study. She said that he knew the issues and had been a resource for them in doing their study. He also works in a position in the provincial government where it is relevant that he is an Aboriginal person, so it was also appropriate to interview him for the position of responsibility he holds. Prior to the interview he asked that I fax over the questions and the consent form. He sent back an e-mail saying that he felt comfortable commenting about funding and jurisdictional issues but was not that familiar with issues specifically relating to persons with intellectual disabilities.

The next interview was with a man from the federal government. In the past his department held responsibility for the relationship between government and Aboriginal people. I had no leads in making this contact so I simply phoned this department, described the nature of my project and asked who I should speak with. This individual had worked with the department for a number of years and was able to outline changes

that had happened over the years and the effects of the decrease in funding and government restructuring.

The final interview in this group was with an individual who is responsible for children in care in non-institutional settings for the provincial government. She was familiar with funding issues related to the community placement of children with special needs, in particular, those with the highest level of need. Her name was passed on to me by another individual working for the provincial government who used to be responsible for services to children with special needs. He felt, and rightly so, that she would be able to provide information about the number of Aboriginal Children in care, the nature of the disabilities, and estimated costs of providing care in the community.

Representatives of organizations run by or for Aboriginal people. I wanted to talk with personnel from Aboriginal agencies who might have a perspective on a desirable future for Aboriginal people with intellectual disabilities as well as ideas about over-representation in institutional settings. Four of the interviews were with personnel from Aboriginal agencies. Two of these were with individuals primarily involved in rural reserve communities and two were with people working in urban centres. These agencies were usually related to the provision of either health, or child and family services.

The initial interview was with a man who holds a managerial position in an agency that provides social and family support to Aboriginal people in reserve communities. This individual was very helpful in clarifying how support is provided in reserve communities. He also describes some of the attendant difficulties in sorting out jurisdictional and funding issues. Following the interview this individual provided us with recent reports that the agency has made. These further clarified the kinds of 'catch 22' situations that

organizations face and the funding difficulties that they frequently encountered.

The next participant was responsible for health care and social issues for a reserve region in western Manitoba. Her district is addressing their own health and social issues. The research assistant who attended this interview lives in the same general area of the province as this participant. They did not know one another but during the interview it became clear that they were familiar with the settings being referred to and with the same people and processes. This was quite a lengthy interview (one and a half hours) and it seemed that this individual was interested in the topic and had already begun to think about the circumstances of people who are Aboriginal and have intellectual disabilities.

The third individual was in a management position for a large urban organization that provides supports primarily to Aboriginal families and children. It was recommended in an earlier interview that I talk with personnel from Aboriginal agencies to understand from their perspective, what had happened in the past to Aboriginal children and how they were supporting families with children with disabilities in the present. This is one of the key Aboriginal run agencies in the city and perhaps the province so it is important to understand their perspective on the experience of Aboriginal people with disabilities.

Part of my intent in this study was to better understand the way Aboriginal people were currently accessing medical services. This is partly because it seemed that medical services were often the first personnel to have contact with Aboriginal families who had children with disabilities. I thought that perhaps personnel from a new centre for Aboriginal culture, which is currently being developed, could help shed light on this issue. One of the research assistants also recommended that this site be contacted for an interview. An interview was conducted with two individuals, one of whom had worked in

a nursing station on a reserve community. As this organization becomes more established as a resource in the community for Aboriginal people it is important to understand their perspective on disability issues.

Twelve of the thirteen interviews fit within the categories identified at the onset of the study. I also contacted a local provincial advocacy organization for people with intellectual disabilities. I had interviewed the director in the beginning study and had heard in that in the meantime the agency had hired someone to work with reserve communities. I phoned to speak with the individual who had been hired for the position however, it turned out that his contract was over. The woman I spoke with, who has worked on advocacy, planning and family issues for many years, was interested in the topic and described some of the work that her husband was doing with health organizations; about 90% of which was with various band councils. Her husband was also familiar with the workings of various government departments. It seemed evident that both she and her husband had thought about this issue.

Chronologically, this was the first interview of the study and it proved to be a very positive starting place because I had met these individuals before so it was easy to talk with them. They were also instrumental in making suggestions about other people who could be interviewed. This was a very helpful first start, and the following three interviews were based on the connections or suggestions of these individuals.

I had originally planned to do from seven to ten interviews - with perhaps one to three people in each of the groups described above. Until near the very end of the study it seemed that I would not be able to contact any family members. For this reason I continued to do interviews until I had nine non-family interviews completed. When the

family interviews did become a possibility, these four interviews were added to the nine that had already been completed.

Potential participants not interviewed. I had hoped to speak with someone from the federal department responsible for the provision of medical care to reserve communities, but I was not able to do so because the organization was going through an extremely stressful period. One individual I was able to speak with made a recommendation that I interview a person they felt would be very knowledgeable and it happened to be someone who had already been interviewed. I felt that individuals from this branch would have been helpful in clarifying the kinds of recommendations that are made to families in reserve communities.

In the beginning study a participant recommended that I also speak with the person in the province responsible for advocacy for children. This was a good recommendation, but I wanted to ensure that the breadth of the study included adults as well as children. As I was able to complete three interviews that focused almost exclusively on children I didn't pursue this interview.

I was also interested in what happens in the education system because I felt this might be a point where children are identified as having intellectual disabilities. I tried to set up an interview with an Aboriginal woman who worked as an educational consultant to reserve communities, however, she was no longer in this job. She also recommended that I speak with someone who had already been interviewed.

Data Analysis

Bogdan and Biklen (1992) describe data analysis in the following way, "Analysis involves working with data, organizing them, breaking them into manageable units,

synthesizing them, searching for patterns, discovering what is important and what is to be learned, and deciding what you will tell others" (p. 153). It is in data analysis that all of the collected information must somehow be sifted, sorted, and coalesced into the answers or responses that most clearly shed light on the topic. The largest and most substantial source of data in this study was the transcriptions of the participant interviews. These were supplemented with debriefing notes done with the research assistants, contextual notes and the findings of the telephone survey. There were a number of steps in the data analysis process.

Debriefing Sessions with the Research Assistants

This was an initial opportunity to think about and evaluate what had just been said. Usually the research assistant and I would begin by identifying key content areas the participant had mentioned. For example, we might note that a particular participant seemed to really feel that poverty was a key issue. We also talked about our general impression of the interview. For example, we might comment if someone seemed particularly rushed or uncomfortable with certain questions. As interviews progressed, we would also note when something new or different was identified as a key issue.

In some instances the debriefing was an opportunity for the research assistants to clarify issues. For example, one participant mentioned the topic of nepotism in Band Councils. The assistant clarified that this is something that councils are frequently accused of, but it is hard to know if nepotism was more rampant in Aboriginal communities than anywhere else. The debriefing sessions were the first stage of reflection on the interviews and the notes taken remained as a record of this early stage of analysis.

During the debriefing sessions we also discussed the possible need for changes in

the design of the interview. In qualitative research it is consistent that in some instances

the process may alter as the interviews begin to build on one another. This happened in a

number of small ways in this study. For example, in the first interview the research

assistant and I each asked several questions in a row rather than alternating questions. We

felt this had not flowed as well as it could have so the format was changed in subsequent

interviews. Likewise, in one interview the question of why there was a discrepancy in

services between rural Aboriginal and rural non-Aboriginal people came up. This

discrepancy seemed like an interesting issue and it was asked in some of the other

interviews. These issues did not alter the core of information being collected.

The Transcribing Process

I did all of the transcribing for both the beginning study and the thesis. Typing up

the interviews often involved very focused and concentrated listening to ensure that I was

writing what people had actually said. Transcribing is essentially a prolonged listening

period where I reviewed every word. I tried to consistently complete the transcript within

a week of having done the interview. This provided an opportunity to review the ideas

that had been presented and confirm or disprove ideas presented in the debriefing.

Developing Themes

After completing the transcriptions I prepared a very brief contextual summary of

each of the interviews. This helped to refocus my attention on the individuals with whom

I had spoken. Following this I reread all of the transcripts, highlighting important

responses and making notes in the margins indicating the key points made by each

individual. My advisor also read the transcripts and debriefing notes and commented on

key themes and issues. Her column notes were also reviewed and considered in

determining themes.

Reviewing the data in this way would be consistent with what Patton (1990),

refers to as analyst triangulation. In analyst triangulation "multiple analysts review the

findings" or data in a study (p. 464). In this study the data were triangulated through the

presence of research assistants in the data collection and debriefing sessions, the review

and analysis of the data by the study advisor, and finally in my review of the data. I believe

that triangulating the data in this way adds to the validity of the study as a check to ensure

that accurate interpretations were made (Fraenkel & Wallen, 1996, p. 462; Taylor &

Bogdan, 1998).

After my advisor reviewed the data I returned to my white board and again went

through each transcript listing on the board the points or themes. I started with interview

one and wrote down each different theme in a column. As I went through successive

interviews I was able to add new references to the various themes already listed and add

new themes that were indicated in later interviews. I then typed out this rough sketch of

themes and again reviewed the transcripts for specific references for each of the points

made.

I found that in the beginning study the final stage in data analysis occurred in

actually writing the information in a themes paper. Here presentation and content came

together and thoughts that were floating around in my head necessarily became concrete.

Strauss and Corbin (1990) talk about this when they say, "Writing and thinking have now

to play back and forth in your head and on the page" (p. 234). I think that writing is

difficult because it requires a kind of commitment to an idea. In writing, things start to

appear like truth and it can be difficult to make a commitment to an idea because you

cannot be absolutely sure it is right. Writing is a complex and difficult process. Fraenkel and Wallen (1996) say that "qualitative investigators, then, are less definitive, less certain about the conclusions they draw from their research. They tend to view them as ideas to be shared, discussed, and investigated further" (p. 465). For me, this is certainly the spirit in which this information is intended.

Researcher Role

In completing the interviews there were several instances in which I was very conscious of being a white, middle-class person. In particular, when Aboriginal participants would either recount their experiences with the service system or identify injustices that have their roots in either broken treaties or current practice I would often feel a kind of responsibility. I'm not really sure how a white person can live comfortably in light of the injustices that still seem to happen to Aboriginal people far more than to non-Aboriginal people. I have tried to think about whether or not these feelings are problematic in both doing the interviews and interpreting the data.

Essentially I have tried to determine if someone else asking these same research questions might have come up with different conclusions. Researcher bias, which undoubtedly exists, is I think, a problem if it in some way influences the participants resulting in them saying something they did not believe to be true. It would also be problematic if it lead to disregarding parts of the data because it did not fit in with researcher beliefs. My approach to both the interviews and the data analysis was to remain true to the questions with which I approached the study and to listen respectfully to what participants said. I think that the checks and balances put in place by the presence of the ethics committee, my advisory committee and in particular, the Aboriginal

research assistants who were part of the interviews provided assurance that the researcher

influence was as limited as possible.

Chapter 4: Themes in the Study

The themes are key ideas or responses from participants that addressed the questions of the study: namely, what is the experience of people who are Aboriginal and have intellectual disabilities and why do these individuals seems to be over-represented in institutional settings.   In reading through the transcripts it became evident that various issues were repeated in different interviews. It was possible to group some of these topics together into more general headings or themes. The frequency with which an idea was repeated was not the only thing that determined what would be included in a theme. In some instances participants had particular expertise or insight which made their comments compelling even if they were the only person making a point.

In this chapter I have grouped together the issues related to each theme and supported relevant points with references from various participants. There were five broad themes or topics in my findings. The first theme focused on determining who was responsible for the delivery, coordination, and funding of needed supports to Aboriginal people with intellectual disabilities. In addressing this theme participants were asked to identify the roles of federal and provincial governments. The second theme that participants identified related to the nature of resources in remote communities. Thirdly, poverty was identified as a key theme. Poverty effected individuals whether they were in reserve or non-reserve communities. A history of institutionalization following colonization was identified as a fourth theme. Finally, racism was identified as a factor for consideration as a final theme in the study.

Table 2 provides a summary of key themes.

Table 2.

Summary of Key Themes

Responsibility for the Delivery, Coordination, and Funding of Needed Supports
Role of the Federal Government
    Lack of a federal mandate to provide support.
    Lack of a provincial mandate to provide support.
Role of the Provincial Government
Problems of Jurisdictional Confusion
Problems of Fiscal Restraint
Problems of Current Systemic Change

Resources and Remote Communities
Lack of Services in Reserve Communities
The Size of the Reserve Community
Lack of Training About Disability
    The confidence gap.
Concerns About Services, Staffing and Program Design
Services and staffing in off-reserve communities.

Aboriginal People are Poor
Reserve Communities
Non-reserve Communities
    Poverty and service access.

History and Institutionalization
A History of Being Sent Away for Services
A History of Being told What to do
History and Service Utilization
History and Non-institutionalization

Racism and Institutionalization
Racism and Deinstitutionalization

Other Considerations
Advocacy for Change
Fetal Alcohol Syndrome/Fetal Alcohol Effect
A Focus on Traditional Values
Summary of Themes

Responsibility for the Delivery, Coordination, and Funding of Needed Supports

It is very difficult to summarize or clearly define the roles of the various

government departments that are involved in the lives of Aboriginal people. Depending on

who is speaking, there may be a variety of interpretations about lines of responsibility. The

two key players are the federal and provincial governments and each of these branches of

government have varying responsibilities and funding contingencies. One participant

responded to the issue of responsibility by saying that if you walked into a group of people

from all branches of government and asked who is responsible for making life good for

Aboriginal people with disabilities, "No one would put up their hand" (Transcript 1, p. 8).

This was substantiated in several other interviews and a variety of perspectives about who

should be responsible became apparent.

Role of the Federal Government

The federal government, through the Department of Indian and Northern Affairs,

has primary responsibility for Aboriginal people when they are on reserve communities.

As well, Health and Welfare Canada, another federal department, channels funds to

reserve communities through a branch that provides medical services (Transcript 5).

These are the two key federal branches that have relevance for Aboriginal people with

intellectual disabilities. One participant outlined the responsibilities of the Department of

Indian and Northern Affairs in the following: "they pay for housing and infrastructure, . . .

the public works, the chief and council operation, the school and social assistance, but

very limited services beyond the pure dollar value for basic necessities. There's virtually

no mental health services on the reserve anywhere in Manitoba" (Transcript 5, p. 15).

The services funded through the health branch of the federal government address

different needs. Another participant clarified, "They'll provide funding for community based services like nursing. Nursing and addictions programs, and medical transport. . . they'll cover off some benefits for psychological therapy . .. dental care, vision care, prescription drugs and stuff like that" (Transcript 3, p. 25). Funds from the Department of Indian and Northern affairs tend to be only used on the reserve whereas the benefits for health are still applicable for a registered Aboriginal person whether they are in or away from a reserve community. One participant concluded, "Indian Affairs, they've defined their mandate very narrowly, that they're only responsible for Status Indians on-reserve" (Transcript 5, p. 15).

Lack of a federal mandate to provide support. Services for children and families are not specifically mentioned in the above list, however these services exist and are funded through Indian and Northern Affairs. This happens because people on reserve communities are subject to the same provincial laws as other citizens of the province. One participant explained this as follows, "under the Indian Act, there's a section that states that provincial laws of general application apply on reserve, and the exception to that is if the federal government has exacted legislation to take over that arena" (Transcript 7, p. 4). In most instances, the province has the authority to enforce legislation and it delegates this authority to bands within local communities. Bands may individually oversee the enforcement of legislation or a number of bands may group together to form regions. This has happened to some extent in the areas of health and in child welfare administration. This consolidates administration and may help to ensure uniform practice across different reserve communities.

A practical example is evident in the area of child protection. In this instance

Aboriginal run agencies receive funding from the federal government because they must uphold provincial legislation that governs the protection of children in reserve communities. Provincial funding does extend to reserves so federal funding is accessed for these services. In these instances the costs are based on the same fee scale that exists in other areas of the province.

Services for people with intellectual disabilities, or any other disabilities for that matter, are also not identified as part of federal responsibility. It seems that at present services are simply not available for people with intellectual disabilities via federal funding. Participants said that the service system for people with intellectual disabilities is pretty well non-existent in Aboriginal communities. One participant responded to the question of whether services were available as follows, "In the Aboriginal community? I doubt it. We never get that kind of money . . . It's true . . . I've never heard of any" (Transcript 6, p. 7). Another said, "But right now, I can tell you truthfully, there is nothing there for them at this point" (Transcript 3, p. 7). One of the child protection agencies, in a report that they prepared in 1994, described the problem of service provision in the following way:

> Where there are healthy communities with strong front end services in the areas of
>
> education, health and social programs, and strong internal support systems, child
>
> and welfare concerns . . . are intended to be 'agencies of last resort'. However, in
>
> communities where these front-end services are non-existent and strong support
>
> structures are lacking, . . . (these) agencies become the 'agency of only resort'. (p.
>
> 5)

The lack of services means that there is nothing in place to support Aboriginal people with intellectual disabilities, and the limited resources or services that are there are

often overtaxed and inappropriately accessed.

Lack of a provincial mandate to provide support. Currently the provincial government does not have a mandate to provide services for adults with intellectual disabilities. For non-Aboriginal people with intellectual disabilities there is no certainty of service provision nor is there a legal obligation on the part of government to provide service. In some ways, services for people with intellectual disabilities in the province have often had to take a `cap-in hand' approach when trying to access provincial dollars. The provincial government does provide funding for services that are mandated such as child protection, but its funding to non-mandated services such as those for adults with intellectual disabilities, is much less certain.

The Vulnerable Persons Act (1996), which is provincial legislation, outlines various rights related to decision making, abuse, neglect, and protection for people with intellectual disabilities. People have the right to a substitute or to a supported decision maker if they are unable to make decisions and choices on their own. It also indicates that people with intellectual disabilities will be involved in a planning process, which is to occur on a yearly basis. As part of planning they will be asked about the kind of life they would like to live. Service provision within this legislation is designed to solicit and support the choices and decisions of people with intellectual disabilities. While this legislation outlines some rights of citizens with intellectual disabilities it does not entitle them to services.

The fact that services for adults with intellectual disabilities are not mandated in legislation has always been problematic from an advocacy point of view. It means that service provision is dependent on available funds within the Department of Family Services rather than on the need for service as it exists in the community. In practical

terms this means that often people do not get the services they need. Students

transitioning from the school system may have to go on waiting lists in order to line up for

service. Service providers report that many people wait as long as two years before

getting into services. Adults with intellectual disabilities who have lived with their parents

may find themselves without support when their parents are no longer able to care for

them. Decisions about who will get services are often made based on the advocacy that

exists in the community and the perception of need by community services workers and

other decision makers.

The Vulnerable Persons legislation has a clause that states that it cannot be used to

access or influence the provision of funding. A planning manual prepared by the

Department of Family Services and a local advocacy group includes a standardized form

which states that no funding is available to ensure the fulfillment of the plans created for

individuals. Essentially, the legislation is able to ensure that there is a response to

situations of abuse and neglect, but it is unable to ensure the provision of planned and

appropriate service.

It is difficult to say what the implications of the new legislation will be for people

who live in reserve communities and have intellectual disabilities. It would seem that it

should be applicable on reserve communities in the same way that all provincial legislation

is applicable. However, since there is no avenue for enforcing the legislation from within

the reserve community and since provincial workers have no access to reserve

communities, it is unlikely that it will be of use in the reporting of neglect and abuse.

Also, even though the legislation stipulates and annual planning process, it is unlikely that

the province will pursue the development of plans when it does not see the reserve

community as part of its jurisdiction. It would be interesting to see what would happen if someone from a reserve community were to pursue the application of the law within the reserve and if the federal government would cover the cost of services in the same way that they do in instances related to child protection legislation. I think it is safe to say that the full extent of the new legislation for Aboriginal people has yet to be discovered.

Role of the Provincial Government

The provincial government is the primary funding source for services to adults with intellectual disabilities. The province supports a "continuum of services" (Transcript 4, p. 3) ranging from institutional care to highly integrated community residential and day programs. Aboriginal people with intellectual disabilities can receive support from the provincial government provided they are not living on their reserve communities. One participant explained this as follows: "It's a provincial policy that I believe cuts across all departments, that the province provides supports to people who are not on reserves. People who are on reserves, I believe, are thought to be the federal governments responsibility" (Transcript 4, p. 3). Another explained, " the province will not step one foot on the reserve" (Transcript 3, p. 25). Essentially this means that the province may provide services to all people with disabilities across the province with the exception of people who live on reserves.

Though it is clearly practice for the province not to provide funding to reserve communities, some participants felt that this was not an appropriate state of affairs. They pointed out that the block funding which comes to the province from the federal government is meant to provide health, education, and community services to all Manitobans including people in reserve communities (Transcript 2, p. 7). A point similar

to this was made in the beginning study. One participant from an Aboriginal organization noted that service agencies such as the C.N.I.B. often receive funding based on a total provincial population, but these services never reach reserve communities (Beginning Study, Transcript 5). Some participants in the study suggested that the province should be responsible for all citizens of the province including Aboriginal people in reserve communities.

At present, the provincial government will provide funding for Aboriginal people with intellectual disabilities if they are not on the reserve and if they meet the same criteria as all other applicants. However, if an Aboriginal person is funded by the province and is in an institution, the provincial funding that is currently being paid for the person would not follow him/her back to a reserve community should he/she return home. This is the case even though, as a provincial government official confirmed, the costs of institutional care and community care are about the same (Transcript 4). The province has no objection to providing funding to Aboriginal people with intellectual disabilities, it simply will not have the funding go to the reserve community.

Problems of Jurisdictional Confusion

It is very difficult to understand how decisions are made about who receives funding and who does not. While the general rule appears to be that the federal government provides funding on reserves and the province provides funding off-reserve, there are exceptions to this rule. In some instances federal dollars do follow individuals off-reserve. Anecdotal reports from the eighties describe how an agency was able to bill the Department of Indian Affairs directly for services provided off-reserve to Status Aboriginal people with intellectual disabilities. Another exception was for post secondary

education, one person explained, "my understanding is that you're covered for secondary

(education) funding through our department whether you live on or off reserve"

(Transcript 7, p. 3). Another person sited an example of someone who was funded to stay

in a personal care home, they added however "the federal government would pay for that

space, but that's another one of those areas where in recent years they've kind of pulled

back" (Transcript 5, p. 14).

For children in care there is also the possibility of payment coming to a service

outside of the reserve community. One participant explained, "If a kid comes into care

and they have to go to one of our institutions, . . . if they're federal (from a reserve), the

agency will get their money reimbursed from the feds for the per diem rate, if they're

provincial (living off-reserve), (the provincial government) pay(s)" (Transcript 9, p. 16).

If a child is apprehended and he/she happens to have a disability and is sent to a home in

the city they may be funded through the federal government, however, if an adult person

with a disability leaves the reserve community there will be no dollars from the federal

government to assist in their support. It appears in some instances federal dollars can be

spent off the reserve, but for adults with intellectual disabilities this is certainly not the

practice at this time.

At present, if people on reserve communities do receive service, it is typically

carved out of federal funding sources that have been delegated to other services. For

example, one participant described a situation where someone with an intellectual

disability is living in a senior citizens housing unit (Transcript 7). Another said that often

child protection or health related agencies become involved, when protection and health

are really not the issue. For example, in one instance a child who did not need protection

was taken into care so that he/she could leave the community and access a provincial

special service for children with disabilities. Once was off the reserve he/she was not able

to access the special services because he/she was 'in care' and therefore under the

auspices of a federal government branch. He explains, "there is a provision there that if a

child is 'in-care' they are not eligible so we ended up bringing the kid into care for no

reason . . . it was a catch twenty-two" (Transcript 2, p. 7).

It would seem that the long term consequence of using funds designated for other

sources to assist people with intellectual disabilities, may not be positive. It is likely to

lead to unequal quality in services because the provision of service will be dependent on

the good will of a person in charge at a particular time. Over time there may also be

growing resentment from those individuals needing the services for which the funding was

initially intended. All of these factors point to a need for some sort of resolution regarding

very complex jurisdictional issues.

Problems of Fiscal Restraint

There are other issues that further complicate the question of responsibility. The

federal government has been in a period of fiscal restraint for a number of years. The

practice of withdrawing funds was expressed by one person as a "tightness in the system"

(Transcript 5, p. 13). Another explained, "My understanding is that the Aboriginal

agencies had their family support dollars cut out about three years ago. So although they

have the expectations to provide those services, I don't believe they have the dollars"

(Transcript 9, p. 18).

Like the federal government, the province also reports that it has insufficient funds

(Transcript 4). In this context it is unlikely that the province will free up funds for service

delivery on reserve lands. For Aboriginal people with intellectual disabilities, one of the outcomes of the confusion about responsibility between the province and the federal government is that the flow of expertise may be restricted. The well developed knowledge base related to service provision for persons with intellectual disabilities will likely remain with the province rather than be passed on to personnel outside of provincial jurisdiction.

Problems of Current Systemic Change

Related to these jurisdictional and funding issues is fact that the federal government, in consultation with provinces, and Aboriginal groups, is dismantling the Department of Indian and Northern Affairs. The plan is that "departmental functions" will be taken over "by First Nations bodies, and, so all of our programs are moving in that direction" (Transcript 7, p. 9). Simultaneously, a similar kind of withdrawal is taking place in medical services. Soon the provision of all services in reserve communities will be over-seen by First Nations people. In general, the Aboriginal participants in this study viewed this change to increased self government as a positive thing but the implications for people with disabilities are hard to predict particularly since people living in institutions may have lost their links to particular bands.

Several participants related stories about the current nature of negotiations between various governing bodies. One participant described a three-year fight related to trying to establish a framework for health care. He said, "It all fell apart because of one clause where some lawyer said that we cannot have the minister signing anything that implies that health is a treaty right" (Transcript 1, p. 18). Another person described a fight that has gone on for two years, "we keep the papers ready to sign, and the province keeps saying, this is not worded properly, and it could be interpreted this way . . ."

(Transcript 2, p. 21).

One Aboriginal participant described a situation that again illustrates the complexity of issues and the current state on tension in these discussions. She was sitting on a regional health authority when she made the following request, "All I want is for you to give me a letter saying that you cannot provide home care on the reserves . . . because your letter is going to indicate to us in black and white that you cannot come over here and provide health care" (Transcript 3, p. 26). The authority was very reluctant to provide such a letter claiming that it was a jurisdictional issue.

This is a period of negotiation between the federal and provincial governments and Aboriginal people. The issue of support to people who are Aboriginal and have intellectual disabilities has never adequately been addressed by any of these governing bodies. No one is claiming responsibility for Aboriginal people with intellectual disabilities. The result of not addressing the issue of responsibility is that Aboriginal people with intellectual disabilities must take what they can get in terms of services. Often this results in institutionalization because no one is actively trying to prevent this or provide other alternatives. The path of least resistance is chosen. It seems unlikely that anyone will be jumping at the opportunity to address this issue in this present state of flux and uncertainty.

Resources and Remote Communities

In Manitoba, Winnipeg is home to half of the province's population. While there are other fairly large towns there is no other location that comes close to matching its size. This has lead to a situation where the majority of resources tend to be congregated in Winnipeg and to some extent, the other larger towns around the province. The farther

people live from urban centres the less accessible resources tend to be for them. Reserve

communities are amongst the most remote settlements in Manitoba. Lack of access to

resources in reserve communities is a key reason for institutionalization. Appendix D

contains a list of locations for Family Services offices and for Community Living

associations.

Lack of Services in Reserve Communities

There are sixty-one First Nations communities in the province of Manitoba. Many

of these are located in remote areas far from the large urban areas where most services

tend to be congregated. According to the Royal Commission on Aboriginal Peoples, over

one third of the reserves in Manitoba, "have no ready access to a service centre" (p. 133).

One participant explained, "there just isn't enough resources in the area to provide

resources to everyone, everywhere in the province, so, services tend to be congregated in

the areas with the large population centres" (Transcript 5, p. 10). Often, for people who

are Aboriginal, the pattern for accessing services is to be flown out of the community to

an urban centre. For people with intellectual disabilities who are institutionalized coming

from a remote community means that typically you might only get to see your parents

once or twice a year.

Remoteness naturally affects service accessibility. However, I don't think

remoteness explains the lack of service provision entirely. If we look at the difference

between Aboriginal and non-Aboriginal rural or remote communities, often rural

communities will have provincially funded services such as community residences or

employment services. The fact that these are not present in reserve communities is

probably related more to funding issues than issues of remoteness.

The Size of the Reserve Community

Another related issue has to do with the size of reserve communities. There is at least one community with an on-reserve population approaching 4000 people while there are other reserves that may only have 100 people (Transcript 7, p. 5; Royal Commission of Aboriginal Peoples, p. 130). Communities with larger populations are more able to develop a base for service provision than smaller communities. So, for an Aboriginal person with a intellectual disability, one of the factors that will affect whether or not he/she receives service, is whether he/she was born into a large or small reserve community. This is interesting because typically there is nothing about the provision of services to people with intellectual disabilities that requires a large urban centre. The size of the community need not be a factor, but it appears that it is.

Lack of Training About Disability

One resource that is often missing is trained staff to work with people with intellectual disabilities. One woman asked the following question, "Would it be a beneficial for them to come home, if you don't have anything ready for them" (Transcript 3, p. 12)? Another said, "The problem in the reserve communities . . . is that there is nobody trained" (Transcript 7, p. 18) and another commented, "It's going to take awhile and there's a need for a lot of training and a lot of support" (Transcript 9, p. 19). Lack of trained personnel in reserve communities means that often people with intellectual disabilities must go off reserve for support. Also, they are deinstitutionalized less frequently because there are concerns about health and safety should they return to reserve communities.

Lack of trained staff has implications in a number of ways. For example, sometimes medical and educational assessment for children may be delayed because there

is no one to do it (Transcript 3, p. 23). In another instance it was noted that funding was not accessed because of the involved nature of funding forms and requests (Transcript 1, p. 19). Similarly, it was noted that requests for special funding for programs for people with disabilities had not been made to the Department of Indian and Northern Affairs (Transcript 7, p. 8). Sometimes the complicated nature of applications, and the lack of awareness about community need may mean that available moneys are not accessed.

At present most of the jobs related to supporting Aboriginal children and adults with disabilities go to workers from outside of Aboriginal communities. These employment opportunities are lost for Aboriginal people on reserves because people with disabilities are sent elsewhere for care. Even in non-reserve communities such as Winnipeg, Aboriginal people appear to not be highly represented in staffing groups. The family members interviewed commented that they seldom encountered Aboriginal staff.

It should also be noted that training need not be a terribly complicated matter. In the past, deinstitutionalization has taken place without an existing body of trained personnel in the community. Training has been addressed as the need arose. In reserve communities there will likely be little call for trained staff, since there is no capacity to pay them and people with intellectual disabilities are institutionalized elsewhere. Again this ties in with funding and the need for jurisdictional clarity about responsibility.

The confidence gap. While lack of trained staff to support people with disabilities is a problem it should also be noted that things are changing in terms of training. One Aboriginal person noted that they used to always look to outside expertise, but they have more recently begun providing training so that the expertise stays within organizations, he commented, "we have eleven Masters graduates . . . we're developing expertise and

professionalism within our community" (Transcript 2, p. 18). At the same time as people are becoming trained, participants also referred to a 'confidence gap'.

A 'confidence gap' occurs when the status of Aboriginal professionals is believed to be less than that of non-Aboriginals. The participant gave the following example, "when I've gone on to reserves and the Aboriginal leadership would rather sort of deal with a non-Aboriginal person, because they see a non-Aboriginal person as having the power, even though I may have an equal position" (Transcript 6, p. 19). Along a similar vein, another participant said, "Well, the Aboriginal is always put down for their skills, they'd rather get someone who was non-Aboriginal" (Transcript 12, p. 12). Needless to say, Aboriginal people need to be recognized for their training and expertise. The future is bleak if this 'confidence gap' continues. There will be little incentive for training and the resulting lack of trained people will foster on-going concerns about having people with intellectual disabilities in reserve communities.

Concerns About Services, Staffing and Program Design

Participants in the study expressed some concern about the nature of existing off-reserve services. One participant commented, "These are not the kinds of systems, I don't think, that we would set up for our families or for our children" (Transcript 6, p. 7). She went on to comment that Aboriginal people have not been involved for very long in the existing service system, so time will be needed before a vision of a new and better way of doing things becomes apparent.

Participants also expressed other apprehensions. One person pointed out that in some instances the existence of a service may actually generate the need for the service. Likewise when a particular problem is labeled, the label may suddenly acquire broad usage

and acceptance regardless of whether or not the label serves a meaningful purpose. He sited the example of ADHD (Attention Deficit Hyperactivity Disorder) where it seemed that once the disability was identified, there may have been a tendency to find lots of people, or children, who have it, "the next thing you know there's kids springing up all over the place who are ADD (Attention Deficit Disorder) or ADHD or - you've got to be careful" (Transcript 8, p. 6). Another noted that once services are in place they are in danger of becoming self-perpetuating, he said, "organizations are like human beings, they have a survival instinct" (Transcript 2, p. 22). This survival instinct may contribute to keeping people in institutions; "If there's a little, or not much intake, you tend to keep people there long" (p. 22). So while it is recognized that lack of services and lack of training are part of the reason for institutionalization, it is also important to note that there is little desire to simply mimic what is available in non-Aboriginal communities.

Services and staffing in off-reserve communities. In non-reserve settings Aboriginal people do not currently use 'community based' services as readily as other citizens. The informal phone survey, mentioned earlier, of community based services for people with intellectual disabilities in Winnipeg, shows that about 5 percent of participants are Aboriginal. The Aboriginal population of Winnipeg is at least 10% of the total population so this would seem to suggest that Aboriginal people are under-represented in community-based services.

The community-based services that are being referred to are the agency-run, private board organizations that provide day-to-day support for people with intellectual disabilities. A residential service, for example, may include apartment support programs, group homes, supported foster situations, and so on. They may be large or small in

nature, with as few as eight people supported by an organization or as many as a hundred or more. A day program may support people in activities such as games, crafts, and tours, or in work related programs such as those offered by sheltered workshops. Individuals with disabilities may also be in supported employment where they are assisted to acquire paying jobs in the community. In reserve communities virtually none of these kinds of services exist and off-reserve Aboriginal people tend not to be involved in these services.

There are also no services that adopt an Aboriginal perspective or are particularly culturally sensitive to Aboriginal participants. One participant noted that even in services located close to reserve communities, the values of the typical white culture tend to predominate, "so for example, if you look at (name of service) by and large there's a fair number of people who are Aboriginal who have a (disability), and yet the association there is largely non-Aboriginal" (Transcript 1, p. 5). This is not to say that the culture of every Aboriginal person is ignored if they are involved in a service. No doubt there are staff people in agencies who will want to help an individual with a disability stay in touch with their culture. There is however, no formal approach to ensuring the provision of services sensitive to Aboriginal culture.

Participants offered a variety of reasons for why Aboriginal people are not accessing community-based services. One person suggested that people are simply unaware of services and may be "a bit on the shy side about going out and asking strangers for help" (Transcript 5, p. 9). Another suggested that people may be more inclined to believe that nothing can be done. The dominant culture may say, "the more you cry out, the more you advocate, you're going to get those services," but for Aboriginal people, when they are told "we can't do this . . . and the people say, 'oh, I'm

not being heard' so they settle for that" (Transcript 8, p. 10). This different approach is interesting since most of the changes in services in the community have come about because of fairly aggressive advocacy.

Another factor that helps to explain this under-use of community services is that people may tend to feel more comfortable with services that are designed by Aboriginal people or have Aboriginal personnel. "I do know though" one participant said, "from Non-Aboriginal agencies that have had an Aboriginal team - or whatever - they do serve more Aboriginal people . . . Aboriginal people will seek out the service more . . . there's a comfort" (Transcript 6, p. 15). Currently agencies do not have an Aboriginal perspective and this may be why Aboriginal people are not comfortable in approaching community services. In some instances outreach programs might also be an appropriate means for ensuring that Aboriginal people feel comfortable and welcome in services.

Aboriginal People are Poor

When participants were asked to identify possible reasons for the institutionalization of Aboriginal people with disabilities, the most frequent response was related to the financial poverty of Aboriginal people. High levels of poverty mean that people must focus their energy and resources on basic survival. Money is not available for the development or demonstration projects that might illustrate alternate ways of providing care. Poverty means that often people do not feel they have the power to bring about change. These factors result in people opting for the most conservative option in care provision, namely institutionalization. The Royal Commission Report (1997) points out that in 1991, "over half of the total Aboriginal population received social assistance or welfare payments" (p. 176). Poverty exists for Aboriginal people both on and off reserve

communities.

<u>Reserve Communities</u>

In reserve communities poverty is often related to basic creature comforts such as heating, electricity, running water, and so on. Often in reserve communities these utilities do not exist. Also, in remote communities the cost of food, clothing and other supplies are excessive because of transport costs. High unemployment, reliance on welfare, and under-employment in reserve communities result in these communities being considerably poorer than non-Aboriginal urban and rural settings.

Deteriorating housing stock and overcrowding in existing homes are other factors that make it difficult to get out of poverty. Often is seems that money may be available for operating costs, but capital funds to improve or develop housing are very hard to come by (Transcript 3, Transcript 12). Bands must have loans for housing approved by Canada Mortgage and Housing Corporation (CMHC) and often because of existing poverty it is difficult to get approval. One participant described what happened when a nursing home was built in a community, "well that used up 36 CMHC units when they built it, and I don't think our regional allocation from CMHC has ever been more than 300 a year" (Transcript 7, p. 20). Three hundred units per year across a population of approximately 95,000 people in sixty-one communities is not likely to go far, particularly in light of the extensive demand for new and improved housing.

For Aboriginal people with intellectual disabilities the result of poverty in reserve communities is that there is no resource base upon which to draw in developing supports. In practical terms, it means that it would be hard for a person with a disability to get a home, in that it is hard for anyone to get a home. Likewise, if someone wanted to support

people with disabilities to find jobs, it would be very difficult because there simply are no jobs. There are further implications for people whose disabilities have a medical component. The lack of electricity is problematic for people who need dialysis or have respiratory conditions. For children with complex medical needs, poverty results in a lack of resources that may mean that people have to leave the community simply to survive. One participant observed that in order to make services in reserve communities on a par with other services off the reserve a great many things would have to change,

> It isn't just the support to the family and the child but the whole issue of housing
>
> would have to be addressed the whole issue of services to the town-site would
>
> have to be addressed in terms of running water, central heat, all of those things . . .
>
> proper roads, you know, just to get a wheelchair around is a huge issue.
>
> (Transcript 1, p. 8)

Another participant commented that when life is emotionally and physically hard and we then say to people, "you are going to nurture and have the energy and the love and the caring to look after a handicapped child at the same time," it is sometimes a tall order (Transcript 1, p. 14). In contrast to this, non-Aboriginal families may be eligible for respite, Special Education staff and teaching assistants in school, medical equipment, transportation and other services and programs.

Non-reserve Communities

In non-reserve communities, poverty is still an issue for Aboriginal families. The Royal Commission on Aboriginal Peoples (1997) outlines two key factors related to the level of poverty of Aboriginal peoples who don't live on reserves. Obtaining employment off reserve is very difficult for Aboriginal people. Only four out of ten people find

employment when they leave the reserve (p. 145 Royal Commission Report). Those who

do find employment tend to find it in part time as opposed to full time positions, and their

pay levels tend to be significantly lower than other Canadians; "The earnings from

employment per person (age 15+) for Aboriginals is almost half that of all other

Canadians" (p. 145). Discrimination also plays a role in that Aboriginal people may be

paid less for doing the same job (p. 147). Lack of employment also means that there is

increased reliance on welfare, which by definition ensures that people are poor. Off-

reserve people continue to be poor, unemployed and underpaid.

Concerns about the circumstances of off-reserve Aboriginal people with disabilities

also came up in the study. One participant commented, "even in Winnipeg, more

Aboriginal kids end up in institutions and that's more a function of poverty and how

difficult life was, just normally, apart from having to maintain - to give the special energy

and nurturing that the child with a developmental problem . . . (needs)" (Transcript 1, p.

14). Another commented, "you can't philosophize with me if I don't know where I'm

getting my next meal for my kids." (Transcript 9, p. 15) So poverty is a problem in off

reserve communities as well.

Poverty and service access. It seems that poverty may lead to an over-

representation of Aboriginal people in some services and an under-representation in

others. One person explains, "I think the Aboriginal community of Winnipeg doesn't fit

the mainstream community in terms of, you know, where they are socio-economically and

yet a lot of the programs that are offered are made for the mainstream" (Transcript 8, p.

7). Problems that were mentioned included: lack of child-care for other children in the

family in order to attend meetings, lack of transportation to meetings, and difficulty in

acquiring bus fare for a parent and other children, as well as difficulty sometimes in filling out forms. In some instances a parent may need the approval of their Child and Family Services worker in order to visit a program, and depending on the relationship with the worker, people may or may not feel comfortable in requesting this. This participant concluded, "I think Aboriginal people access certain services and non-Aboriginal people access other services . . . it's created a dichotomy" (Transcript 8, p. 8).

This was reiterated by another participant who described it like this, ". . . this may also be classism, you know, somebody from a totally different class or a totally different culture walks into a home and sees poverty, there may be a wonderfully functioning, loving, caring family, but they're overwhelmed with the poverty" (Transcript 6, p. 10). Outcomes of these various factors are: that sometimes the typical more middle-class model of services may not be appropriate for others, people who are poorer may not feel welcome in services that are primarily middle-class in nature, and in some instances circumstances may be inappropriately interpreted in a class relative way.

In conclusion, the participants in this study saw poverty as being a key factor for children and adults with intellectual disabilities. In reserve communities poverty is related to the lack of capital and operating funds needed to provide both infrastructure and support services. Aboriginal communities are also faced with so many issues that at times it is very difficult for issues of disability to make it on to the agenda. In non-reserve communities Aboriginal people still tend to find themselves in circumstances of poverty that may hinder their access to the more middle class community based services. If there were ever to be any hope of Aboriginal people with disabilities having the same service resource base as other Canadians the issues related to poverty would need to dealt with.

History and Institutionalization

Prior to 'colonization' Aboriginal people enjoyed a cohesive political, social, economic, cultural, and religious life (Frideres, 1998). It was not part of this traditional value system to segregate and congregate individuals in institutional settings. After colonization however, Aboriginal people were frequently removed from their communities to receive various kinds of support services. They have also endured a lack of respect for their ideas and values and have frequently been 'told' what to do. Participants also commented that a pattern of service utilization over the years has included institutionalization. All of these factors have relevance for the institutionalization today of people who are Aboriginal and have intellectual disabilities.

A History of Being Sent Away for Services

People who are Aboriginal have a history of being taken from their home communities. One participant commented, "It seems that the kids that are born with severe disabilities are whisked way very quickly" (Transcript 1, p. 5). The most notable of these is the experience of being plucked from home to attend the residential school, but people have also had to leave for medical care, and to advance their education or access training. Perhaps it is this history of being taken away to receive services that, in part, accounts for the high incidence of institutionalization. When the pattern that has developed over the past century, is one of leaving the community for care, it is not surprising that this becomes the practice for children with intellectual disabilities. One participant drew the following link between the residential school experience and institutionalization:

there's the whole historical kind of things . . . the residential school sort of

experience, so it's not so foreign for us to send . . . we end up sending our kids to

an institution because we see that as, that's what you do. It's part of our history

that's not necessarily a part of non-Aboriginal people's history, so I think that gets

played out a little bit more. (Transcript 6, p. 18)

She went on to explain that this was not necessarily a conscious decision, but the

experience of having to be sent away yourself may make this an option you might never

otherwise have considered.

A History of Being told What to do

Another historically founded problem that participants pointed out is that

Aboriginal people have frequently been 'told what to do'. One person said, "You know,

they're so used to going to a clinic and somebody saying ' well, you know, you really need

this, and it's not ideal" (Transcript 8, p. 5). Another said, "So if somebody from, a

professional comes and tells you, this is sort of what you should do, you're probably likely

to listen to that person" (Transcript 6, p. 8). It is fair to say that in the past the protests of

Aboriginal people have seldom been listened to, so it is quite likely that now people will be

inclined to follow the suggestions of others, particularly when there are no other

alternatives. For Aboriginal people with intellectual disabilities this may mean that when

institutionalization is recommended that advice will be more readily heeded.

History and Service Utilization

Some participants in this study felt that Aboriginal people frequently had high

representation in other institutional and government services. One person said,

"Aboriginal people use the health systems to a larger extent, and Aboriginal people are

more highly represented in the justice system" (Transcript 5, p. 20). In this example there

is nothing pejorative about hospitalization, whereas being jailed has negative connotations. This participant was commenting on service usage rather than on the nature of the services. Another said, "(a) high percentage of kids in care are Aboriginal . . . in foster (and) group homes are Aboriginal, in jails, in the youth centre" (Transcript 9, p. 10).

Institutionalization in a hospital setting for extended periods of times was also cited in at least three interviews (Transcript 11, Transcript 8, & Transcript 9). These participants recounted how people were removed from their homes as children in order to receive health care in an urban centre. They then remained outside the reserve community for much of their lives often loosing contact with their families due to a combination of hospital and foster stays.

People rarely have a choice about their involvement with services such as hospitals, jails, or foster care. The institutionalization of individuals with intellectual disabilities is unlike these services in that it is not mandatory. Even though it is not mandatory Aboriginal people are frequently institutionalized. Perhaps the overall increased general institutionalization of Aboriginal people has made them tolerant of institutionalization simply because of the lack of choice that has been their experience historically. This may be a factor in the increased institutionalization of people with intellectual disabilities.

History and Non - Institutionalization

There were a couple of other comments about history and institutionalization that should be noted. While institutionalization was imposed by lack of choice for many people from reserve communities, both participants and research assistants could also recall individuals with intellectual disabilities who had remained in their home community

(Transcript 1, Transcript 5, Transcript 6, Transcript 8). Historically there appear to have been a variety of scenarios for Aboriginal people with intellectual disabilities.

One participant identified another historical consideration. He said that as far as he could remember, Aboriginal people with intellectual disabilities were not admitted into provincial institutions in the "early days, and I guess we're talking fifties and sixties. The institution in ------ would not admit Indian children" (Transcript 7, p. 10). It was also mentioned that in some instances people were sent to other provinces, for example, "there's been some taken away and placed in other provinces, when they've been children, and now they're adults" (Transcript 3, p. 14). One person mentioned that repatriating Aboriginal people from institutions in other provinces was one of the first jobs he had, (Transcript 7) so it would seem that there certainly was a history of sending people to other provinces for care.

When the institutional options did become available they may have become the only resource that was readily used, or as one woman from the provincial government commented, "my thought would be primarily that it was the only resource that was available" (Transcript 4, p. 12). Often community placement is difficult to arrange, for example, an individual might visit three or four potential residential service providers to see what they like best, then they would do the same to find a day program. Social workers or advocates are involved at each of these visits, so the process can be quite involved. Institutional options provide greater ease in terms of access because all services are provided in one location. The process can be completed in one trip. This kind of easy access may have contributed to the increased use of the institutional model in the past.

A history of having to export people from the reserve community for services has

no doubt had an effect on the increased institutionalization of people with intellectual disabilities. As one participant succinctly put it, "We get institutionalized a lot easier" (Transcript 2, p. 22). Whether it was because it was the only option provided, because it was most accessible, or because it was something that was familiar because so many others experienced the same thing, the result may be the increased institutionalization of Aboriginal people with intellectual disabilities.

Racism and Institutionalization

When I began this study I was curious about the possible effects of racism. In the beginning study the Aboriginal participants felt racism was an issue regarding services and placements and the non-Aboriginal participants felt it was not. The responses in this study were not as clear. Not all participants felt it was an issue and those that did think racism was an issue were both Aboriginal and non-Aboriginal.

The issue of racism is very complicated. One participant said, "I think racism today, when it does happen is so much more subtle. We almost sometimes don't recognize it anymore as racism" (Transcript 8, p. 15). Webster's Dictionary defines racism as, 'A belief that race is the primary determinant of human traits and capacities and that racial differences produce an inherent superiority of a particular race.' The definition also includes 'racial prejudice or discrimination'.

In general, participants in the study tended to feel that overt racism was not a primary problem leading to institutionalization. For example, one person said, "The jurisdiction is more heavier than the racial thing" (Transcript 3, p. 24), another said, "I don't know, if it's really had to do with racism, than it is bureaucracy and what is (money) saving tactics" (Transcript 2, p. 12), while still another said, "I don't know how much of it

is racism and how much of it is classism and how much of it is just cultural difference - so,

I'm not saying that the person is necessarily racist . . . but they just see the world

differently . . . so they may over-react to that situation in a racist way and not necessarily

be a racist" (Transcript 6, p. 11).   It seemed that perhaps because of the complexity of

issues such as poverty, lack of health care and so on, that racism, as we traditionally think

of it, may not be the predominant factor.

While this seemed to be the majority perspective, there were also some statements

that identified overt racism as a problem. One person commented that, "it's presumed by

some Medical Services Branch people, some nurses and staff that are hired by them, that

of course if you are Aboriginal, you can't parent a child with a disability" (Transcript 1, p.

15). Another added that in talking with an Aboriginal parent, a worker may find, "the

person's on social assistance, doesn't have their own home, maybe doesn't have very

much in the way of family support, and the school in the home community doesn't have

special services, they don't have transportation set up for handicapped children, and all of

that," in some instances workers may conclude, "the best place for this child is the

institution" (Transcript 7, p. 13). Here the assumptions seem to be that the child would

have a better life elsewhere, and the outcome is that the child moves from an Aboriginal

culture and language to a predominantly white culture and language.

Racism and Deinstitutionalization

Another factor that may be related to race is that Aboriginal people in institutions

may be less likely to be returned to their home communities.   During the late eighties the

province undertook a deinstitutionalization project.   The project focused on returning

people to their home communities.   One of the conditions of returning home was that

there needed to be a support system in place to receive people. Typically such systems could not have been in place for Aboriginal people because there was no service delivery mechanism. Also, in light of the fact that this was a provincial initiative and that provincial dollars will never be spent in reserve communities, there was essentially a systemic as well as a programmatic restriction on the return of Aboriginal people with disabilities to their home communities. If Aboriginal people were deinstitutionalized to non-reserve communities it is unlikely that their culture and language were maintained in any kind of deliberate way because at present there are no services that consciously focus on including an Aboriginal perspective.

The kinds of services developed might also reflect racism. These might not be the kinds of services Aboriginal people would want given their choice. One participant made the following point, "Most systems are not set up by Aboriginal people, like they're not designed by Aboriginal people for Aboriginal people, so, I think there is probably always an element of sort of systemic racism, just purely by that fact" (Transcript 6, p. 10). The idea of setting up services to deal with human problems is essentially a white, occidental approach to the human condition. At present Aboriginal people are faced with the problem of living within the context of one culture and trying to design services to address their own cultural perspectives.

For me, the question of racism seems to lead to more questions. I wonder, for example, why the profound lack of services is only happening to Aboriginal people if racism is not an issue. The Royal Commission on Aboriginal Peoples drew the conclusion that Aboriginal people "lead marginal lives characterized by poverty and dependence . . . they (are) alienated from middle-class Canadian society through White racism" (p. 194). I

think it is safe to say that racism has had an influence on the institutionalization of

Aboriginal people in both an overt and a systemic way.

Other Considerations

Some issues mentioned were important but they did not really constitute a theme.

These included references to the role of advocacy, concerns about Fetal Alcohol

Syndrome. and reflections on traditional values.

Advocacy for Change

Parents of children with intellectual disabilities have been the backbone of the

advocacy groups which have brought about changes in services over the past thirty to

forty years (Dybwad, 1990; Scheerenberger, 1987). It is primarily because of advocacy

that institutionalization is no longer the sole option for most parents in the mainstream

culture. Within the Aboriginal community there has been little opportunity to form similar

advocacy groups or to join existing advocacy movements. One participant commented

that "people who are Aboriginal in developmental centres lose contact with their families,

and they have nobody advocating for them" (Transcript 4, p. 16). Simply being separated

may lead to a lack of knowledge about the circumstances of a son or daughter with a

disability and the need for advocacy may simply not be known.

There are numerous reasons advocacy has not developed for Aboriginal people

with intellectual disabilities. One participant pointed out that within white culture there is a

tendency to believe that "the squeaky wheel get the grease" and that this may not be a

value of people from other cultures. For people who would prefer to "speak softly and

not raise a fuss" (Transcript 8, p. 10) advocacy as it has occurred in the mainstream, might

not feel like a suitable option. The point in addressing this issue is simply to note that

Aboriginal people have not had advocacy up to this point and that may have a bearing on their higher rate of institutionalization.

Fetal Alcohol Syndrome/Fetal Alcohol Effect (FAS/FAE)

This topic came up in virtually every interview. While it does not seem that FAS/FAE will lead to disabilities that automatically result in institutionalization, participants were concerned because it was such a prevalent intellectually disabling condition. One participant indicated that perhaps as many as half of the children in care have FAS/FAE and that a large percentage of these children are Aboriginal (Transcript 9, p. 6). Another related concern was that while people with FAS/FAE may not be institutionalized specifically because of their disability they may be more susceptible to institutionalization in other settings. One person said, "the fetal alcohol kids, their institutionalization happens at a later date when they go to prisons or jails" (Transcript 1, p. 11).

It is difficult to focus on the concerns related to intellectual disability and people who are Aboriginal without considering the drastic effects that alcohol has had on people's lives. For this reason it frequently appeared as a concern in the study, but more in relation to social issues such as foster care, education, employment, health care, and so on as opposed to being directly related to institutionalization. Participants also felt it was a problem that in the future would result in greater care needs in the community.

A Focus on Traditional Values

Without fail, participants felt that traditionally institutionalization would never have been what Aboriginal people would have accepted for people with intellectual disabilities. In the beginning study one participant said,

I think that if we look at our society, historically there was always a role for people

. . . so people may have been born with some disability but the way in which we

responded or the way that our values and practices - and the distribution of care

might have helped in those situations so that everybody was responsible for that

child. (Beginning Study, Interview 2, p. 2)

It would seem that people with intellectual disabilities would have been included in the life

of the community.

About half of the participants also mentioned people with intellectual disabilities

whom they personally knew in reserve communities, who had remained in their homes.

One woman refers to her reserve community in the following, "we had people with

intellectual disabilities and within the community we were able to somewhat - like - I think

it was recognized that everybody sort of had gifts, and families were able to sort of take

care of you in a small community" (Transcript 6, p. 5). Family networks operating within

tightly knit communities were better able to manage, accept and indeed appreciate the

presence of people with intellectual disabilities.

Some participants, instead of remembering people with intellectual disabilities,

were hard pressed to recall any individuals with disabilities in their reserve communities.

Comments such as, "There was not many in the past" (Transcript 3, p. 16) or "when I was

a kid, I don't remember seeing anyone who was retarded," (Transcript 7, p. 11) reflect

this. Another participant, who also said that in the past there were few children with

disabilities, felt that perhaps the 'clan' system may have been partly responsible for a lower

incidence of disability. In the clan system family bloodlines were traced and unions or

marriages were within approved bloodlines so that disabilities related to heredity would

not be passed on. It is difficult to know at present how prevalent intellectual disabilities

may or may not have been in the past, and there are different notions coexisting at present.

Participants also talked about the way people with intellectual disabilities may have

been perceived in the past. One person described how people were seen as a blessing

from the creator, "those are the most blessed people, cause of their innocence, they're

forever innocent. And it was a blessing if you had one. It's as if they were your guardian,

like the creator blessed you most because of the innocence" (Transcript 11, p. 12).

Another person said, "traditionally someone who may be diagnosed with a mental

disability today, may have been revered" (Transcript 8, p. 11). It would seem that in the

past disability was not necessarily seen as a negative quality and that in fact people with

disabilities may have had additional status within the community.

Ideas about people with intellectual disabilities having gifts, contributions to make,

and roles within society are fairly new to the non-Aboriginal disability service system. It is

only in the past twenty years or so, with the increased focus on deinsitutionalization for

people with intellectual disabilities, that new perspectives focusing on giftedness have

begun to flourish. Participants described these as being traditional values within

Aboriginal culture. It is clearly not a traditional value to institutionalize people with

intellectual disabilities.

<u>Summary of Themes</u>

There is no single, simple answer to the question of why Aboriginal people with

intellectual disabilities are over-represented in institutional services. At present there are

no services for people with intellectual disabilities on reserve communities.

Institutionalization is typically the only alternative that families have available. There is no

clear legislation indicating which branch of government is responsible for Aboriginal people with intellectual disabilities. Because of this, it is not clear who should fund services to Aboriginal people with intellectual disabilities and no branch of government is taking a leadership role to ensure the provision of services. Rather than rising to meet an evident need all branches of government are instead going through a period of restraint.

Problems such as poverty, racism, and a history of off-reserve service provision further compound the problem. The parent advocacy that has fostered the development of services for non-Aboriginal people with intellectual disabilities has not developed because of these problems. Chances of advocacy developing are slim because parents in one reserve are miles from parents experiencing the same frustrations in other reserves. Even if parents did get together, jurisdictional issues are such that it is difficult to know to whom they would address their concerns. In off-reserve communities Aboriginal people are not highly involved in typical community based services. Perhaps this is because community organizations have done little to welcome Aboriginal people.

Despite the numerous difficulties that have resulted in the over-representation of Aboriginal people in institutional services, participants clearly indicated that there is reason to hope that things will change. They maintained that traditional Aboriginal values foster an acceptance of all community members including people with intellectual disabilities. The attitudinal foundation necessary for people with intellectual disabilities to remain in their home communities is consistent with traditional Aboriginal values. Several participants also indicated that the time may be right for things to begin to change.

Chapter 5: Individual Stories

In this study I wanted to learn why people who are Aboriginal and have intellectual

disabilities are more highly represented in institutional settings. The most revealing way of

finding out about this is to have people who are Aboriginal and have intellectual

disabilities describe what has happened in their lives. I was able to learn about the

circumstances of four Aboriginal families with individuals who have disabilities and I

would like to briefly relate their stories. My goal is to give a human face to a topic that

might otherwise be solely bureaucratic in nature. Also, many of the realities faced by

these individuals are echoes of the themes described.

Donald Morgan and his Family

Donald was born in 1963 and he currently lives with his mother in a town near a

reserve community. He was born in a nearby town to a family of six girls and six boys.

His father worked in a garage as a mechanic though, as Donald's mother points out, "he

never went to school - not a day" and, "yet he knew"(Transcript 10, p. 5) how to be a

good mechanic. Donald's mother attended a residential school but she quit when her sister

died in order to raise her sister's children. Donald's father died in 1975 and Donald and

his mother have gone through the deaths of six of his brothers and sisters. She explained

that when the children were young they were very poor.

When Donald was about two years old he experienced seizures that lasted for

about eight hours. He was taken to the local hospital and when he came out of the

seizures he was paralyzed on one side. His mother, father and a social worker then took

him to a hospital in Winnipeg. He stayed in hospital for awhile and then returned to his

family. When he was three or four he was placed initially in a city hospital and then in a

TB sanitarium because, like all of his brothers, he had TB. Donald's mother explained

that their father had pleurisy which lead to him having a lung removed. Following the stay

at the sanitarium Donald went to stay with a couple who knew him from the sanitarium,

namely a doctor and his wife, who was a nurse. This was a very unusual situation in that

Donald's parents were not consulted or asked for their consent in this move. "They never

told me nothing" (Transcript 9, p. 16) was the way Donald's mother remembers this

experience.

While Donald was never placed in an institution for people with intellectual

disabilities, he certainly has extensive experience in institutional settings of other kinds.

The periods of institutionalization meant that he was taken from his home and his contact

with his family was limited. Donald has lived most of his life in poverty which was

identified by participants as a common factor for Aboriginal people with disabilities. The

fact that a Dr. and his wife could take him home to live with them without his parents

consent, seems only possible in a situation where his birth parents were totally

disregarded. This reflects the classism or racism mentioned by participants (Transcript 7

& Transcript 8).

As life went on Donald spent some time again with his family, and then for

extended periods he would be in foster families. He has lived in many small communities

in south central Manitoba. He also spent one more year in hospital in the city when he

was eleven or twelve. In his teens, Donald was again in foster care, working on a farm.

He says that he was told he would be there for a very short time but he was kept there

much longer. In explaining this, Donald recounts the " They were making up stories,

right. Saying that my mom didn't want me, that she gave me up for an adoption. And

that was just a lie" (p. 18).

There are several events Donald specifically mentioned as indicative of the kinds of struggles he has faced in his life. When Donald was going to a school he encountered a teacher who pinched his ears as a form of discipline. When asked why she did that, Donald explained, "just because I was slow at learning, right" (p. 6). When I asked if this affected the way the other kids viewed him, he adamantly said, "it was the teacher - it wasn't the kids it was the teacher" (p. 13).

Another incident that Donald describes occurred when he was working on a farm in a foster situation when he was in his late teens. "I had my chores done - I had everything done - But he didn't like the way I did them - right - so he go mad and he went to the barn and he came out with a milk hose. (Question - Like with a rubber hose?) A milk hose - and he whipped me with it. And I mean he whipped me with it - like a bull whip" (p. 19). In addition to being treated badly, Donald was also not paid for his labour on the farm.

While at this placement, Donald was working during the day at a local sheltered workshop. When he showed his social worker what had happened she arranged for him to move to yet another small town, this time to a group home setting where he would again work in a sheltered workshop. When I asked about the group home, Donald explained, "that's a big group home for handicapped adults. And um - they - I stayed down there for eleven months. And I didn't like the company. (Question: What was it like there?) It's like a jail cell" (p. 22).

Many of the things that happened to Donald are typical of the life experience of people who have intellectual disabilities. Often his choices were not respected and in

some instances his preferences were not even solicited. He has experienced physical abuse and has never been paid for his labour. When he was abused charges were never laid against his abusers and he has never been compensated for damages. Many people with intellectual disabilities share these kinds of experiences (Lovett, 1985; Rioux, 1988).

Finally, in the late eighties, Donald was able to move back home with his mother. For awhile he worked at another sheltered workshop in his hometown, but Donald felt that his supervisors were showing favouritism to other people. He said he explained to his worker, "I'm getting sick and tired of certain people around here having favouritism" (p. 25). I then asked Donald, "Do you think that they treated Indian people the same as they treated white people?" "No, no, nope" (p. 25) was his emphatic response. His mother then said "I don't know why it's like that. And yet we were the first ones here. Indian people were here first in Canada" (p. 26).

Donald also describes himself as a Catholic and he told us how many books are in the Bible, the relevance of the number 666 and the horror of the coming Battle of Armageddon. He also mentioned that in one of the Mennonite homes where he lived, "they had their religion - they forced it on you" (p. 27). Donald clearly makes his own choices about his beliefs however they are probably not the same beliefs he would have had he been brought up with his traditional Aboriginal language and beliefs.

Donald is a very confident person who plays a valued role in his family. There were two young children in the home who popped into the room occasionally to show something to "Grandpa" as they referred to him. Donald and his mother's home is filled with pictures of family members. On several occasions when family members were mentioned Donald would show on the pictures who he was talking about. As Donald's

mother is getting older he is also taking on more responsibilities around the home for shopping, getting movies and so on. Through out the interview, Donald's mother frequently pointed out that often people wrongly underestimate Donald. "They think Donald is stupid you know, people talk to Donald - he talks right. Even the condition he is, you know . . . Donald is smart" (p. 12). He is clearly respected and admired in his home.

Donald also refers to his friends, some of whom have disabilities. He has one friend who uses a communication board to say what she wants, or as Donald puts it, "you point at it and her eyes will tell you" (p. 35). When I asked if there was anything that could make life better for him and his friends he said, "If they want us handicapped people to work - right - they should find us an easier job. That we can do and that we don't have to do too much and get tired as fast" (p. 35, 36).

Despite the sad stories that Donald related this was a very positive and up-beat interview. Often in the interview, Donald's mom would whisper something, in Ojibway, to the Aboriginal research assistant. Near the end of the interview, this happened and Donald said, "I know what you said mother, that I got a big mouth" (p. 36). This kind of humour made this a very pleasurable and informative meeting. This interview was certainly helpful in identifying many of the issues such as poverty, lack of support for families, removal from parental homes, and in some instances, racism that lead to the institutionalization of Aboriginal people with intellectual disabilities. These issues are also consistent with what other participants said.

Colleen and Jim Simpson and their Sister Joanne

This interview was with a woman named Joanne Simpson She has a brother and a

sister currently living in an institutional setting. Her sister, Colleen, has lived in this setting

for about twenty years and is currently in her late thirties, and her brother, Jim, has been

there for all of his life. Joanne recounted the history of the institutionalization of both

Colleen and Jim.

Colleen was not born with a mental disability but when she was about three

months old she fell off of the bed. This seems to have caused some damage, which down

the road, when she was about six, resulted in her having epileptic seizures. As a result of

the medication for the seizures, Colleen's appearance and demeanor where significantly

changed. Joanne explained, "I guess that medication gave her some kind of 'retarded'

features, so people labeled her a mentally handicapped, and that label stuck" (p. 4).

Colleen went to school until she was about twelve years old at which time the

teacher told her mother "that she didn't belong in school" (p. 5). For the following two

years she stayed at home with her family and was active in family life, taking care of

herself, baby-sitting, and so on. When she was fourteen her family was told about a

special program in Winnipeg, and "she went to a special school" (p. 6). When she came

home from the school at about age sixteen, her mother noticed a difference in her

behaviour, "she was more withdrawn, she had no patience, she wasn't tolerant with my

brothers and sister, and then her outbursts of violence . . . she would strike you" (p. 6).

At this time Joanne's mother felt that she could no longer understand what was happening

to her daughter. Joanne was not certain of the exact steps that followed but the outcome

was that Colleen was institutionalized.

She has remained in the institution to the present with the exception of a period in

the late eighties when Colleen tried living in a community setting in a town near her

reserve. Joanne feels that the move to the community was not successful because at this point her sister was so used to the institution that she could not readjust. "She was so institutionalized by then, you know, she was so used to the routine that she was lost when it come down to it" (p. 6) is how Joanne explains it.

For Joanne, the medication and related issues that fostered her sister's disability is a source of on-going anger and frustration. Joanne had to find out for herself which pills Colleen was taking and how they interacted with one another. In reference to this Joanne said, "She was not mentally retarded, and then she took these pills for her epilepsy, to control her dizziness and then to control her vomiting and to control her, and not to reject those pills and psychotic pills, and she took pills to calm her down and pills to put her to bed" (p. 5). She recalls a situation where she was talking to someone from the institution, "I practically kind of screamed at them over the phone, I said, 'Hey, my sister's not retarded, what the hell is she doing there? And I said, my sister could have been normal" (p. 13). The lack of attention paid to the medication and the sense of not having been told what was happening, and of having to find out by doing the research herself, are things that incense Joanne to the present day.

Several of the themes identified by study participants are evident in Colleen's experience. She lived in a reserve community and was removed to receive services in a large urban centre. The move resulted in her losing contact with her family and it is only her sister Joanne who maintains a connection with her. Like Donald, things happened to her that were never fully explained to her family. An example of this is the drugs she was taking, which appear to have been inappropriate. While an attempt was made at deinstitutionalization it was unsuccessful, perhaps because unlike most participants in the

deinstitutionalization project, Colleen was not returned to her original community.

The situation for Joanne's brother was somewhat different. He was born with a mental disability, possibly the result of a medical prescription taken by his mother before he was born. Joanne describes her mother's feeling about this as follows, "the doctors didn't explain to her and she - she said she had a lot of great regrets with that" (p. 7). The brother left home shortly after his birth. "It's just as if he was born and the he was gone" (p. 7). He went to live in a private home placement in an urban centre and after that he was moved to an institutional setting. The 1985 study by Evans, Hunter, Thompson, and Ramsey noted that often the Aboriginal children in institutional settings had come from foster care homes. Joanne's brother's life seems to have followed this pattern. He is now thirty-four and has lived most of his life in an institutional placement.

Joanne describes her mother's parenting as having been a "hardship" (p. 9). Joanne has another brother who had a respiratory problem. From the time he was two until he was twelve he stayed in a hospital in a large urban centre. Essentially he nearly became lost for a period of time. Her mother tried to find out where he was through a branch of government related to health care but she ran into dead ends. He was reconnected with his family when one of his brothers was hospitalized and the nurse recognized a family similarity in the two boys. Joanne's mother is a well educated woman, trained to be a teacher, but the struggles of her life have lead to on-going difficulties in the family. Joanne explains that there is still bitterness between her brother and mother. Joanne's mother has confided, "He thinks I didn't care, but you know what I went through, the agony of the silence" (p. 9). She further explained, that from her mother's perspective, she did not have a choice, "It's either death or the hospitalization" (p. 9).

Within the family, "she had three children that would have been in the institution or the system, two passed away, and then there were several, five of us, at home" (p. 9).

Joanne is currently the only family member who has contact with her brother and sister. She has tried over the years to increase the contact with other family members including her mother but this has not worked out. She speaks very affectionately about her sister Colleen, and the abilities she has, for example. to remember her language, to be bubbly and out-going, to remember long unseen family members and so on. I think she also feels that she should be doing more for Colleen and her brother and mentioned that in the past she had tried to bring Colleen home for a short time to be with her. The amount of supervision Colleen needed was understandably more than Joanne and her young family could provide. She is satisfied with the care her family members receive and feels there is open and helpful communication between herself and the institution.

Joanne identified with many of the themes raised by other participants. She clearly saw the lack of family and community resources as being a key factor in the institutionalization of her family members. She said that her mother received no help from anyone in supporting her children who had extreme difficulties. In addition to this there was the sense that things were out of her control. She says, "all the responsibilities were not in the hands of my mother, or even the family members. So we never made any decision, we never knew what was happening" (p. 17).

When asked about systemic issues Joanne said that poverty was a root cause in the institutionalization of people who are Aboriginal. She also noted that all of the jobs that go along with supporting people with disabilities naturally go to people in urban centres because the services are not provided on reserves. "Poverty, priority, prejudice,

discrimination," (p. 22) these are the reasons for the over-representation of Aboriginal

people in institutional settings as Joanne sees it.

Darrel Fournier, his mother Kelly Fournier, and her partner

This interview was held in Kelly's home on a reserve community north of a large

urban centre. She lives here with her partner and their children and sometimes with foster

children. Her partner was able to join us part way through the interview. Darrel is Kelly's

adopted son and at the time of the interview he was twelve years old. She adopted him

when he was five days old and he was able to stay home until he was about eighteen

months old. At that time Kelly became pregnant and was no longer physically able to

handle him because of her increasing size and his need for twenty-four hour care. Darrel

contracted herpes from his birth mother when he was about a month and a half old, which

resulted in brain damage and fairly extensive physical disabilities. His need for twenty-

four hour physical care and nursing care was a determining factor in his

institutionalization.

Kelly describes Darrel's placement in an institution as follows: "How that came

about is that, well they suggested, the doctors kept telling me to put him in there, but I

wanted to take care of him at home, but it got to a point where I couldn't take care of him

anymore because of me being pregnant" (p. 4). The doctors providing this advice were

with a large hospital in the city. At one point Kelly moved to another province with her

children and she took Darrel out of the institution to come with them. The treatment that

he received in that province was unacceptable to her and her desire for him to have good

care was the main reason for their return to Manitoba. At different points Kelly has also

lived in the city so that she had increased access to her son. At these times she would visit

him on a regular basis and have him home for visits.

At the time of the interview it was nearly impossible for Darrel to visit his family in the country. Their home was too small for Darrel's wheelchair to be maneuvered and there was absolutely no place for him to sleep. Also, the house does not have a ramp and Darrel was getting to be a young man and was too heavy to lift and carry. Maurice, Kelly's partner, mentioned that making an addition to the house might be a possibility in terms of comfort, but added that there are built in disincentives to doing this. Because the house belongs to the band, loans for construction cannot be made against the property and the family does not really benefit from having invested money in the property. Also, the house has black mold and Maurice believes that if "the right health department checked here, this house would be condemned" (p. 24). It is obviously impractical to make any kind of modifications to the home. Having Darrel come home is further complicated by the lack of adequate medical care in the community. If he were to become ill during a visit he would have to be rushed to a nearby community and Kelly commented that, "the hospital's not that great. There's a lot of prejudiced people in there" (p. 10).

Kelly was very pleased with the support that Darrel received in the institutional setting. She felt that for other children with intellectual disabilities, the community is the more appropriate placement, but for someone with 24-hour nursing care needs like Darrel, the institution is the only alternative. She and her partner indicated that other changes would have to take place in the community before children with disabilities can be adequately accommodated. Kelly has a natural son and an adopted son who have attention problems in school and though she has met with the school, she says, "I'm having a hard time with him at the school here . . . I don't believe they can really help. . . .

There's nothing here" (p. 19). She later commented that perhaps people had not been adequately trained for their positions and in one instance she noted that when she was meeting with the principal, her son's file had not even been read, even though the individual had had it for some time. A lack of resources for medical and educational needs was clearly an issue for this family.

Kelly was able to have contact with Darrel and felt that the institution was responsive to her needs and wishes, for example, she wanted to ensure that his hair was kept long, and this was respected. Through the Vulnerable Person's Act, Kelly and her family have also ensured that they have a say in the decisions regarding Darrel. When asked what was important for Aboriginal families of children with disabilities Kelly said, "that they respect the parents and their culture" (p. 28). In the institution Kelly pointed out the Darrel, " has a medicine bag, they know that when there on their time they do not touch those things, those things are in his plan" (p. 28). Kelly further said however, that if there were someplace where he could receive the nursing care that was closer to home and incorporated Aboriginal values. "I wouldn't think twice about moving him" (p. 30).

Kelly and Darrel's experiences illustrate many of the difficulties faced by Aboriginal people with intellectual disabilities. Like other mothers of people with disabilities, Kelly shares the experience of being told by doctors to institutionalize her son. Living in a reserve community has meant that she also faces the problems of inadequate housing with little means of addressing the situation. The community has insufficient health care and an insufficient educational system. There are no people adequately trained to care for people with physical or intellectual disabilities. She worries about having her son in a nearby hospital because of racist attitudes evident there. Again it seems that

Aboriginal people who have family members with intellectual disabilities must face all of the same problems as others with disabilities, but the difficulties are compounded by the additional stresses of racism, poverty and inadequate resources.

In Kelly and her partner's home there are family pictures everywhere and Darrel is clearly part of the family. He has been an influence on Kelly and her family and the decisions they have made. Decisions about him always focused on what would best meet his needs. Darrel is the young man mentioned earlier who passed away shortly after this interview.

Tom Robinson and his sister Cassandra

Cassandra is currently a college student studying nursing. She has a brother, Tom, who has been in an institutional setting for about eighteen years. She and her family came from a northern reserve community. Her parental family is still up north but she has made her home with her husband and two children in a large urban centre. She left home when she was thirteen because she needed to attend high school elsewhere as her local school had burned down. In recalling how her brother was institutionalized Cassandra said, " I was still pretty young when he did leave, so I didn't really know very much that was happening, but I think he was diagnosed as mild retardation due to solvent abuse" (p. 3). She said that Tom's behaviour started to change, his school started going down, he started getting into trouble and finally he began running away from home. She feels at this point that the solvent abuse has caused brain damage and the result is that "his total personality is different . . . his speech is pretty well gone" (p. 4).

Cassandra says that when her brother left she was not really sure about what was going on. This was partly related to the fact that she was young, but she also says that it

was not something that the family talked about, " It happened, everyone was so, 'be quiet about it,' you know, it's kind of done in secret, because, you know, I don't know if it's the stigma of the community" (p. 4). She said that when someone is taken and never heard form again, "It almost feels like a death in the family" (p. 22). Another aspect of Tom's past that she feels has never been fully explained is his reason for abusing solvents. She recounted that she had been abused when she was a child and it lead to a feeling of wanting to be elsewhere, "I knew I didn't want to be there, cause there was really nothing there . . . I just sort of grew up with this thing, lacking in self esteem, whatever. Well, I was struggling, I just needed to get out of there" (p. 9). Cassandra says that she knows Tom is in an institution because of solvent abuse and running away but she wants a deeper explanation, "I'm not satisfied with that, I sort of want to know, okay, what lead to the abuse of solvents, was there something in his childhood that was bothering him, that he needed to escape" (p. 24)? She feels that until the problems of his running away can be addressed it will be very difficult for him to live in a community setting, and that the running away will not be stopped until "we can resolve why he runs away" (p. 23). These are underlying issues that Cassandra would like to understand.

Tom has spent most of the past eighteen years in the institution, with the exception of a period about ten years ago when he tried staying with his family on the reserve. Cassandra describes how this worked out, "They had tried to release him and send him home to my mom and dad. And it didn't work out, because there was no support" (p. 6). Over the years her family has paid regular visits to see her brother, Cassandra says, "My mom gets about one trip a year, from the band to come down and see him. And she usually gets . . . her costs for maybe one or two nights. So there is support there, in that

sense" (p. 12). Cassandra appreciates that her family has maintained contact with Tom,

"My parents made an effort to go and keep contact, they didn't just say, 'okay he's fine

and then just leave him there" (p. 10). About two years ago Cassandra took Tom home to

visit with their mother. She said that Tom talked almost non-stop most of the way and his

being home caused a great deal of tension because of the concern about him running away,

" my mom was like a basket case . .. It was just hard" (p. 7). At this point Cassandra

feels that perhaps Tom is past the point of being able to live in the community.

     I think one of the key frustrations for Cassandra is that there seemed to be little or

no support for her family over the years. She felt that in the early days if counseling

supports had been in place her brother might not have turned to solvents and her parents

might have known better how to deal with Tom. She mentioned that when she went home

with her brother, family members did not seem responsive, " The thing that sort of upset

me, was that there was no support. Even within the immediate family members . . .

they'd come and say, 'Oh Hi' you know, we'll come back but they never showed up" (p.

7). These same community members seem then to have been somewhat judgmental of

Cassandra's parents for not having kept Tom at home. She said people would comment

to her. "Oh, your brother went back, too bad, you know, your mom should have just kept

him" (p. 17).

     Cassandra felt that often the community could have been more supportive and

responsive to the needs evident in her parental family. She mentioned instances when

people had children who were taken away and they have made little or no attempt to stay

in touch and she also felt that sometimes within families, the foster children or children

with slight disadvantages were treated less well than the other children in the family. In

discussing these issues the research assistant at the interview felt that perhaps "five hundred years of being abused" (p. 19) might in fact have proved an effective model for this kind of behaviour.

Cassandra's experience shows again the lack of resources in reserve communities. It seems that her family was left to cope alone with the difficulties they encountered. The lack of community support also made it very difficult for her brother to return to the community and his deinstitutionalization was unsuccessful. Cassandra has really only reconnected with her brother in the past two to three years as part of a planned visitation program at the institution.   At present, I think it is fair to say that this is something she is doing for her brother because he enjoys the visits and seems to be benefiting from them.

Summary of Family Interviews

The family stories confirm many of the themes mentioned by other participants who did not have a family member with a disability. All families report a lack of resources in reserve communities and for Colleen, Jim, and Tom the remoteness of their communities compounded the problem. Their institutionalization resulted in a loss of connection with family, a loss of advocacy, and a loss of language. In the two instances where people with intellectual disabilities had returned to the community, the deinstitutionalization process had been unsuccessful because of a lack of support. All family participants described how institutionalization was the only option that parents felt they had available; it was either "death or the hospitalization" (Transcript 11, p. 9).

Poverty was another problem sited in all of the family interviews. In some instances participants referred to personal poverty and in others to the overall material poverty of the reserve community. Three of the four families indicated that racism was a

factor that in some way affected the institutionalization of Aboriginal people with intellectual disabilities. In Donald's, Tom's, Colleen's and Jim's stories the family member related that decisions were being made that were out of their hands and in some instances they were not informed about decisions. This feeling of not being in control was identified most clearly in the family interviews.

Chapter 6: Recommendations for Service Provision

One of the questions that participants were asked was what they would 'like to see' for people who have intellectual disabilities and are Aboriginal. Many of the responses focused on the nature of supports or services. Others focused on the philosophical perspectives that would underlie supports.

A fundamental issue that must be noted before thinking about services or supports is the complicated issue of the legal, jurisdictional, and policy conundrums related to responsibility for Aboriginal people with intellectual disabilities. Without some focus on responsibility or appropriate mandates by the federal, provincial, or band governments, it seems unlikely that there will be any change. What needs to be determined is where Aboriginal people with intellectual disabilities or their families should go to have their support needs addressed. At present governments have provided little clarity about this.

The issue of responsibility seems most crucial for Aboriginal people with intellectual disabilities in reserve communities. Once an individual has left the reserve, he/she is as entitled as other citizens to services offered by the province, though as has been discussed, these services appear to be accessed less frequently by Aboriginal people than by others. While on the reserve an Aboriginal individual with an intellectual disability has no avenue for addressing service needs. It is difficult to know what would be effective in having governments begin to address this issue. At present there is no evidence of any political will to bring about change. Without change Aboriginal people with intellectual disabilities will continue to be over-represented in institutional settings.

Every branch of government seems to have ways of abdicating responsibility, for example, the federal government can argue that disability is not really a health related issue

so it is not covered by treaty considerations. The new provincial legislation for people

with intellectual disabilities, namely, the Vulnerable Persons Act, has not yet been

effectively used to ensure service in non-reserve communities so it's difficult to know

what the effect of a challenge would be on reserve communities. The provincial

government can argue that its service to people with intellectual disabilities is not a

mandated and that they have no jurisdiction on the reserve. Bands that administer funds

can argue that the funding is allocated to specific things and that they are barely able to

provide a minimal level of service to those without disabilities let alone supporting

individuals who may need more.

In an atmosphere where everyone is abdicating responsibility the people who loose

out will be Aboriginal people with disabilities and their families. This means that the

federal government, the provincial government, and band leadership need to begin to

consciously decide to address the needs of Aboriginal people with intellectual disabilities.

It would seem that minimally citizens should be able to expect the same level of support

regardless of where they live in the province. That various levels of government will begin

to address this need for fairness is doubtful as long as there is little or no demand for

change.

There may be a role for the broader disability movement in bringing about change.

Typically individuals advocating for the rights of people with intellectual disabilities have

assumed that they were fighting for all people with disabilities regardless of race. If, as

this study is suggesting, some racial groups may be being left out of services, there may be

a need to address this omission. Also, in the broader community, service development

typically occurred because families and advocacy movements lobbied for necessary

changes. No doubt, this same advocacy is needed by and for Aboriginal people with intellectual disabilities. Participants suggested however, that the advocacy methods used in non-Aboriginal communities may not be effective or culturally appropriate in reserve communities.

Aboriginal people living off reserve may choose different models of service delivery than what is typically available. Ideally, different service models should be possible through the planning process developed by the province. The low representation of Aboriginal people in off-reserve services may also mean that some kind of outreach or welcoming process should be in place. This would ensure that Aboriginal families felt a sense of welcome in existing services as well as ownership for the kinds of service models that they might develop.

Related to advocacy was the idea of forming an association for families of people who were Aboriginal and had intellectual disabilities. This suggestion was made by one of the family members. She said that she felt it would be helpful if there were opportunities for increased awareness and training for Aboriginal families who may have been away from their institutionalized family member for some time. She also saw this as a way of linking Aboriginal people who had been institutionalized with their culture. No doubt the formation of such a group would facilitate increased understanding of advocacy issues.

In terms of service design and delivery it was an over-riding response that people would be best supported within the context of family and community. This priority was described as being essential whether support was provided in rural reserve communities or in urban centres. What follows are key ideas about the philosophical underpinnings of systems that might be appropriate for people who are Aboriginal and have intellectual

disabilities.

Language. In various interviews the importance of language was mentioned. In some instances participants referred specifically to the importance of understanding language in order to correctly interpret treaties. The correct interpretation of treaties is at the heart of the jurisdictional question. In terms of service delivery, it is important that services be provided in the language of the person with disabilities. One of the family members that was interviewed recalled with pride that her sister could still remember her language even after having been institutionalized for many years. For another participant, the fact that he had spent many years in foster care meant that he could no longer speak his own language. This fact was recounted with regret.

Holistic approach. Aboriginal participants in this study tended to refer to disability in a broad or holistic way. For example, one participant felt very uncomfortable referring to people as having disabilities and said that she preferred to say "the less fortunate people" (Transcript 3, p. 5). In another instance a participant said that he preferred a much broader definition, one that could include a concept of "spiritual loss" (Transcript 2, p. 24). Still another person advocated a 'holistic' approach whereby someone may be assessed according to alternate means such as the 'medicine wheel'. In this instance an individual might consider their spiritual, emotional, or intellectual needs. "We help them to assess what their needs are and then we help them to determine how the needs can be met" (Transcript 8, p. 9). This was supported by another person who said, "there's also ceremonies and things that can be made available I think to Aboriginals around some of these issues" (Transcript 6, p. 6). These approaches are somewhat different than the prescriptive ways of assessing people with intellectual disabilities that are

typical of a more western perspective.

Giftedness.   Another factor related to the nature of service delivery had to do with the focus on giftedness that was mentioned earlier. One young man was described who was:

> very violent, and mentally challenged and was in an institution, and when we went down there and these people did some work on this person. traditional work. - It sounds really strange, but all this person needed to do was to use their gift that they were given. And for him it was singing. And they got him a drum and started teaching him songs and, this person was, like he was taken out of the institution and - very calm, very happy. (Transcript 8, p. 14)

While this is an example of an individual discovering his particular gift, there was also a more general recognition of giftedness. Another person said, "Everybody has a gift, drawing out those gifts that they have, because they have them, until that gift doesn't come out, it's going to stay there" (Transcript 3, p. 8). Others reinforced that people with disabilities have things to offer, "a lot of people say, these kids are important to us, they made us feel needed" (Transcript 2, p. 24), another said the following in reference to communities where children are removed, "Those communities don't share in the gifts that you and I share when those kids are born and cared for in our communities, there's a lot that they contribute to the community" (Transcript 1, p. 6). These statements reflect the perspective that people with disabilities not only belong in their communities but have contributions to make.

Developing giftedness is related to focusing on the capacity of a community. In terms of having things happen within a community it was noted, that the time for doing

things had to be right. People would have a sense when it was the right time to bring

about change and it would not be wise to do something if the time was not right.

Likewise, in three interviews the developing role of women was mentioned. One person

said, "there was a time when it was the women - they were the voice of the community"

(Transcript 12, p. 25). This was sited as an indication that there is hope that

circumstances will change. The need for research, awareness and opportunity related to

people with intellectual disabilities was also mentioned. Giftedness, building community

capacity, noting the growing role of women, and sensing that the 'time is right' are all

distinct elements that affect the likelihood of things changing for people with intellectual

disabilities.

Building on these underlying ideas, participants had more specific

recommendations about what they felt would be involved in an effective service models.

These are practical ideas about implementation that coincidentally often reflect what is

currently believed to be 'best-practice' in the field of intellectual disability.

Community based and controlled. Services must be "community based and

community controlled" (Transcript 2, p. 24). It is important that people receive services

in their home communities and that services be individualized to the specific needs of

families. In several instances it was pointed out that each community is different and

communities must feel that they have a system controlled by them that will work for them.

Keep kids in families. Services must focus on keeping kids in families and

building supports to families. "Agencies make bad parents" (Transcript 2, p. 16) was a

comment that perhaps best reflects this. Another participant stated that families are the

ones who should say what they need and the service system should be there to help them

get it; "What's the most expedient, least bureaucratic, most humane way of getting this money and this service to this family" (Transcript 6, p. 14). Generally, group homes and other semi-institutional models were not described as being desirable alternatives for people. One person stated strongly, "For me, group homes are just not a good thing, because again, you're institutionalizing people" (Transcript 2, p. 15).

Use flexible models of support.   Service alternatives that focus on flexibility were also identified as being important. For children in foster care, for example, it was suggested that terms of care be as short as possible and that the most humanistic as opposed to legalistic alternative be chosen if children must be taken into care (Transcript 2, p. 16). Providing support to a family, by paying a neighbour, was also sited as another way of using resources in more flexible ways (Transcript 6, p. 16). For adults, the possibility of exploring in-home care programs, similar to services such as home care, or respite were also suggested (Transcript 7, p. 17).

Attach funding to the individual.   A related suggestion, was that the funding used for support be attached to the individual rather than to a particular service or agency. One person describes this as follows: "(having) the money attached to an individual and having circles of friends and supporting people in different circumstances, is probably the best thing we've thought up so far about how to get funds to really help people" (Transcript 1, p. 22). Attaching the funding to the individual would mean that wherever an individual went they could receive service. Currently, as we have discussed, individuals in the province receive very different supports depending on whether they live in an institution, on a reserve, or in non-reserve communities. If a person could continue to receive the same dollars that they currently receive in the institution regardless of where they live,

they would be afforded a great deal more flexibility at no additional cost to funding bodies.

Develop a family centre. One participant referred to the development of a family centre in a reserve community. This would be a place where, "kids could be dropped off, no matter when, or what time, and there would be a combination of volunteers and trained people who would care for the children no matter what the issue was" (Transcript 1, p. 12). This was viewed as a way to provide respite and care to for all children including those with developmental or physical disabilities. The family centre was not intended to be a daycare, as it would also be a place where parents could come with their children and visit other parents and have children play with one another.

Hire Aboriginal staff. The importance of hiring Aboriginal staff to work with Aboriginal people who have intellectual disabilities was mentioned in several instances. One participant suggested that this should be noted as a policy within support organizations (Transcript 3, p. 9). Those who felt that Aboriginal people would feel more comfortable in settings where they were visibly represented advocated the hiring of Aboriginal staff. In supporting this one participant said, " I think that it is really important, in terms of comfort for the community, in terms of the kinds of programs, kind of services, the kind of approach you take with people" (Transcript 6, p. 16). Both within reserve and non-reserve communities the hiring of Aboriginal support personnel could also serve to address the low employment levels that Aboriginal people currently experience. At the present time most of the dollars designated for staffing are paid to non-Aboriginal people in non-reserve locations.

It was also noted that changes cannot only happen within one group in a society.

For things to change for Aboriginal people with disabilities there must be larger systemic change. "It's society itself, it's got to change. It's not only a certain racial group or certain ethnic group - or whatever - it's the whole. And that's why I cannot do it alone, it's got to be done together . . . then and only then I think we can begin to look at having young people like ----- at home" (Transcript 12, p. 28). I suspect it is always easier to look at what we think others should change rather than addressing changes that we, ourselves, should make. In this quotation the participant is suggesting that in order for things for change for Aboriginal people with intellectual disabilities, there must be a rethinking of priorities within the broader society.

Naturally, changing a service system is not an easy thing to do, but many of the suggestions and comments made by participants lead in a positive direction. Within the study, these present many reasons for hope that things will improve for people with intellectual disabilities who are Aboriginal.

Conclusion

Several themes have been identified that help to explain why Aboriginal people with intellectual disabilities have been institutionalized. These include: jurisdictional issues, problems related to being in a remote community, problems associated with poverty, a history of having been exported from home communities in order to get services, problems related to racism, a lack of training about disability issues, problems related to services and resources, lack of clear legislation, and finally, a present lack of advocacy for change. These conclusions were drawn from the words of people in government, in service delivery, in advocacy groups, and from people with intellectual disabilities and their families.

In addition to these themes I feel there are at least four key conclusions that can be drawn from this study. The first is related to the fact that this is a new topic for discussion. It seems that at this point very little thought has really been given to the institutionalization of Aboriginal people who have intellectual disabilities. An initial conclusion is that awareness and thought are needed. Aboriginal communities, people from within the intellectual disability advocacy movement, and people involved in the service delivery system need to consider whether this is an important issue and if it is, what can be done about it.

A second conclusion is that this issue occurs in a very complex environment. It would be an extreme understatement to say that Aboriginal people have a 'lot on their plate' at the moment. Broad issues of disability and health care are just beginning to be addressed. Systemic problems of poverty and jurisdictional wrangling mean that nothing is clear cut in terms of what should happen. Though, without fail, participants said that within the traditional value system people would not have been institutionalized, it is very difficult at this juncture to find easy solutions.

Thirdly, I would conclude that there is a very different level of support services for Aboriginal people with intellectual disabilities than there is for non-Aboriginal Manitobans. At present we have two diverse levels of service in the same province. While participants did not say that this was the result of racism Aboriginal people in reserve communities are the only Manitobans with intellectual disabilities without existing supports. I think there are systemic issues that must be addressed in order for life to change for people with intellectual disabilities who are Aboriginal.

A final conclusion is that there are many reasons to think that things can change

for the better. Participants in this study did not approach issues with any kind of fatalism or despair. They seemed to have confidence that things could change for the better. The numerous recommendations that participants made for improved support to people with intellectual disabilities who are Aboriginal reflect a sense that things can change and that perhaps the time is coming for things to begin to change.

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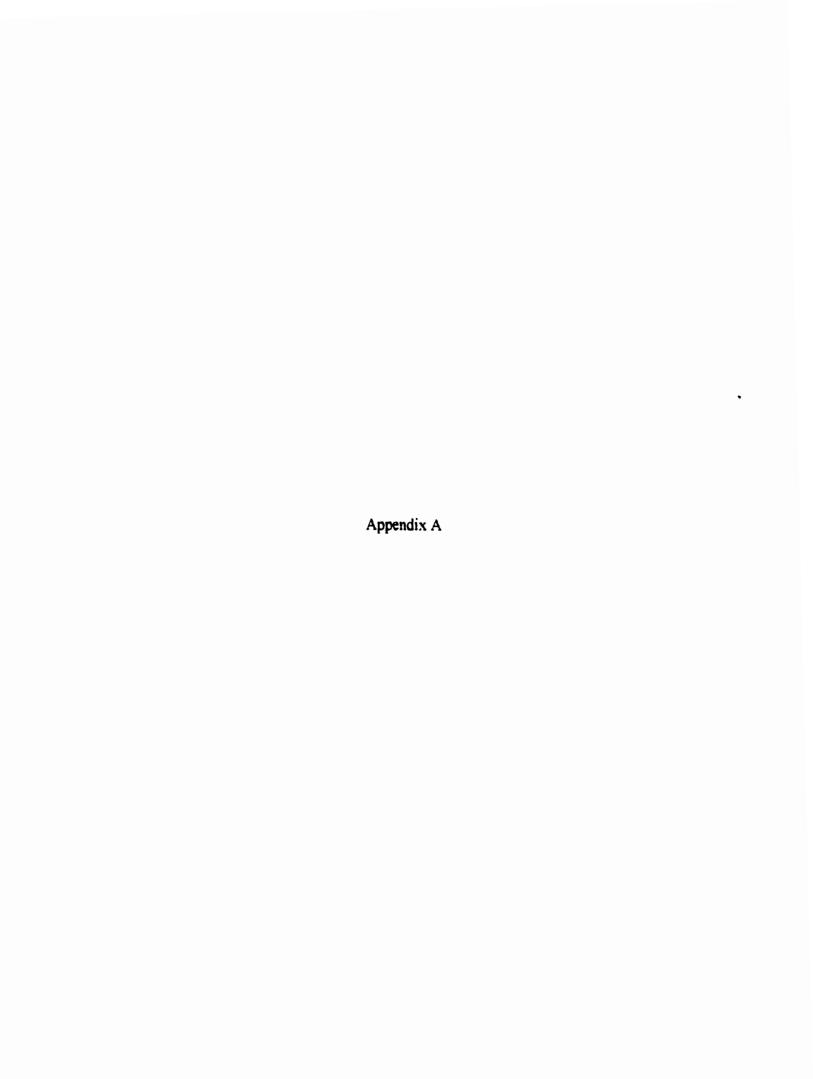
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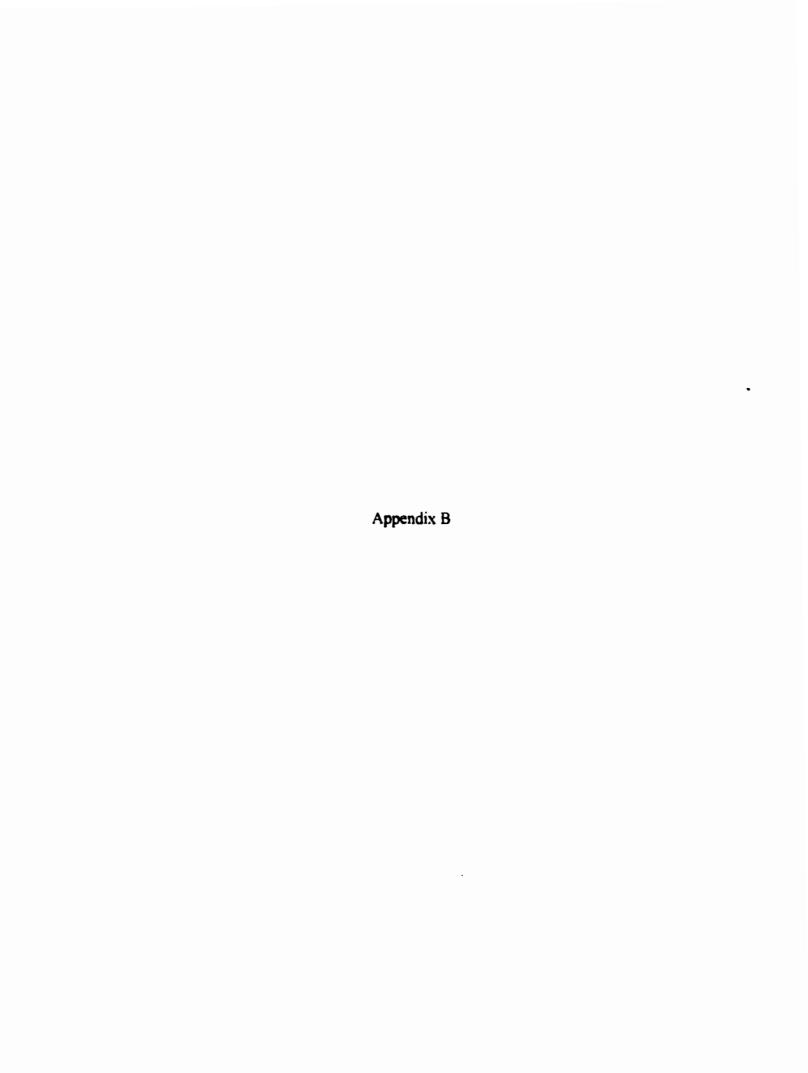
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Appendix A

Faculty of Education Library, University of Manitoba

Journals reviewed as part of the literature search.

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2) Advances in Special Education (1980 - 1994)

3) Behavioural Disorders (1976 to 1997)

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17) Entourage (to 1997)

18) Journal of the Association of the Severely Handicapped (to 1997)

19) Mental Retardation (to 1997)

Appendix B

Beginning Study

Analytic Memo

When I was a child I lived on a farm in Saskatchewan. Our farm was situated immediately next to an Indian Reservation. Both the farm and the reserve were about fifteen miles from the nearest town, which was Garwood. Everyday the school bus would pick up children from the reserve and then pick up me. One day when I was in grade two or three we were waiting at the school in Garwood for one of the reserve children who was taking a long time to get ready. Her name was Sharon Wolf and we were the same age. With growing impatience the driver simply decided to leave her in town to teach her, and I suppose all of us, a lesson. On the ride home her two older sisters wept silently. Somehow I knew instinctively that this would not have happened to me; I would not have been left. This stands out in my memory as my first introduction to racism.

For the past three and a half years I have lived in an area of the city where many of my neighbours are of Aboriginal background. This has lead to an increased awareness of the issues currently facing First Nations people. I think I have become more attuned to news items, reports, issue statements and social commentary that relates to Aboriginal people because of this closer proximity. I am developing a growing understanding of the historical and current injustice that many First Nations people experience.

I also teach in the Developmental Services Worker program where for the past two years we have had Aboriginal women as students. They began asking questions about how services were provided to native people. They indicated that there were lots of Aboriginal people receiving services in institutional settings but very few in the community agencies they visited.

These factors have lead to a growing interest in finding out more about the experience of Aboriginal people with mental disabilities.

The purpose of this study is to consider why Aboriginal persons are so highly represented in institutional settings. Aboriginal people typically make up about 10% of the provinces population, however in institutional settings for the developmentally disabled they comprise between 20 and 25%. During this study I spoke with five individuals about why they thought Aboriginal people are so highly represented in institutional services.

Identifying Informants

At the time of the study I was working half time at the Lifespan and Disability Research Office at the University of Manitoba and half time with the Developmental Services Worker program at Red River Community College. Both of these environments provided me with individuals who were familiar with disability issues and who suggested people I should speak with. Also, because of the nature of the topic, it was clearly important that I speak with individuals from within the institution. Had they not been open to being interviewed it would have been extremely difficult to find other participants with their experience and knowledge. Because of this I spoke with a key individual from the institution prior to attempting the study. It turned out that there was interest on their part as well. This openness made it possible to proceed with the study. The first interview was with institutional personnel.

The second interview was with an Aboriginal woman currently working as a faculty member in the School of Social Work at a local university. This recommendation came in a rather round about way, through a co-worker at the university who had taken classes with a young man in social work who was interested in Aboriginal issues and had lots of contacts. He

recommended that I speak with this woman. She was particularly helpful at providing a

historical perspective to the issues of poverty, loss of traditional values and the importance of

communities sharing responsibility for all community members. She also clearly outlined the

historical and current affects of the federal government '.s policy of assimilation.

Shortly before starting this project I was able to attend a public lecture at the Centennial

Library. Four Aboriginal women who had disabilities spoke about the issues they faced and the

current need for awareness regarding their struggle. One of these women provided a good deal

of both historical and current information and she agreed to speak with me about my topic. She

became my third interviewee. Upon interviewing her, it became apparent that she had an even

broader scope of experience than was initially evident. Because of her personal experience, her

expertise as a long standing worker in Aboriginal organizations and her current efforts to

advocate for Aboriginal people with disabilities, she was a very valuable resource.

The fourth interview was with the director of a local advocacy agency. Following the

first three interviews it became apparent that part of the explanation for the high percentage of

Aboriginal people in institutions was not new admissions, but lack of deinstitutionalisation for

people who had been there for longer periods. This development lead to a need to determine why

deinstitutionalisation was not more prevalent for this group of people. Because advocacy often

plays a key role in deinstitutionalisation it was important to interview someone from within the

advocacy field. This interviewee effectively outlined the deinstitutionalisation process and

expressed an interest in pursuing new opportunities for deinstitutionalisation and community

building. His organization has already collaborated with various First Nations communities and

feels that a foundation may be there for further exploration.

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The last interview was with an Aboriginal woman with a vision impairment who works for a large local Aboriginal organization. This person was also involved in researching issues related to Aboriginal people and disabilities so the topic was familiar for her. This was an excellent final interview because she was able to draw together the various issues that had been raised in previous interviews and present an overall perspective.

I feel that this combination of individuals effectively addressed my topic. I would however have also liked to speak with individuals from within both the provincial and federal governments. They could perhaps provide a clearer perspective on funding dilemmas and jurisdictional concerns. I tried to contact personnel within the provincial government. I was passed from one individual to another and to another - who said that the first person was actually the one I should have spoken to. These phone calls were placed in March, which is the government year end, so perhaps this was not the ideal time for interviews. In any further study these contacts would be important.

I also tried to get in touch with a local social planning organization that has played a leading role in addressing both native and disability issues. Personnel were willing to talk but because they were in the midst of putting on a conference no one was able to meet within the limitations of my time lines. In the future I think their perspective would also be important.

In the early part of this study it seemed that I might not be able to find enough people who would be willing to be interviewed. Altogether I spoke with about fourteen people before I was able to find five people who were willing to discuss this issue. During the interviews however, several suggestions were made about others who should be interviewed including: a children's advocacy organization, personnel within the field of health, personnel from other

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disability and advocacy agencies, the public trustee, child and family services and so on. I think

that in the future it would also be important to get a clearer understanding of jurisdictional

issues. Additionally I would like to talk directly with families to hear their personal experiences.

With these additions I feel a very complete picture of this issue could be developed.

Data Collection

The process involved five interviews over a period from March 11, 1997 - April 1, 1997.

All of the interviews were audio-taped and then transcribed. Typically interviews were about

one hour in length. In three instances they took place in the participant's workplace. In one

instance the interview was at my office and in another at a conveniently located restaurant. The

interviewees seemed to feel comfortable with the process and even though they initially made a

comment or two about being tape-recorded this seemed to disappear once the interview had

begun.

As each interview progressed it seemed that new questions were raised. For example,

following the initial interview with personnel at the institution it became apparent that the

primary problem was not recent institutionalization but institutionalization from the past. The

real problem was related to practises from the fifties to the eighties when perhaps Aboriginal

people were institutionalized at a greater rate. This also raised the possibility that perhaps they

were not as readily deinstitutionalised as other residents. Again the focus shifted because

attention was drawn to the importance of service options for people returning to their

communities.

In another interview, the role of the new Vulnerable Persons Act came into question.

The participant and I wondered if the planning process required in the act would be applicable to

Aboriginal people and if in fact this might lead to greater deinstitutionalisation. On the other hand we thought that the act might not apply because Aboriginal people are seen as being the responsibility of the federal government and the act is a piece of provincial legislation. Questions such as these then became relevant in the interviews that followed. In this way the interviews tended to build on one another.

Data Analysis

When the interviews were completed the work of analysising the information began. Following each interview I recorded information about the context of the interview. This included the location, time and duration of the interview, any external factors that may have influenced the participant, and any items that seemed noteworthy or unique to the particular interview. The contextual notes were usually about one page in length. These contextual notes along with the transcriptions of the interviews formed the main body of material or data. This information was read and reread and gradually the key themes related to the topic became clear. In some instances participants stated directly what they felt the issues were while others sort of 'thought outloud' and their information was more descriptive. When three or four people mentioned the same issue it became apparent that this was a key theme.

Setting the Context

If we were to attempt to look at the stereotypical native resident of an institution for the developmentally disabled we would probably find someone over the age of thirty-five who was admitted to the institution as a child sometime between the 1940's and the 1970's. At the time of his or her admission it would have been common practice to remove children from their family home to attend a residential school. Having a child taken away was thus fairly common place

for Aboriginal families of the time. Also, there were no resources for Aboriginal families to draw on to support this child with the possible exception of very limited health services. Families had little recourse but to accept these enforced decisions.

At present, our hypothetical individual has now spent almost all of his or her life in an urban, institutional environment. His or her family may have been able to visit once or twice a year depending on the monies made available by very financially restricted band offices and there may have been the occasional visit from someone else of their original community. There is a good chance however, that his or her sense of identity has been formed by the current environment rather than family traditions. Back in his or her home community people have little experience of supporting someone with a developmental disability. Few services have been developed because the individuals requiring them have been removed. Also, the skills of caring for people with disabilities have been developed elsewhere.

This scenario begins to illustrate the complex nature of this issue and the variety of influences that affect it. Each participant in the study offered a unique perspective to further explain the institutionalization of Aboriginal people.

Systemic Problems: Getting to the heart of the issue

Jurisdictional Issues. In each interview the current discussion between the federal government, the provincial government and Native Bands over who should have the right and responsibility for governing Aboriginal people became apparent. This issue is relevant to my topic because it relates to both funding and advocacy. Currently there are no institutions on reserve lands so in order to be in an institution first nations people have left the reserve. When Aboriginal people are on reserve lands they are the responsibility of the federal government. As

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soon as they leave they are viewed the same as other citizens of the province. The fact that Aboriginal people lose their status when they leave the reserve is a bone of contention for Native Leaders.

When individuals decide to move from a provincially funded institution into the community their funding source may vary depending on whether they go to a rural reservation or another location. Because neither provincial nor federal governments are prepared to provide any new funding, there is considerable tension regarding any kind of change. Advocacy is also an issue in that it is difficult to know who to address with concerns about needed change. Determining who should pay and who should be responsible for Aboriginal people is a large part of this jurisdictional issue.

Historical Issues. Closely linked to jurisdictional issues are historical factors. Lack of commitment on the part of the federal government to maintain treaty agreements was cited as a frequent underlying cause of the current situation in which Aboriginal people find themselves. One participant said that, "after the treaties were signed with these promises government never maintained its part - they took on an assimilation policy" (Interview three). Several participants indicated that health, education, housing and economic welfare were all responsibilities upon which the federal government had reneged. When asked why this had happened one participant stated that in her opinion the government had never intended to honour these commitments (Transcript three). This lack of historical commitment has left Aboriginal people in a position of powerlessness and lack of confidence with the federal government. Participants believe that historically there was a lack of commitment to fulfilling treaty promises and this lack of commitment continues today.

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Poverty. Poverty frequently appeared to be an issue. There was general agreement that poverty was far more prevalent for first nations people than for other Canadians. For the Aboriginal participants the roots of poverty lie in the federal governments lack of willingness to fulfill treaty responsibilities. Poverty both on and off the reserves was seen as problematic. One woman explained, "The bands are so underfunded they don't have the economic base to meet the needs of special needs children" (Transcript three). Another said, "We have not been included in the economic structure of society" (Transcript two). The effect of poverty is important to note on two fronts. First, it is often seen as being at the heart of related problems such as poor nutrition, poor housing, alcohol and substance abuse and a growing sense of hopelessness. In one incident that was cited, a family did not have a house and this was the presenting problem that inhibited their ability to support their child. Secondly, there is the realization that in order for things to change there needs to be increased funding. To develop services both in urban and reserve communities there will be a need for renewed resources. One participant explained, "government likes us to try . . .to be as innovative and be as creative as we can about our approaches . . . - as long as we don't ask them for money" (Transcript five). At a time when there is increasing awareness of the importance of services there is also an understanding that little or no money will be easily forthcoming.

Racism. The Aboriginal participants also indicated that racism was an underlying factor in the institutionalization of Aboriginal people. They suggest that this is typically not overt racism but rather systemic racism, whereby the source of the problem is much more difficult to pinpoint but it becomes evident that one group in society tends to benefit while another forms a social under-class. When asked about the role of racism one participant said, "I think that's

what this country is built on" (Transcript two). These participants point to fundamental cultural differences that have never been accepted by mainstream society. In describing the way systems have developed this same person says,

> They (systems) were built for mainstream society by mainstream society and when the legislation changed to enable non-Aboriginal people to go into communities what values did they use? . . . What lifestyles did they come form? What philosophical base do they hold? They transplant that into a community that is very different.
>
> (Transcript two)

Because of racist practises it has been more acceptable to institutionalize Aboriginal people. The prime example of government policy has been the residential school. The effects of residential schooling and the consequences for communities are still being experienced. The practise of forcibly removing large numbers of people, namely the children, set a precedent for taking people from their community and providing services in an institutional setting. One woman explains that they have been institutionalized in the "residential school system, people have been institutionalized in health care - in child welfare systems" (Transcript two) and that these experiences have had far ranging consequences.

Racism also becomes an issue when we consider that Aboriginal people appear to access so few community based services. The non-Aboriginal participants were adamant that community supports were the same for everyone, that it is "purely typical of anybody else in Canadian society" (Transcript four). Yet Aboriginal people are less likely to draw on community disability services. It was suggested that perhaps cultural adaptations are necessary to make services more accessible. It was noted that services like, respite for example, fit in well

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with a typical mainstream lifestyles but they may not be as appropriate for other cultural groups. (Transcript one) Also, Aboriginal people may not feel that these services are truly their services. One participant commented that there is still a stigma of being Aboriginal, "even a lot of non-Aboriginal disabled people don't like Aboriginals - whether they're disabled or not" (Transcript three). There is no foundation of trust upon which to build.

Closely related to the issue of service access is the awareness that there are so few Aboriginal professionals to whom first nations people can turn. One participant asked, "how many speech therapists are there that are Aboriginal, how many physio-therapists are Aboriginal ... they're quite capable of taking care of their own but they don't have the skills as yet and the resources" (Transcript three). It was also suggested that Aboriginal children may be diagnosed differently from other children. This was described as being particularly true if children spoke their mother tongue in their homes, "when they speak another tongue it's another way of thinking" (Transcript three). It was felt that they may not perform as well on standard tests and may consequently be diagnosed less positively that mainstream, non-Aboriginal children. There was also an indication that native people might more readily be offered the institutional option, "How may parents have told me that they were told right off - as soon as their child was diagnosed ... well, you know, we have some really good institutions" (Transcript five). All of these factors are related to different treatment or different alternatives that seem to be founded on race.

All of the responses listed so far may seem to have little direct affect on the rate of institutionalization of Aboriginal people. However these are the underlying cornerstones of the matters at the heart of the issue. In order to understand why there is a higher rate of

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institutionalization all of these underlying causes must be understood and then addressed.

Process of Institutionalization

Most of the institutionalization of Aboriginal people appears to have occurred in a period prior to the 1990's. It is no longer the practise to readily institutionalize anyone, including Aboriginal people. Institutional personnel were very clear about this. One individual said that each time they were faced with making a decision about the institutionalization of an Aboriginal individual they asked, "do we really want to be having another person leave their community and family to come and live here - and is this truly what the system should be doing - and I think not" (Transcript One). There is a strong commitment to think carefully about the on-going institutionalization of first nations people. An individual outside of the institution concurred that institutionalization has not been the "option of prime choice for the last five years" (Transcript four).

Much of the institutionalization of Aboriginal people occurred in the previous two to three decades. There appear to be two factors influencing this. One is that in society in general there was a greater propensity for institutionalizing individuals. As one participant said, "twenty years ago - well thirty years - in this field - everybody was being institutionalised whether they were Aboriginal or non-Aboriginal" (Transcript four). This coupled with a history of removing children to attend residential schools and removing adults for health services made the removal of Aboriginal people with disabilities seem like the natural or typical way of dealing with the problem.

From within the Aboriginal community this removal of people may have been anything but typical. All of the Aboriginal participants indicated that it was not consistent with

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Aboriginal values to take children away and institutionalize them. One participant explained, "I think that if we look at our society historically there was always a place for people . . . the role of extended family allows for the distribution of responsibility for children and other people" (Transcript two) so that there was a way of caring for individuals with varying needs. In some instances it seems that persons with disabilities were seen as gifted or insightful individuals, people from whom others could learn. In other instances one woman suggests the "the sick and the disabled they were just left to die . . .That's just the way it was . . . Each culture had their own way of dealing with it" (Transcript three). The value placed on caring for family members, particularly in the sense of the extended family, seems to have been a high priority and was a fundamental belief in Aboriginal traditional culture.

At present all participants viewed the institutionalization of first nations people as a last resort; an alternative that was considered when all other options had failed. The key factors that lead to institutionalization currently are: the extensiveness of the disability particularly instances where there are health related issues and the lack of community alternatives or resources. Several participants suggested that the health issues were the final determinant in deciding if an institutional placement would be made. While these problems lead to institutionalization for both Aboriginal and non-Aboriginal people, the resource issue is most critical for Aboriginal people. In reservation communities there typically are no resources to support people with disabilities. In urban centres Aboriginal people seem less inclined to access services. Also, it was mentioned that sometimes there are jurisdictional squabbles between various urban agencies. For example, the same agency that is responsible for support may also be responsible for protection. Community members are likely to be reluctant to trust agencies that they feel

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may also be judging them. These factors place Aboriginal people with developmental disabilities at greater risk of institutionalization than their non-Aboriginal counterparts.

Another consideration related to institutionalization has to do with the level of stress experienced by families. Institutional personnel commented that, "a lot of the literature said that the families ability to cope, you know, with stress and whatever else in everyday life" (Transcript one) is important in determining if the child will be able to be supported in the home or if other alternative will be sought. For Aboriginal families facing extensive problems with poverty, lack of housing and lack of sufficient health care this coping factor may be exacerbated. As one woman said,

> It's not because they don't care about their children. I really feel that sometimes
>
> when families are struggling - you know sort of economically to live and if there's
>
> other children involved that might be sort of the most practical thing to do. Even
>
> though you don't want that for your child, but what's your option. (Transcript five)

The willingness of Aboriginal people to accept the advice of medical professionals and experts was also seen as a problem. Not surprisingly, when people are in disadvantaged or powerless situations where they are unaware of other options, they may accept the only advice provided. As one participant suggested, the decisions are only as good as the information received. (Transcript one). Several participants, both Aboriginal and non-Aboriginal called for increased advocacy and improved information for parents and families facing difficult decisions about institutionalization. This ties in as well with a need for trained Aboriginal professionals in areas of diagnosis and therapy. Institutionalization may be less likely if there is strong advocacy for other options.

The stress of facing such a myriad of issues also means that Aboriginal organizations have many things on their plate. Not surprisingly, disability issues are not always front and centre. But advocacy for change in services for people with disabilities needs to come from Aboriginal leaders. This leaves Aboriginal advocates within native organizations with a huge task. They must ensure that leaders in the communities are aware of disability issues and that leaders fight to unsure the development of a broad base of supports. One woman who has a disability said that there seemed to be an assumption that what exists at present is acceptable, "the service delivery system that currently exists now - for anybody with a disability is just fine" (Transcript five). Advocacy was seen as crucial to the development of alternate resources.

Lack of deinstitutionalisation

Another way to look at the high percentage of Aboriginal people in institutions is to consider that perhaps they have not always made up 20 - 25% of the population. Perhaps the percentage has become that high because non-Aboriginal people have been deinstitutionalised at a faster rate. In other words, the percentage used to be 10% which would mirror the population in the community, however when others were deinstitutionalised the total number of people in the institution went down so the percentage of Aboriginal people would appear higher. At this point in the study this option has not been examined, but there is plenty to suggest that lack of deinstitutionalisation is a problem.

The problem of lack of services in rural reserve communities was touched on earlier, but here it should be identified as perhaps the greatest contributor to both institutionalization and the lack of deinstitutionalisation. An advocate for people with disabilities observed, "if Indian Affairs had funded the development of community options inside reserve communities for the

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last twenty years, - we probably wouldn't see people leaving the community in the first place" (Transcript four). If Aboriginal individuals are to be repatriated there must be services within their chosen communities, be they rural or urban communities. Any talk of repatriation naturally engenders questions about who should pay. Again the jurisdictional battle comes into play. Aboriginal leaders say that money for support should be provided to them and they will develop services as they see fit. These are problems related to self government that will not be easily resolved. All participants agreed that Aboriginal people with disabilities will not be supported in their home communities until support services are developed.

For reserve communities, a final factor that has not yet been noted, is the effect of the remoteness and size of the communities. Many rural reserves are small, isolated and removed from mainstream services. In these instances location makes access very difficult. Often people are removed from these communities for services. This problem is clearly expressed in the following: "the remote geography and the lack of services work(s) against families in poverty" (Transcript one). When transported to institutions in the south families may loose touch with their sons or daughters. Also funding for bands is based on the size of the band not on the number of specific individuals requiring services in that band. As a result some bands may receive more than they actually need while people in other bands who need support simply do not receive it. The problems related to remote communities will not likely be addressed by traditional service models. Innovative support services will probably prove more successful.

A final reason for the lack of deinstitutionalisation, is the lack of effort to do it. There has not been an attempt to deinstitutionalise Aboriginal people. Programs such as Welcome Back and Company of Companions have included less than a dozen Aboriginal people. This is

again related to the lack of resources in communities and the lack of jurisdictional clarification, however, it seems to also indicate that greater attempts should be made to reintegrate Aboriginal people into their respective communities.

Additional Themes

A few issues were raised that don't fit neatly into any of the above sections. The first of these has to do with the nature of on-going funding. A question was raised about whether government would continue to provide large amounts of needed funding to specific needy individuals or if they might opt for cutting this funding in favour of small amounts of support to a greater number of people. As the size of the funding pie is shrinking there may be an attempt to redistribute the limited dollars.

Secondly, the point was made that currently a lot of support dollars that could be spent within the Aboriginal community are being allocated to mainstream society. This happens when salaries for service jobs are spent in urban centres rather than in reserve communities. Paying people within reserve communities to provide services would stop this drain of financial resources from the community. A similar point was made regarding the way service agencies currently apply for their funding. Often agencies base their requests on a percentage of the total population of the province. When they include Aboriginal people in those requests but in turn do not provide services to Aboriginal people, and argument could be made that a certain portion of those budgets should be redistributed to native communities.

Another factor is that there seems to be a lack of ownership of the problem of institutionalized Aboriginal people with disabilities. The federal government through the department of Indian Affairs no doubt bears a large part of the responsibility because of past

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practices, but since they appear to be restricting their responsibility in fairly significant ways it seems unlikely that any change on their part will be forthcoming. Advocacy agencies and First Nations agencies seem also to have been focused on other priorities. All of these factors mean that little attention has been paid to the repatriation of these individuals.

Finally, all participants expressed concern over Fetal Alcohol Syndrome and Fetal Alcohol Effect. While participants did not think that FAS/FAE would have an effect on institutionalization they did feel that it effected the number of developmentally disabled people who would be part of their communities. They indicated that there would be significant consequences in the areas of education, health care and employment if issues related to FAS/FAE were not addressed. The presence of this disability related condition was seen to have its roots in the poverty and hopelessness that many Aboriginal people experience.

Themes of Optimism

There were several positive trends and recommendations that participants also shared. All participants agreed that services should be provided in the communities where people were born or where they would like to live. There was common recognition of the current jurisdictional struggle as a key barrier to progress. There was also shared recognition of the need to develop awareness of disability issues amongst both native groups and mainstream advocacy groups.

Several participants also indicated positive trends. For example, one participant shared a story of a young man with a mental disability who is responsible for chopping wood in his community. When people need wood they give him a call and comes over and chops the wood for them. While he is doing this he frequently shares a meal with the family and feels a sense of
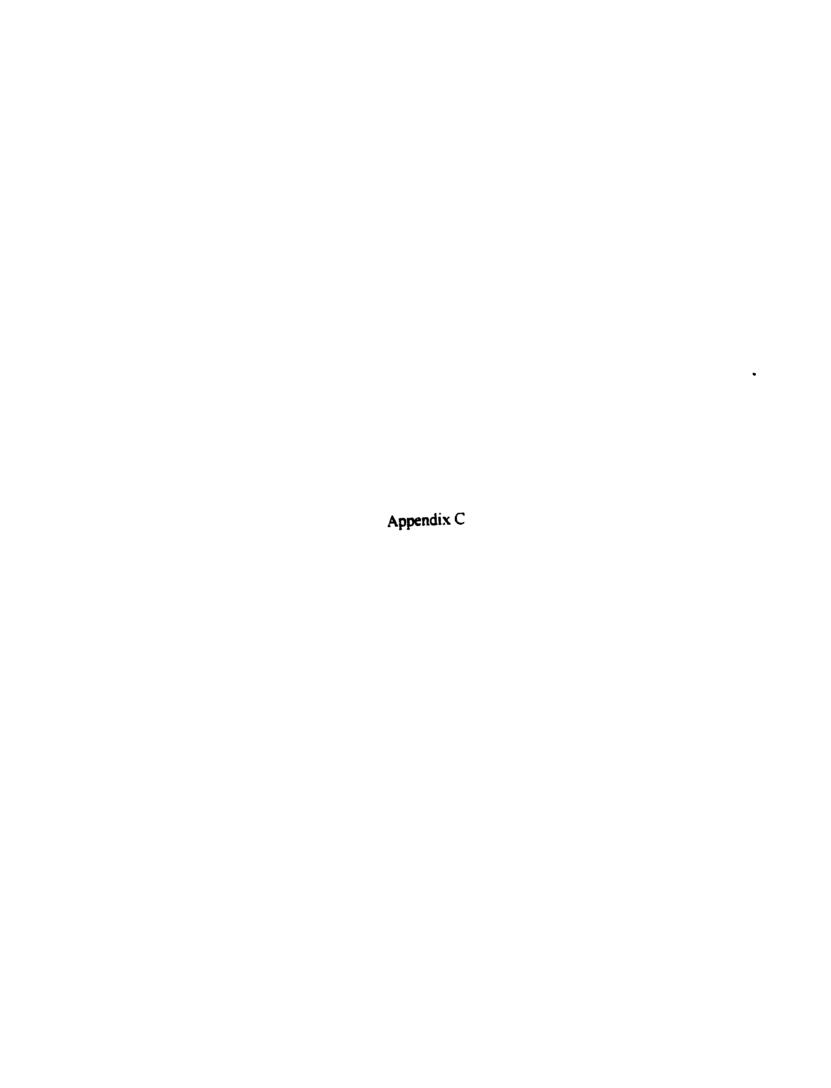
belonging and responsibility within the community. This has been arranged through the band council. Another participant commented that there seems to be increasing advocacy being done by Aboriginal women and this was described as being very positive. Communities were described as being "striking in their caring" (Transcript four) by another participant who had worked with family members. Participants also suggested that perhaps an Aboriginal parent support group could be of use as a venue for people to connect with others experiencing similar difficulties. One participant suggested that perhaps a small group home setting in the city could be developed that would focus on Aboriginal values. Another participant advocated the development of pilot projects whereby supports would be developed in communities and Aboriginal community members could be returned home. Several participants also identified the need for Aboriginal people to regain their sense of power as a culture. One person summed this up well in the following:

> I think that that's part of the solution - that strengthening our foundation, our
>
> spirituality, and our traditions and customs and values and beliefs and all the
>
> things that come with it . . . that in combination with a political voice that means
>
> something, that has some legitimacy to it (Transcript two).

Conclusion

The purpose of this study was to gain a better understanding of why so many Aboriginal individuals with developmental disabilities are placed in institutional settings. The five participants in the study provided information and insight regarding this topic. They described underlying problems related to poverty, racism and unresolved jurisdictional issues. The also related how the actual process of institutionalization occurred and how the lack of services

within Aboriginal communities was a paramount problem. In the process of conducting the interviews it became evident that there had been little focus on deinstitutionalising Aboriginal people and this was an area requiring future attention. The information provided clarifies the reasons for institutionalization and suggests possible alternatives for the future.

Appendix C

Faculty of Education
ETHICS APPROVAL FORM

To be completed by the applicant:

Title of Study:

Developmental Disability and Aboriginal People:

An overview of current practice and process in institutionalization

I/We, the undersigned, agree to abide by the University of Manitoba's ethical standards and guidelines for research involving human subjects, and agree to carry out the study named above as described in the Ethics Review Application.

CHERYL MARTENS

Name of Principal Investigator (s)(please print)   Name of Principal Investigator (s)(please print)

Signature(s) of Principal Investigator(s)   Signature(s) of Principal Investigator(s)

To be completed by Thesis/Dissertation Advisor or Course Instructor (if Principal Investigator is a student):

Please note that by signing this form, you are acknowledging that you have read the completed Ethics Approval Form of the above named student and are satisfied that it is ready for submission to the Research and Ethics Committee.

Signature   ZANA MARIE LUTFIYYA
                 Name (please print)

To be completed by Research and Ethics Committee:

This is to certify that the Faculty of Education Research and Ethics Committee has reviewed the proposed study named above and has concluded that it conforms with the University of Manitoba's ethical standards and guidelines for research involving human subjects.

David H. Jenkinson   15 June 1998
Name of Research and Ethics   Date
Committee Chairperson

Signature of Research and Ethics
Committee Chairperson

Revised 22 September 1997

Faculty of Education
ETHICS REVIEW APPLICATION

Part A of this application provides background information on the type of research and the investigator(s) involved in the data collection. Part B describes the proposed study. Part C is to be used as a check list to confirm that the application is complete. The last page of the application is to be signed by the chairperson of the Research and Ethics Committee and forwarded to the applicant(s) when the project has been approved.

Complete all parts of this application (TYPED) and submit it and any required supporting documentation to:

> Facilitator, Research & Ethics Committee
> Room 230 Education Building
> Telephone: (204) 474-7402
> Fax: (204) 474-7551

Part A: Background Information

1.   Type of Study:

____	Faculty Research	_x_	M.Ed. Thesis
____	Ph.D. Dissertation	____	Course Requirement

2.   Principal investigator(s):

Name: __Cheryl Martens_____

Address: __554 Furby St. Winnipeg, MB_____ Postal Code: ___R3B 2V8_____

Telephone: Office: __632-2573_____   Home: ___774-5111_____

Name: _____

Address: _____ Postal Code: _____

Telephone: Office: _____   Home: _____

3.   If the data collected is being collected for an M.Ed. thesis or Ph.D. dissertation, specify the date on which the thesis/dissertation proposal was successfully defended: __April 6, 1998_____

4.   Where the principal investigator is a student, identify the research supervisor (thesis/dissertation advisor or course instructor):

Zana Lutfiyya	Educational Psychology	474-8285
Name	Department	Telephone

Part B: Description of Proposed Study

1.   Title of Study

__Developmental Disability and Aboriginal People: An overview of current practice__

__and process in institutionalization_____

Please use clear non-technical language in responding to the following questions.

2.   What is the purpose of the study?

The purpose of the study is to increase understanding of the experience of individuals

who are Aboriginal in institutions for the developmentally disabled. I also plan to discover

why individuals who are Aboriginal are highly represented in these institutional settings.

3.   Who are the proposed subjects of the study? How are they to be recruited? What procedures will you use to request from them their "informed consent"? Attach a copy of your Letter of Consent/Survey Cover Letter.

I plan to interview 7 - 10 individuals, including:

* individuals with disabilities who are Aboriginal and their families
   - I hope to interview 3 - 4 participants from this group

* personnel from institutional settings who are familiar with funding arrangements and demographics

* personnel familiar with funding arrangements within both the Department of Indian and Northern Affairs and the Department of Family Services, and
   - I hope to interview 2 - 3 participants from the two groups above. (Both of these groups have been included to address issues related to funding.)

* personnel from Aboriginal organizations who are able to clarify jurisdictional issues.
   - I hope to interview 2 - 3 participants from this group

I have received a grant from the Scottish Rite Foundation for this study. A portion of the grant is allocated to the services of a research assistant who is Aboriginal. The research assistant will do the following:

* serve as either a linguistic or cultural interpreter, or

* may facilitate contact between me and potential informants.

As part of a qualitative research course I completed a beginning study on this topic. I may go back to these informants for further recommendations for participants.

Prior to the interview participants will be asked to sign a consent form. The consent form is attached.

4.   What do you want subjects to do in the study? How much time will be required of them?

Participants will be asked to take part in one or two in-depth interview(s), each lasting about

one hour. The participants will be asked to respond to questions about the topic.

5.   What procedures will be employed in the study? Append a copy of all instruments and/or protocols which will be used. Describe any deceptions to be employed in the study. Outline any instructions, stimuli or procedures that will be used that might cause participants to experience anxiety, embarrassment, distress, or any other 'negative' state.

The in-depth interview is the primary procedure in this study. These interviews will be taped and transcribed.

People will be told that they can end the interview at any time. There will be no deceptions in this study.

The interview guide is attached.

6.   University policy specifies that participation should be an educational experience for research subjects whenever possible. Therefore, subjects are to be fully informed of any deceptions and of the nature of the study as soon as possible after participation. In addition, participants should normally have a summary of the major findings of the study (with appropriate explanations) delivered to them. What positive steps will you take in these regards? What information will be given to participants, when and how?

Participants will be offered a copy of the consent form prior to the study. In the event that

an individual with a developmental disability has a legal guardian, I will seek informed

consent from the guardian. I will also ask the individual with a developmental disability

to give her/his consent as well. Following the study, I will offer participants a copy of the

summary report and send a letter thanking them for their contributions.

Part C: Checklist of Salient Points Regarding Ethics Review Applications

Complete the following to confirm that the submission is complete:

		Yes	No
1.	**SIX TYPED COPIES** of the completed Ethics Review Application and all supporting documents have been provided.	_x_	_ _
2.	A letter of consent to research subjects (where required) or survey cover letter has been appended to the application.	_x_	_ _
3.	The Letter of Consent/Cover Letter includes the following:		

- sponsorship of the study   _x_ _ _

- a brief non-technical description of the purpose of the project   _x_ _ _

- a brief but sufficient description of task(s) required of subject(s)   _x_ _ _

- an estimated time required of subject(s)   _x_ _ _

- assurance of the right to confidentiality of personal information   _x_ _ _

- a clear statement indicating the subject(s)' right to withdraw at any time without penalty   _x_ _ _

- an offering of the opportunity to obtain a summary of the results of the study   _x_ _ _

- the name and/or address of a contact person for obtaining additional information about the study   _x_ _ _

- the signature of researcher and a space for "signature of consent" (note: "signature of consent" is not required in a survey cover letter)   _x_ _ _

- indication of disposition of audio and video tapes once research is completed   _x_ _ _

4.	A copy of letters of information and request for consent to all stakeholders in the research. These stakeholders include school divisions and/or school superintendents, school principals, and others associated with the administration of the organizations or sites for the research.	_x_	_ _
5.	A copy of all instruments and/or protocols has been appended to the application	_x_	_ _
6.	The **Ethics Approval Form** (page 5), has been completed **and** signed by the investigator(s), and, where appropriate, the research supervisor	_x_	_ _
7.	A copy of the Thesis/Practicum Proposal Approval form, with Section 1 appropriately completed, indicating that the thesis/practicum proposal has been successfully defended. [NOTE: **Applications lacking such documentation will be returned unreviewed to the applicant.**]		x

THE UNIVERSITY OF MANITOBA

FACULTY OF GRADUATE STUDIES
•••••
MASTER'S THESIS/PRACTICUM FINAL REPORT

The undersigned certify that they have read the Master's Thesis/Practicum entitled:

DEVELOPMENTAL DISABILITY AND ABORIGINAL PEOPLES:

AN OVERVIEW OF CURRENT PRACTICE AND PROCESS IN

INSTITUTIONALIZATION

submitted by

CHERYL MARTENS

in partial fulfillment of the requirements for the degree of

MASTER OF EDUCATION

The Thesis/Practicum Examining Committee certifies that the thesis/practicum (and oral examination if required) is:

APPROVED

(Approved or Not Approved)

☒ Thesis   Advisor:

☐ Practicum

Date: __April 6, 1998__

Faculty of Education
ETHICS APPROVAL FORM

To be completed by the applicant:

Title of Study:

Developmental Disability and Aboriginal People:

An overview of current practice and process in institutionalization

I/We, the undersigned, agree to abide by the University of Manitoba's ethical standards and guidelines for research involving human subjects, and agree to carry out the study named above as described in the Ethics Review Application.

CHERYL WALTERS

Name of Principal Investigator (s)(please print)

Name of Principal Investigator (s)(please print)

Signature(s) of Principal Investigator(s)

Signature(s) of Principal Investigator(s)

To be completed by Thesis/Dissertation Advisor or Course Instructor (if Principal Investigator is a student):

Please note that by signing this form, you are acknowledging that you have read the completed Ethics Approval Form of the above named student and are satisfied that it is ready for submission to the Research and Ethics Committee.

Tanis Bretagne

Signature

TANIS MARIA LUTFIYYA

Name (please print)

To be completed by Research and Ethics Committee:

This is to certify that the Faculty of Education Research and Ethics Committee has reviewed the proposed study named above and has concluded that it conforms with the University of Manitoba's ethical standards and guidelines for research involving human subjects.

Name of Research and Ethics
Committee Chairperson

Date

Signature of Research and Ethics
Committee Chairperson

Revised 22 September 1997

Cheryl Martens
554 Furby Street
Winnipeg, Manitoba
R3B 2V8

May 30, 1998

Dear Participant:

My name is Cheryl Martens and I am a Master's student in the Faculty of Education at the
University of Manitoba. I am conducting research as part of my Masters in Education thesis
requirement and the findings will form the basis for my thesis.

Letter of consent:

You are being asked to take part in a study that is looking at the experience of individuals who
are Aboriginal in institutions for the developmentally disabled. Your perspective on the
practises and processes that lead to the institutional placement of children and adults with
developmental disabilities who are Aboriginal will help to shed light on this topic.

If you decide to be involved in this study, you will be asked to take part in one or two audio-
taped interview(s) that will last for about one hour. In the interview I will ask you some
questions about the experience of institutionalization of children and adults with developmental
disabilities who are Aboriginal.

You are free to withdraw from this study at any time. All of the information you share will be
kept strictly confidential and the tapes will be erased after the study is completed. In these ways,
identity will be protected for all participants.

I will send you a written summary of the study when it is completed. If you have any questions
or concerns please contact me, **Cheryl Martens at 774-5111** or my advisor, **Zana Lutfiyya,
Ph.D, at 474-8285**, Faculty of Education, University of Manitoba, R3T 2N2.

★★★

I have read and I understand the above information, and I agree to participate in the study. A
copy of this form has been given to me.

_____   _____   _____
(name of participant)   (signature or signature of guardian)   (date)

Cheryl Martens
554 Furby Street
Winnipeg, Manitoba
R3B 2V8

May 30, 1998

Dear Stakeholder: (specific names and roles will be indicated)

My name is Cheryl Martens and I am a Master's student in the Faculty of Education at the
University of Manitoba. I am conducting research as part of my M. Ed. thesis requirement.

I am writing to request your assistance in helping me to identify participants for my research
study. The study is looking at the experience of Aboriginal children or adults who are in
institutions for the developmentally disabled. I am hoping to speak with individuals who can
describe the practices and processes that have lead to the institutional placement of children and
adults with developmental disabilities who are Aboriginal. I am asking that you provide me with
names, addresses and telephone numbers of potential participants.

Participants will be asked to take part in one or two audio-taped interview(s) that will last for
about one hour. In the interview I will ask participants questions about the experience of
institutionalization of children and adults with developmental disabilities who are Aboriginal.

Participants will be free to withdraw from this study at any time. All of the information shared
will be kept strictly confidential and the tapes will be erased after the study is completed. In
these ways, identity will be protected for all participants.

I will send all participants a written summary of the study when it is completed.

I trust that I have clarified what participants will be asked to do. If you have any questions or
concerns please contact me, **Cheryl Martens at 774-5111** or my advisor, **Zana Lutfiyya, Ph.D,
at 474-8285**, Faculty of Education, University of Manitoba, R3T 2N2.

Thank you for assisting me in finding participants for this study.

Sincerely,

Cheryl Martens

Cheryl Martens
554 Furby Street
Winnipeg, Manitoba
R3B 2V8

May 30, 1998

Dear Parent: (specific names will be indicated)

My name is Cheryl Martens and I am a Master's student in the Faculty of Education at the University of Manitoba. I am conducting research as part of my M. Ed. thesis requirement.

The study is looking at the experience of Aboriginal children or adults who are in institutions for the developmentally disabled. I am hoping to speak with individuals who can describe the practices and processes that have lead to the institutional placement of children and adults with developmental disabilities who are Aboriginal. I am writing you to ask if I may speak with your son/daughter (name) about his/her experience of institutionalization. As your son/daughter is unable to give consent, I am also asking that give consent on his/her behalf. You are also very welcome to be present at the interview.

Participants will be asked to take part in one or two audio-taped interview(s) that will last for about one hour. In the interview I will ask participants questions about their experience of institutionalization of children and adults with developmental disabilities who are Aboriginal.

Participants will be free to withdraw from this study at any time. All of the information shared will be kept strictly confidential and the tapes will be erased after the study is completed. In these ways, identity will be protected for all participants.

I will send all participants a written summary of the study when it is completed.

I trust that I have clarified what participants will be asked to do. If you have any questions or concerns please contact me, Cheryl Martens at 774-5111 or my advisor, Zana Lutfiyya, Ph.D, at 474-8285, Faculty of Education, University of Manitoba, R3T 2N2.

Thank you for assisting me in this study.

Sincerely,

Cheryl Martens

Questions for Participants who work for government departments or in institutional settings:

<u>Introductory Questions</u>:

1. Please tell me who you are and what you do.

2. From your perspective, what is the process that an Aboriginal child (or his/her family) might encounter when it is determined that he/she has a developmental disability?

3. Would you briefly describe the ideal scenario - or what you wish would happen for children with developmental disabilities who are Aboriginal?

<u>Content Questions</u>:

4. Currently children with developmental disabilities who are Aboriginal are more likely than other citizens to reside in institutions for the developmentally disabled. Why do you think this is?

    Probes:
    a) Are there particular problems that Aboriginal Peoples face that lead to increased institutionalization?

    b) Are you familiar with traditional Aboriginal values - If so, how do you see these relating to institutional care?

    c) Are there particular types of developmental disabilities that children who are Aboriginal may have? Are these better served by the institutional model?

    d) Are poverty issues related?

    e) Is racism related?

5. Funding related questions:

    a) What is the per diem funding for someone in an insititutional setting?

    b) For a resident who is Aboriginal what is the source of the funding?

    c) What are the variables that influence funding sources for residents who are Aboriginal?

    d) How does funding someone in an institutional setting compare with funding someone in the community? How is the amount of funding affected? How are funding sources

affected? What are the differences in funding for individuals who live on or off 'reserve'.

Concluding Questions:

6. Are there areas of support for families who are Aboriginal that you feel are particularly needed?

7. Are there other issues that we haven't talked about that you think lead to the institutionalization of individuals who are Aboriginal?

Questions for Participants from Aboriginal Organizations: '

Introductory Questions:

1. Please tell me who you are and what you do.

2. From your perspective, what is the process that an Aboriginal child (or his/her family) might encounter when it is determined that he/she has a developmental disability?

3. Would you briefly describe the ideal scenario - or what you wish would happen for children with developmental disabilities who are Aboriginal?

Content Questions:

4. Currently children with developmental disabilities who are Aboriginal are more likely than other citizens to reside in institutions for the developmentally disabled. Why do you think this is?

    Probes:
    a) Are there particular problems that Aboriginal Peoples face that lead to increased institutionalization?

    b) Are you familiar with traditional Aboriginal values - If so, how do you see these relating to institutional care?

    c) Are there particular types of developmental disabilities that children who are Aboriginal may have? Are these better served by the institutional model?

    d) Are poverty issues related?

    e) Is racism related?

5. Who is currently financially responsible for the support and care of persons with developmental disabilities who are Aboriginal?

    a) What are the factors that influence funding responsibility?

    b) Could you describe the jurisdictional issues related to providing support on or off reserve communities?

    c) Ideally, how do you think people with disabilities who are Aboriginal should be supported and how should funding arrangements work?

Concluding Questions:

6. Are there areas of support for families who are Aboriginal that you feel are particularly needed?

7. Are there other issues that we haven't talked about that you think lead to the institutionalization of individuals who are Aboriginal?

Questions for Individuals with Disabilities who are Aboriginal and/or their families:

<u>Introductory Questions</u>:

1. Please tell me who you are? How would you describe yourself? (or you son or daughter?)

2. If the person is in an insititutional setting I will ask: How did you come to live here? or, What steps did you (and your family) go through that led you to an institutional setting?

   Were you (or your family) given other ideas about where you could live?
   (If the person has difficulty with the term 'institution' I will use the name of the place where they live or perhaps substitute the term 'hospital'.)

   If the person is in a community setting I will ask: Have you always lived in (name of town or city)? Do you get help or support from others? Has anyone ever suggested that your son or daughter be placed in an institution?

3. What do you wish would happen for children with developmental disabilities who are Aboriginal? (If the term 'developmental disability' is unfamiliar I will ask either what terms they use to describe themselves or there family member or substitute mental handicap or mental disability for the term developmental disability.)

<u>Content Questions</u>:

4. People who are Aboriginal and who have a developmental disability are more likely to live in institutions than other people with disabilities. Why do you think this is?

   Probes:
   a) Are there special problems that Aboriginal Peoples face that lead to them being placed in institutions?

   b) Are you familiar with the way Aboriginal people lived long ago? - How do you think people who are Aboriginal used to take care of people with disabilities?

   c) Are there particular types of developmental disabilities that children who are Aboriginal may have? Is the institution the best place for these people?

   d) Are poverty issues related?

   e) Is racism related?

5. How often do you see your family? (Or family member?) Do you go to see them or do they come to see you?

<u>Concluding Questions</u>:

6. Are there areas of support for families who are Aboriginal that you feel are really needed?

7. Are there other issues related to this that we haven't talked about?

Appendix D

Locations of Associations for Community Living	Locations with Family Services Offices
Arborg	Beausejour
Beausejour	Brandon
Brandon	Dauphin
Dauphin	Flin Flon
FlinFlon	Mordon
Gimli	Portage la Prairie
Morden	Selkirk
Portage la Prairie	The Pas
St. Malo	Thompson
Selkirk	Winnipeg
Steinbach	
Stonewall	
Swan River	
Virden	
Winkler	
Winnipeg	

Churchill

Lac Brochet
(Northlands)

Sayısı Dene First Nation
(Fort Churchill)

Brochet
(Barren Lands)

Bird River
(Fox Lake)

South Indian Lake
(Nelson House)

Lynn Lake

Leaf Rapids

Split Lake Cree First Nation

Gillam
(Fox Lake)

Granville Lake
(Mathias Colomb)

York Factory First Nation

Ilford
(War Lake)

Nelson House

Shamattawa First Nation

Thompson

Flin Flon

Oxford House

God's River

Cross Lake First Nation

Red Sucker Lake

Pukatawagan
(Mathias Colomb)

Opaskwayak Cree Nation

Norway House

Gods Lake First Nation
Wasagamack

St. Theresa Point

Moose Lake

Cedar Lake

Grand Rapids

Chemawawin First Nation

Poplar River First Nation

Sapotaweyak Cree Nation

Lake Winnipeg

Indian Birch

Berens River

Paungassi First Nation

Pine Creek

Dauphin River

Jackhead

Little Grand Rapids

Waterhen

Lake St. Martin

Bloodvein

Valley River
Treaty Alliance #4

Fairford

Fisher River First Nation

Crane River

Pequis

Hollow Water
First Nation

Ebb and Flow

Dauphin

Lake Manitoba

Waywayseecappo

Keeseekoowenin

Little Black River

Gambler

Sagkeeng/
Fort Alexander
First Nation

Rolling River

Sandy Bay First Nation

Birdtail Sioux First Nation

Brokenhead
Ojibway Nation

Portage la Prairie

Brandon

Dakota Tipi

Long Plain
First Nation

Sioux Valley First Nation

Dakota Plains
First Nation

Winnipeg

Oak Lake First Nation

Swan Lake First Nation

Buffalo Point
First Nation

Roseau River Tribal Council

Location of First Nations Communities in Manitoba 1994

LEGEND

Community Accessible by All Weather
Road and or Rail   ●

Community Inaccessible by All Weather
Road and or Rail   ◉

Non Indian Communities   ■

Community and Band Name   Swan Lake

Band Name When Different From
Community Name   (Mathias Colomb)

Scale 1 : 5 000 000

Kilometres 20   0   100 Kilometres

Canada