

Identifying First Nations Students with Invisible Disabilities

by

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A Thesis submitted to the Faculty of Graduate Studies of

The University of Manitoba

in partial fulfillment of the requirements for the degree of

DOCTOR OF PHILOSOPHY

Faculty of Education

University of Manitoba

Winnipeg

Abstract

Countless studies have employed the term *disabilities* as an all-encompassing umbrella for both visible and invisible disabilities. Scholars and practitioners have relied on medical criteria and corresponding diagnostic tools as the standard for verification of all disabilities. However, invisible disabilities are difficult to identify, not only because they are not obvious, but also because they represent a wide range of characteristics, fall along continuums of severity for certain disabilities, and lack the verification criteria and diagnostic tools available for visible disabilities. In addition, difficulties and obstacles for students with invisible disabilities are experienced daily in the educational environments of First Nations schools, and little is known about these students and their experiences. Are teachers working in First Nations schools able to identify students with invisible disabilities? Are the teachers cognizant of invisible disabilities? Do the teachers understand the impacts of invisible disabilities on students' identity, learning and socialization?

This study focused on establishing a baseline of teachers' knowledge of invisible disabilities. One goal was to develop a protocol for identifying First Nations students with invisible disabilities. Teacher questionnaires and resource teacher interviews were employed to gather data. As this study explored a new area, great care was taken to record all aspects of the research with the hope that other researchers will further explore the connection between identification of First Nations students with invisible disabilities and appropriate educational programming for them.

This study's findings exposed the presence of a vast gap in teachers' understandings of exactly what invisible disabilities encompass. Something as seemingly simple as consensus on

the categorization of disabilities as visible or invisible, by the teachers in this study, was absent. Other areas connected to identifying invisible disabilities were equally blurred.

Many avenues for future research were suggested by the data collected, but the recommendations based on this study's findings focus on: (a) what actions are needed to develop and implement an early identification protocol for students with invisible disabilities, (b) how to create better teacher awareness of all aspects of invisible disabilities, from definition to barriers to presenting characteristics, (c) how to organize professional development to improve FN teachers' awareness of invisible disabilities as well as knowledge of effective adaptations and accommodations, and (d) how to implement regular basic screenings that can assist in identifying FN students with invisible disabilities.

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Chapter 1 Introduction

Purpose

As an educator with an invisible disability working primarily in the area of special education, I observed the steady increase of First Nations (FN) students being referred to First Nations schools' resource programs. A large number of these students displayed no observable disabilities but many experienced one or more invisible disabilities such as learning problems, mild to moderate hearing loss, Irlen Syndrome, culture shock, or other conditions that had not been diagnosed. I also observed that the end result for such students was often either wrong, inappropriate or no supports throughout their educational career.

In order to design a study investigating the topic of invisible disabilities, the term needed to be defined first. Originally, three sources were selected to review for their definitions of the term invisible disabilities. These three sources were: Invisible Disabilities Association, Disabled World Association and Canadian Medical Association. They were chosen because of their direct working connection to people and their disabilities. But as the search for an all-inclusive definition for invisible disability progressed, other sources like the Diagnostic and Statistical Manual of Mental Disorders V (DSM V) were also examined to for their definitions of invisible disabilities. Even the less than scholarly Wikipedia was examined for its definition of invisible disabilities. It summarized the term invisible disabilities briefly but very concisely as “disabilities that are not immediately apparent. Invisible disabilities are chronic illnesses and conditions that significantly impair normal activities of daily living” (Wikipedia, 2015).

The Invisible Disabilities Association stated,

The term invisible disabilities refers to symptoms such as debilitating pain, fatigue, dizziness, cognitive dysfunctions, brain injuries, learning differences and mental health disorders, as well as hearing and vision impairments. These are not always obvious to the onlooker, but can sometimes or always limit daily activities, range from mild challenges to severe limitations and vary from person to person. (Invisible Disabilities Association, 2015)

The Disabled World described invisible disabilities as,

...an umbrella term that captures a whole spectrum of hidden disabilities or challenges that are primarily neurological in nature. ...Invisible Disabilities are certain kinds of disabilities that are not immediately apparent to others. ...Invisible disabilities can include chronic illnesses such as renal failure, diabetes, and sleep disorders if those diseases significantly impair normal activities of daily living. (Disabled World, 2015)

Unfortunately, there was no universal definition for the term invisible disabilities. When definitions for invisible disabilities were stated, they were as varied as the invisible disabilities themselves and seemed to depend upon the definer's own limiting paradigm, rather than one comprehensive concept of what exactly constitutes invisible disabilities. This was the case with the Canadian Medical Association. It provided no definition for the term invisible disabilities while the Diagnostic and Statistical Manual of Mental Disorders V (DSM V) did not use the term, invisible disabilities, but rather dealt with medically identifiable conditions individually (American Psychiatric Association, 2013). Therefore, as there was no universal medical or academic consensus regarding a complete and all-encompassing definition for invisible

disabilities, the closest to a comprehensive and inclusive definition for invisible disabilities was given surprisingly by Wikipedia (2015), a source considered to be non-scholarly. It encapsulated in the briefest but clearest terms of any of the reviewed sources, the elements involved in invisible disabilities.

Despite the diversity of definitions proffered, none of the researched sources referenced the cultural or social aspects of disabilities for FN students caused by traumatic historical events and the intergenerational effects of factors such as residential schools, segregation and poverty. Extenuating issues associated with such disabilities often manifest themselves in FN students in countless forms of mental disabilities other than those of a purely cognitive nature. As Berube (2015) stated in his article, “Depression, anxiety, family violence, suicidal and homicidal thoughts and addictions are some of the behaviours our mental health therapists see when working with clients who have experienced direct or intergenerational trauma” (p. 1). Regrettably, the impact of these invisible disabilities is the same as all other invisible disabilities.

The importance of negative impacts such as depression, low self-esteem, high dropout rates and un-employability, caused by invisible disabilities, needs to be taken seriously by everyone, and especially by teachers. All students with invisible disabilities face as many difficult challenges daily as those students with visible disabilities (Roman, 2009). FN students with invisible disabilities face even more barriers. All FN students must navigate between two worlds where cultures, traditions, languages, and even teaching and learning styles are very distinct from each other (Medina, Jones & Miller, 1998). When an FN student has an invisible disability, additional barriers arise that demand more time and effort by the student. Yet, little to nothing is known about invisible disabilities by most people, including teachers (Mullins & Preyde, 2013).

For beginning and experienced teachers, who have not studied or personally experienced invisible disabilities and their negative social, psychological and educational impacts, the lack of comprehension regarding invisible disabilities' issues can severely limit the type of accommodations and adaptations they provide (Boer, Pijl & Minnaert, 2011; Brady & Woolfson, 2008; Parasuram, 2006). It is for this reason that the aim of this study is to answer two questions. What are the factors that influence teachers' perceptions of invisible disabilities? How does teachers' knowledge and attitudes about students with invisible disabilities impact the educational programming they provide to those students in First Nations' schools?

Despite this study being small in terms of the number of participating schools and teachers, the importance of uncovering the relationships between invisible disabilities, teachers' support, and students' educational success demands immediate attention that is long overdue. Research on the generic topic of disabilities continues to verify the fact that early intervention is preferable to later remediation and that early intervention is based on early identification (Barnett, 2011). Research on practices, methods, and strategies for the early identification and assessment of students with invisible disabilities in remote First Nations' schools are exceedingly rare and difficult to find. Yet, the issue needs to be investigated without delay in order to identify and assist all FN students with invisible disabilities to reach their full academic potential.

Rationale

Over the past several decades, the social climate concerning individuals with disabilities has progressed from pity and tolerance to acceptance and valuing. This evolution is clearly evident in the educational environment where the inclusive paradigm has advanced from mainstreaming to integration to inclusivity (Konza, 2008). For the majority of teachers, this evolutionary progression no longer means that students with special needs simply attend some

non-academic classes such as art or music in order to experience opportunities to socialize with their peers. Instead, it means daily full time class attendance for all students, regardless of their disabilities, where they can experience not only social opportunities but also participate in all academic settings.

Teachers understand that students with officially recognized disabilities are entitled to adaptations, accommodations and modifications, not only by society's norms, but also under society's enacted laws such as Bill 13, Manitoba's Appropriate Educational Programming Amendment to the Public Schools Act (Manitoba Government, 2005). Despite the legislated and legal mandates to provide the adaptations, accommodations and modifications for students with visible disabilities; when administrative authorities fail to provide adequate funding or other supports, teachers are still expected to carry out those responsibilities (Fuchs, 2010). But as a result of inadequate supports, many teachers experience frustration and burnout (Antoniou, Polychroni & Kontroni, 2009).

Unfortunately, not all disabilities are readily or easily identifiable by teachers. These types of disabilities often are referred to as hidden or invisible because they remain unseen. However, the behaviors and learning difficulties that arise from them may be very observable and often are interpreted negatively. The general populace, including teachers, frequently exhibits skepticism and disbelief about the existence of invisible disabilities (Beyene & Tizazu, 2010; Davis, 2005; Dukmak, 2013). In addition, the limitations caused by the environmental and learning barriers that such disbelief inevitably presents to students with invisible disabilities compounds the problem. This occurs despite the fact that many individuals, at some time in their lives, may have experienced an invisible disability firsthand. At that point they may have

experienced the doubt and cynicism they once expressed towards others. As Henning (2007) stated,

Increasing our awareness of those with invisible disabilities will allow us to provide better service to all our students. These students face challenges that we may never think about. Each of us can assist student with invisible disabilities. The first step is to sensitize ourselves. (p. 29)

Invisible disabilities are not delimited by age, gender, race, economic status, geographic location or cultural heritage. As Anastasiou and Kaufman (2012) stated, “Disabilities are not comparable to ethnic, gender, sexual, or ‘race’ difference” (p. 143). Rather they are present in every demographic possible, along with the accompanying confusions and misunderstandings that surround the meaning of invisible disabilities. Invisible disabilities are extremely difficult to formally diagnosis since the identification procedures rely so heavily on the Western medical model even though most invisible disabilities reside in other domains (e.g. learning, sensory, emotional, etc.). This is particularly problematic for anyone working in the area of education. Many students with invisible disabilities go unidentified or are misidentified leaving a huge and negative wake for both the students and their families. It is vitally important that teachers develop awareness, appreciation and acceptance of students with invisible disabilities and the enormity of the impacts on their success in all domains of school life (e.g., academic, social, behavioral, etc.). Teachers need to consciously and continuously work towards identifying and supporting students with invisible disabilities in their classrooms.

Based on how students with visible disabilities are supported by school administrations and their teachers, a natural assumption might be that students with invisible disabilities would

receive the same types of services. Regrettably, this supposition is not the case. Based on an analysis of available research literature and my personal encounters and work experiences, students with invisible disabilities do not receive the same types of services. The reasons for the differences between the provision of services to students with visible disabilities and students with invisible disabilities need to be ascertained. Then those reasons need to be thoroughly examined and analyzed in order to develop a systematic approach for the early identification of invisible disabilities in FN communities. Only once that understanding has been acquired, can effective supports for students with invisible disabilities be established.

As long as the under-identification and non-identification of students with invisible disabilities persists in FN schools, leading to a lack of appropriate supports, students will continue to be referred to resource programs for behavioral misdeeds (e.g., low attendance, displays of resistance, social issues, etc.) and learning problems (e.g., low comprehension skills, below grade placement reading writing and math skills, etc.). The resulting fallout from this absence of identification and supports also can contribute to students suffering with mental health issues. As Kariuki, Honey, Emerson and Llewellyn (2011) reported, “Young people with disabilities have poorer mental health and are at higher risk of mental health problems than are other young people” (p. 91). It also contributes to students choosing to drop out of school as Wingert and Kantrowitz (1997) have reported,

Children humiliated by their inability to overcome their learning problems also tend to develop behavioral and emotional disorders. Kids with learning problems are twice as likely to drop out of school; a disturbingly high number end up with criminal records. (p. 59)

Consequently, the benefits of early identification and the provision of appropriate supports likely extend beyond the students with invisible disabilities to their teachers, parents and the communities in which they live. In order to uncover as complete a picture as possible of the connection between invisible disabilities and provision of appropriate teaching services in First Nations schools, this project has been designed in accordance with a mixed methods approach.

Format

Following this chapter on the purpose and rationale for the study, I have provided a literature review, in Chapter 2, of other projects and studies conducted on the topic of invisible disabilities and related topics. In Chapter 3, I have explained the logic of the research methodology, the data collection process and the analysis procedures that I followed. All the data collected along with analysis of it and interpretation of the results has been reported in Chapter 4. Lastly, in Chapter 5, I have summarized the findings from this study, drawn my conclusions and offered recommendations for future research on this topic of FN students with invisible disabilities including best practices in FN schools for early identification of invisible disabilities, adaptations and accommodations for those students with invisible disabilities.

Chapter 2 Review of Literature

Introduction

Research specifically centered on identifying, accepting and making academic provisions for First Nations students with invisible disabilities proved to be exceedingly difficult to find. My initial search for information on invisible disabilities began in September 2014. All subsequent efforts at gathering information on invisible disabilities from the university's collection of journals, theses and textbooks met with minimal success. I also enlisted the university's librarian to personally assist me with a search for articles on invisible disabilities. The end result culminated with little more than what had been found previously.

Another source, Manitoba First Nations Education Resource Centre's (MFNERC) documents regarding First Nations' issues concerning students with special needs was also unsuccessful. Their papers primarily focused on building a case for increased funding for students with special needs or developing a response to Canadian Government's guidelines on special needs (Indigenous and Northern Affairs Canada, 2006). None of their documents specifically focused on invisible disabilities in either of those circumstances.

As an alternative avenue of exploration, I asked for information from Indigenous and Northern Affairs Canada (INAC) in February 2015. Any documents pertaining to special education and disabilities including the change from application to intervention based funding were requested. I was then informed that the government was not willing to release any information.

The majority of studies I did obtain on invisible disabilities focused on health concerns that fell into three specific areas. The first area dealt with the identification and confirmation of

the existence of invisible disabilities in children prior to school entry or at initial school entry age. The second area centered on the relationship between invisible disabilities as medical conditions and health risks. The third focus area concentrated on the relationship invisible disabilities as medical conditions and employment obstacles or employability because of invisible disabilities. However, some studies, such as Matthews' (2009), Desjardins' (2010) and Roman's (2009), detailed perspectives on invisible disabilities in relationship to educational issues, such as acceptance and academic achievement.

Many of the most recent studies that have delved into the educational connection between students with disabilities and teachers' attitudes originated outside of North America. For example, in the United Arab Emirates, Dukmak (2013) found "that teachers were more accepting students with physical disability for inclusion than students with other disabilities such as specific learning difficulties, visual impairment, hearing impairment, behavioral difficulties and intellectual disability" (p. 28). In Ethiopia, Beyene and Tizazu (2010) discovered, "Attitudes, which are largely negative, place limitation on students with special needs and inhibit the responsibility for their success" (p. 92). Additionally, De Boer, Pijl and Minnaert's (2010) research findings, in Europe, found "that teachers' attitudes are related to disability categories" (p. 349). These studies strongly indicated that despite education's universal trend towards inclusion of all students regardless of disabilities, teachers have their own perceptions concerning types of disabilities that result in negative biases towards some kinds of disabilities.

The articles that dealt with the existence of invisible disabilities at initial school entry age, generally pertained to physical health issues such as: (a) mobility limitations and personal safety in school environments (e.g., use of ramps, elevators, etc.), (b) medication schedules (e.g., who, where, when, etc.), or (c) handling life threatening medical conditions (e.g., diabetes,

asthma, etc.) (Matthews, 2009; Miskovic and Gabel, 2012). These studies often were very limited in their scope when it came to acceptance in the classroom and the resulting implications for student academic achievement. Regardless of the issue, however, none of these articles included First Nations students in First Nations schools.

When the discovery or disclosure of invisible disabilities came well after initial school entry, researchers focused on the participants' feelings, actions and attitudes that were a direct result of having to deal with their teachers' negative attitudes (Denhart, 2008; Dwyer, 2009; Egan & Guiliano, 2009; Olney & Brockelman, 2003; Parasuram, 2006). The remainder of the published articles concentrated on how "others" respond to invisible disabilities and were focused on issues such as: (a) whether the invisible disabilities truly existed, (b) conflicts about the use of the medical model versus social models to understand invisible disabilities, and (c) minority rights and policy issues concerning invisible disabilities (Blandchett, Kligner & Harry, 2011; Davies, 2005; Matthews, 2009; Medina, Jones & Miller, 1998; Mullens & Preyde, 2013; Paquette & Smith, 2001). In the majority of studies on disabilities and disclosure, the experiences described and detailed by the participants occurred in work situations where the participants were employed or in educational environments where the participants were students enrolled in secondary or post-secondary classes.

The literature sources found to be the most pertinent to the intent of this research project centered on the relationships between students and teachers in connection with educational issues such as fairness in supportive accommodations for achieving academic success (Gaad, 2007; Moore & Keef, 2004; Pearson, Lo, Chui & Wong, 2003). These studies that called attention to this topic only involved participants in a post graduate environment. I was unable to find any research papers that concentrated on either teacher attitudes in relation to First Nations' students

with invisible disabilities in First Nations' schools or how the western medical model influences educators' mindset in First Nations' schools.

Themes. From the relevant studies discussed previously, the findings identified several reoccurring themes linked to the relationships between teachers and students with invisible disabilities, including students' feelings of: (a) low self-worth, (b) battle weariness, (c) isolation, and (d) victimization. These themes began when students first experienced obstacles to learning, and later developed into barriers to acceptance and achievement with residual lifelong negative effects. One example of one of these themes, victimization, was provided in an article by Cornett-Deviot and Worley (2005). They reported a participant's experience with an instructor. The instructor had initially seemed less than enthusiastic with a student's special education learning disability status at the beginning of a course. At the completion of the course, the instructor explained why he felt that student would be the worst one in his class,

His experience had been that students use disability as an 'excuse' or 'they can't do anything', or 'they don't want to learn.' Further he claimed that she was the first person he'd known with a LD that was a decent student. (p. 325)

Despite the instructor trying to justify his rationale for his negative attitude towards students with learning disabilities and declaring the student was the first 'decent' LD student, the instructor displayed a basically unaltered attitude concerning students with invisible disabilities.

Students with invisible disabilities face a variety of barriers on a daily basis in schools. The continual stress of having to navigate through and around attitudinal barriers eventually causes battle weariness in students. Dwyer (2000) stated, "College and university students with disabilities often encounter barriers to their education, including a lack of understanding and

cooperation from administration, faculty, staff and other students, and a lack of adaptive aids and other resources” (p. 123). The barriers Dwyer identified were either primary or secondary in nature.

The primary barriers had a direct correlation with the invisible disability such as negative or disparaging attitudes towards the student. The secondary barriers resulted from the failure to develop strategies and supports to offset or minimize the original impact of the students’ invisible disabilities or the primary barriers they faced. The resulting physical, emotional, social and academic impacts of these barriers on students with invisible disabilities were not fully appreciated by either teachers or other students who had no personal experiences of tackling these barriers daily. It was this lack of awareness that directly contributed and exacerbated students’ feelings of: (a) low self-worth, (b) battle weariness, (c) isolation, and (d) victimization (Egan & Guiliano, 2009; Henning, 2007; Kariuki, Honey, Emerson & Llewellyn, 2011; Mullins & Preyde, 2013; Paetsold, Garcia, Colella, Ren, Triana & Ziebro, 2008; Riddick, 2000).

Identification

The major barrier all students with hidden invisibilities dealt with was the identification of their particular invisible disability (Harrison, Green & Flaro, 2012). Often, the identification came well after the students had entered the educational system. Usually, the identification process began after teachers had begun reporting concerns, issues, and difficulties observed in the classroom to resource teachers and parents; typically involving low academic success or misbehaviors (Ball, 2012; Davies, 2005; Faigel, 1983). The parents of students with invisible disabilities generally stated they were unaware of any problems and that they thought their children appeared to be like all other children (De Boer, Pijl & Minnaert, 2011). Although some parents, who had suspected their children were having learning issues, had expressed concerns,

they felt that they were disregarded because they were not considered to be experts (Bevan-Brown, 2013; Blanchette, Klingner & Harry, 2011; Pivik, McComas & Laflamme, 2002). This negative mindset regarding parents' requests for assistance and support for their children often contributed to the delay in the identification process for invisible disabilities. As Riddick (2000) stated:

What some educationalists seem to be objecting to is parents asking for a previously unmet need to be met. In doing this they are seen to be arguing with professionals about how a problem is defined and dealt with. This is not simply an argument about resources, but an argument about the right to define a problem in a certain way. (p. 663)

As a result of the lack of identification of students with invisible disabilities, even more barriers were established that added further complications for them as students. One of these barriers was the students' perceptions of their teachers' acceptance and understanding of their learning challenges and their need for academic supports. The lack of acceptance and understanding regarding their invisible disabilities was seen as teacher skepticism. From the students' pessimistic perspective, this became a major contributing factor in creating barriers (Chacala, McCormick, Collins & Beagan, 2014; Gill, 1999; Lingsom, 2008). Students with invisible disabilities repeatedly expressed their belief that teachers not only questioned the existence of invisible disabilities but also questioned the necessity for adaptations or accommodations for something whose very existence was questionable because it was unobservable. As noted in Fox and Kim (2010), "There are unique challenges associated with the invisibility of persons' disabilities. Requests for special needs often evoke skepticism" (p. 327). The end result of this skepticism has been that these students with invisible disabilities also came

to believe that their teachers' doubtful and suspicious attitudes had influenced their classmates' opinions in extremely negative ways.

Sparling (2002), Bunch and Valeo (2004), and Gaad (2007) also agreed with that position that teachers' skepticism would transmit itself in daily subtle classroom influences towards students with disabilities, whether visible or invisible. These subtleties would include displaying little to no personal tolerance and patience when interacting with a student with an invisible disability to providing few if any adaptations and accommodations for students with invisible disabilities. The subsequent ramifications of the teachers' influences were that other students exhibited similar attitudes and behaviors as the teachers. Therefore, students with invisible disabilities fearing the skepticism of teachers often chose not to disclose their disabilities.

The laws on confidentiality must be adhered to when identifying a student with a disability even when the disability is invisible. Information concerning an individual student and his or her disability is limited to a small number of people until the decision to fully reveal the diagnosis has been made by either the student or his or her parents or legal guardians. The decision on whether to disclose the invisible disability also can be considered a barrier since disclosure can directly contribute to undesirable reactions towards the student with the invisible disability by others in and outside the classroom (Campbell and Missiuna, 2011; Kleege, 2002; Olney & Brockelman, 2003; Rohmer and Louvet, 2012; Treby, Hewitt, & Shah, 2006).

Repeatedly, the willingness to disclose an invisible disability was not only based on personal fear and other people's skepticism but also involved the students' own belief that if they kept their difficulties hidden from scrutiny or chose alternate actions that are more readily accepted as normal by others, their lives would be less problematic despite the daily academic

challenges. Those students with invisible disabilities often decided that it is more appealing to be viewed as normal person who failed rather than person who is not normal but succeeded (Matthews, 2009).

As Valeras (2014) stated:

Persons with a “hidden disability,” one that is unapparent to the unknowing observer, make daily decisions about which identity to embody. They are constantly negotiating when, where, why, and how to disclose and adopt the disability identity to “pass” and give society the impression of “able-bodiedness.” (p. 1)

Connected to the decision to choose not to disclose an invisible disability and to choose to appear normal, were the varied educational experiences and opportunities that students missed because they were apprehensive about how they would cope in different learning environments and at tackling new tasks. Only as students with invisible disabilities matured, did they realize the extent of the limitations that had been placed on their learning. Esmail, Darry, Walter, and Knupp (2010) further explained, “Many people with invisible disabilities recognize the self-limiting barriers they create to avoid the appearance of their disability. They noted their reluctance to put themselves in situations where they might have difficulty because of their disability” (p. 1153).

Another barrier related to having an invisible disability was accessing the adaptations or accommodations necessary for students to reach their full potential and achieve academic success. As per most educational institutions’ policies, students with disabilities must provide proof before any specialized adaptations or accommodations are implemented. Educational institutions’ policies also typically state that only expert clinical confirmations of disabilities will

be accepted. For students with invisible disabilities acquiring the necessary proof becomes a herculean task and is another barrier to overcome. In some instances, the existence of some hidden disabilities, such as dyslexia or emotional behavior disorder, have been disputed by experts (Mullins & Preyde, 2013). Then, there are times when the professionals from the medical community are resistant to verifying conditions that do not fall clearly in their realm of expertise, such as Irlen Syndrome, because there are no specific identification tests (Davis, 2005; Matthews, 2009).

As a result of the experts' reluctance to definitively confirm numerous hidden disabilities, students with invisible disabilities struggled to deal with barriers without proper support. In some cases, appropriate acknowledgement and supports were obtained only when students pursued formal legal avenues. Konur (2006) stated, "Students have the burden of documenting their disability" (p. 353) and further detailed that, "'learning disabilities' such as 'dyslexia', 'dysgraphia', 'dyscalculia', attention deficit and hyperactivity disorder (ADHD), HIV, 'visual disabilities', 'hearing disabilities', and 'back and repetitive strain injuries' have all been considered by the courts and tribunals as an impairment over time" (p. 355). Despite favorable rulings, it has remained a difficult process to gain recognition as being disabled and therefore entitled to supports. Research also has indicated that the number of students with invisible disabilities was larger than most educators have realized. Matthews (2009) stated, "Students whose 'hidden' needs are ultimately declared to staff may be only a fraction of the number of students whose impairments might never be formally disclosed or accommodated" (p. 230).

As previously reported, research on teachers' perspectives concerning invisible disabilities confirmed that the students with invisible disabilities were often correct in their perceptions of their teachers' negative mindsets regarding invisible disabilities (Dukmak, 2013;

Gal, Schreur & Engel-Yeger, 2010). Further to those studies' findings, several other studies have examined the inclusion of students with disabilities and teachers' attitudes. A difference of feelings was documented between teachers in training and experienced teachers. Teachers in training were very much in support of the inclusion of all students in the regular classroom, regardless of their types of disabilities. But after working in classrooms, the more experienced teachers displayed reluctance in accepting students with certain types of disabilities. In some cases, teachers had even developed their own ideologies for successful inclusion of students with various disabilities in spite of knowing the legal policies. The attitudinal change towards students with disabilities was described by Avramidis, Bayliss and Budren (2000).

Education students favour the idea of integration and are willing to teach in regular classes those students whose handicaps do not inhibit their own learning or the learning of others. . . . Following student teaching, however, there was a significant decline in the favourability of attitudes toward integration. (p. 279)

Hanson et al. (2001) found that the kind of disabilities and their presenting characteristics were the reasons for the teachers' change of attitude.

Child characteristics also played a role in determining the child's access or maintenance in an inclusive setting. These characteristics included the level and type of the child's disability, and the child's personality and behavioral characteristics. Many families and professionals alluded to the degree of the child's "includability". Particular disabilities and certain behavioral characteristics were associated with this ability or desirability to be included. Some children were considered more likely to succeed in inclusive settings than were others. (p. 77)

When the development of this resistance to total acceptance and support for students with disabilities was examined, researchers found that teachers tended to supply one of two reasons for it. The first reason was that they were already experiencing heavy workloads because of curricular demands (Beyene & Tizazu, 2010; van der Veen, Smeets & Derriks, 2010) and the second reason was that they were not sufficiently confident in their teaching abilities due to a lack of appropriate training to meet the special needs of students (Beyene & Tizazu, 2010; Mullin, 2001). Yet, when focusing specifically on invisible disabilities, such as learning disabilities, researchers discovered that teachers' perceptions of fairness also became another reason for the resistance. Egan and Giuliano (2009) reported:

The results showed that granting accommodations to the individual was perceived to be less fair than was not granting accommodations, suggesting that accommodations are believed to give an unfair advantage to individuals with learning disabilities. Moreover, their results indicated that accommodations were perceived to be especially unfair when they helped the individual perform well on the task (Paetsold et al, 2008), even though increased task performance is precisely the goal of granting accommodations. (p. 489)

Vogel and Sharoni (2011) noted that past personal experiences strongly influenced teachers' viewpoints and actions concerning disabilities and whether they were resistant to including students with invisible disabilities in their classrooms. Teachers who had experienced disability personally were more willing to accommodate. The primary motivation for entering the teaching profession was the desire to provide pupils with the positive experiences that they themselves had been denied as youngsters. The teachers perceived themselves as effective teachers who understood the difficulties faced by their pupils. They had an ethos of caring and were committed to making certain that their pupils did not suffer from shame or from lowered

expectations. The teachers viewed their own disabilities as a tool for reaching their pupils (Vogel & Sharoni, 2011).

The cascading negative impact of more barriers resulting from the lack of early identification of the invisible disabilities has caused undue and unseen hardship for many individuals with invisible disabilities, including FN students. Students with invisible disabilities are burdened by their own fears, skepticism expressed by both clinical professionals and classroom teachers, adverse influences projected either subtly, or not so subtly, by classroom teachers, and the attitudes of other students. Perhaps the most difficult hurdle to identification was and continues to be proving the existence of invisible disabilities. But this process of proving the existence of invisible disabilities was, and continues to be, flawed because of the unwavering reliance on a clinical format of assessment.

Assessment

Another common theme found in the research was inappropriate assessments, or the inappropriate use of assessments tools, for confirming invisible disabilities. Historically, the focus in educational assessments, to qualify for special education services, was centered on determining either how far behind individuals were, compared to their peers; or how far below academic outcomes they were. Shealey, Lue, Brooks and McCray (2005) affirmed this point, “Special education was founded on the premise that individualizing instruction for children who were experiencing education problems would help them to catch up to their schoolmates” (p. 114). While Villegas (2009) explained the flaw in the on-going misuse of assessments as, “Education development is not about chasing some norm or bridging gaps, but instead becomes as effort to make the best use of local capabilities” (p. 47).

In order to verify the existence of an invisible disability and qualify for access to adaptations or accommodations, some type of assessment was required. But many professionals have questioned the use of intelligence quotient (IQ) assessments to gauge a student's capability or potential when cognitive ability was not the concern (Hahn and Hegamin, 2001). More questions regarding the connection between the measure of IQ and appropriate supports and services required to assist students with learning needs also have been raised (Ruban and Reis, 2005; Brody and Mills, 1997). But the types of assessment available have been either medically or psychologically based and did not cover other domains where so many invisible disabilities often fall. Wolforth (2012) explained:

To receive disability related services and academic accommodations, a student must present documentation signed by a suitably qualified professional that verifies that they have a disability. In the case of visible disabilities and most medical and mental health conditions, this is quite straight forward. In the case of those diagnosed with a learning disability or attention deficit hyperactivity disorder, not only must the presence of an invisible disability be demonstrated with results from standardized testing but also the disadvantage experienced by the student must be documented. (p. 61)

In addition to the concern about assessments and assessment tools for invisible disabilities, the qualification of the assessors also has been questioned (Cornish, Gorgen, Monson, Olkin, Palombi, and Abels, 2008). As Gill (1999) described in her article:

Evaluators without direct disability experience may miss crucial information, may fail to comprehend it, and may distort its meaning because of their unaware and/or unacknowledged disability biases and the fact that they may not even know what they do

not know. No matter how objective their treatment of the data is, no matter how rigorous their methods, they may not have the knowledge to produce a useful evaluation. (p. 286)

The third issue in disabilities assessment is the potential conflict of interest between assessors as student advocates versus their roles as institutional advocates. As Harrison and Holmes (2012) explained:

Referrals for psychoeducational assessments in a school setting are often for the purpose of determining the student's eligibility for program accommodations and access to assistive technology. Problems in making as accurate diagnosis of LD can arise when the psychological service providers feel that their role when conducting a psychoeducational assessment is to act as advocates for students. (p. 20)

This type of personal conflict among clinicians, whose reports were decisive factors in confirming the existence of visible and non-visible disabilities, was not deemed acceptable (Harrison, Green & Flaro, 2012) because only when there was a confirmation of a disability did access to resources become available. Without the disability verification by certified clinical professionals, the school would not receive any additional funding. Therefore, when future assessments were required, schools would tend to select the clinical professionals who were seen as being more accommodating because of the funding ramifications.

Inappropriate assessments for invisible disabilities, professionals without the proper qualifications, and a funding environment that fosters ethical conflicts all contributed to an ineffective identification system for students with invisible disabilities. Thus, when the purpose for assessment was the verification of a student as being disabled, confirming entitlement to funding along with accessing services and supports, the appropriateness of every component in

the assessment process became highly important. Unfortunately, as a result of these aforementioned problems, students with invisible disabilities often go unidentified and unsupported.

Supports for Students

Another barrier for students with invisible disabilities was whether to actually access adaptations and accommodations, after verification of the non-visible disability and recognition of their entitlement to supports had been completed (Davis, 2005). Students with invisible disabilities needed to decide if the proffered supports were really the most appropriate for their disabilities or if the supports were simply the basic standardized ones that already exist in the schools and that teachers find the easiest to implement. Students with invisible disabilities often required flexibility in their supports that was dependent upon a variety of variables, such as location, noise level, time of day, subject area, and pedagogical methods. Supports needed to be seen as simply scaffolds that changed forms were contingent upon an array of circumstances and conditions. In some cases, specific and set adaptations and accommodations would be appropriate for certain invisible disabilities. But other invisible disabilities required much broader and more malleable strategies and practices in order to provide suitable supports at suitable times.

According to Eleftheriou, Stamou, Alevriadou and Tsakiridou (2013) the main reason for the inappropriateness and ineffectiveness of supports was that “the presence of the medical model is still evident in education practices, due to students’ classification on a kind-of-disability basis rather than on a disabled-needs basis” (p. 663). But Pearson, Lo, Chui and Wong (2003) believed that

“the main problems were kinds of disabilities for example: sensory, physical, cognitive, etc. and degrees of disabilities such as: some hearing loss or deaf, paraplegic or quadriplegic, etc. Their levels of perceived support, and discrepancies between perceived support and resources available, have been found to be related to factors such as types and severity of disability” (p. 491).

Cornett-Devito and Worley (2005) pointed to a third possible problem. The problem of teachers’ failure to understand that the need for support services was as critical for students with invisible learning disabilities as it was for students with physical disabilities. “Students reported that other instructors did not understand the need to accommodate to invisible learning disabilities in the same manner as they might understand the need to accommodate students with visible physical disabilities” (p. 325).

There was also consideration of the degree to which adaptations and modifications aided or hindered students’ lives, not only academically but also socially. As Paetzold, Garcia, Colella, Ren, Triana, and Ziebro (2008) stated, “Peers saw an accommodation as less fair when the person with a disability who received the accommodation outperformed others. Further, peers fairness perceptions were the lowest when the confederate was granted an accommodation and was the top performer” (p. 32). Paetzold et al. (2008) also went on to say, “These unfairness perceptions could lead to negative treatment for the person with the disability. Additionally, because of the potential for negative consequences, persons with disabilities, particularly hidden ones such as learning disorders, may decide not to request needed accommodations” (p. 34). Egan and Giuliano (2009) concurred, “accommodations have negative social consequences when used successfully, students with learning disabilities may be faced with a “no-win” situation when deciding whether to use academic accommodation” (p. 496).

Even when the lack of appropriate support barrier was removed, many students with invisible disabilities still faced other obstacles. Despite achieving higher academic success when accommodations and adaptations were employed, students with invisible disabilities often experienced adverse attitudes and opinions from both their teachers and peers. As a result of their resistance to accepting the concept of invisible disabilities fully, students with invisible disabilities often choose not to utilize their accommodations or adaptations in order to blend in with their classmates.

Indigenous Perspective

As mentioned previously, little research was found on indigenous perspectives of either invisible disabilities or other disabilities. However, numerous authors pointed out that indigenous peoples have always maintained that indigenous thinking did not involve the categorization or quantification individuals' abilities. Everyone was considered as a contributor to the development of the community as a whole. Everyone was thought of as unique with attributes, regardless of type or nature, which were viewed as essential components of the community's survival and success. As Thompson (2012) explained:

Although there is no definitive First Nations/Metis/Aboriginal definition of disability,... there is a general belief with these cultures that tends to locate disability communally. Accordingly, disability may be taken up as a gift to, and responsibility for, the greater community. ... Thus, 'a child with a developmental disability may not be viewed as deficient but as someone able to be part of the community in his or her own way.' (p. 100)

This holistic and community ownership of abilities and disabilities was counter to the educational system operating in provincial school divisions and even in many indigenous communities. In the present educational system, special needs services were and continue to be financed through various funding formulas dependent upon labeling processes based on individuals' deficiencies. Various assessment tools, including intelligence and achievement tests, were (and still are) used to determine these deficiencies. Such tests were deemed fair because they were developed and standardized by experts.

To be considered reliable and valid, IQ tests must be both criterion and norm referenced. But minorities such as FN people have not been adequately represented in the normative samples. The content used for criterion referencing often requires correct responses or solutions that depend on unfamiliar experiences or values. The language used to administer the IQ tests has been English, a second language for the majority of FN students. As Wingert and Kantrowitz (1997) have pointed out, "Many critics of IQ tests believe they are culturally biased and underestimate the intellectual potential of poor and minority children" (p. 60). This puts FN students, especially those with visible and invisible disabilities, at a disadvantage when taking IQ tests. The accuracy of the results remains, at best, highly questionable.

Teachers and other professionals working in indigenous schools or with indigenous students needed to be cognizant of this indigenous and non-indigenous philosophical difference, and to adjust their interactions with students who have invisible disabilities and their parents to reflect respect for the communities' cultural beliefs and goals. As Schissel and Wotherspoon (2001) stated, "In school settings, this involves in part sensitivity to how educational environments may damage students who are placed in situations built around expectations and practices dependent on specified conceptions of normality" (p. 331).

By simply ignoring the labels and focusing on solutions in response to indigenous' perspectives on abilities and disabilities, other dynamics were created in the classroom that required teachers to further evaluate their practices. As Wishart (2009) stated in her article:

Deemphasizing labels and emphasizing diagnosis is clearly not enough. Underlying the complexity of this issue is a paradox. Labels are needed in schools in order to define a particular problem and develop policy, yet these labels create tensions for educators in practice. (p. 472)

In order to achieve a necessary label required by educational policies, classroom and resource teachers were required to obtain full support from parents and students in what was often considered to be a self-demoralizing process that is just a revamped practice held over from residential school days. Unfortunately, many teachers were not aware of historical and educational atrocities experienced by their students' families and made incorrect assumptions about families' reasons for not wanting a label. Stairs and Bernhard (2002) clarified, "Parents' alienation based on their own assimilative, abusive, or otherwise negative schooling experiences must be perceived and dealt with slowly and carefully -not with unreflective critical judgments." (p. 319)

The issue of labeling a student in order to be included more positively in the community's school generally, and in a certain teacher's classroom specifically, when there had been no previous attempts to increase acceptance and belonging, contributed significantly to widening the disconnect between teachers, parents and schools in FN communities. Kanu (2002) explained this disconnect as:

No special effort is made to make them feel part of the life of the school, and the vast majority of teachers in these schools belong to the dominant mainstream culture. The lack of Aboriginal cultural knowledge among these teachers has generally resulted in pedagogical and interaction patterns that have resulted in negative learning experiences for Aboriginal students. (p. 101)

Regardless of ethnicity, students with invisible disabilities frequently tried to assimilate into their environments and to hide their disabilities resulting in their true selves being buried and denied. (Davis, 2005; Olney & Brockelman, 2003; Shah, 2007) Consequently, it is little wonder there was conflict between the educational methods used in the institutionalized Western system and by indigenous parents and communities. As Matthews (2009) expounded, “The medical model with its focus on diagnostic labels presents a number of educational and political problems. From a practical point of view, it falsely implies that students with the same impairment have the same learning needs.” (p. 231) The conflict between western categorical beliefs and the holistic indigenous beliefs was elucidated by Stairs and Bernhard (2002), “Indigenous teaching focuses as much on learning with the heart as on learning with the mind...Indigenous facilitates learning how to see who one really is, rather than an image manufactured.” (p. 317)

Even to this day, the Western medical model dominates society. This domination has resulted in a limited view of disabilities as a whole and invisible disabilities in particular. The impact of this view has dramatically influenced the education system, especially special education. This view also has no commonalities with Indigenous perspectives. The discord between the Western medical model and Indigenous perspectives has only added to the barriers for identification of FN students with invisible disabilities.

Conclusion

Based on the literature reviewed, a major deduction was reached: before a protocol for appropriate early identification of students with invisible disabilities can be developed, several important elements needed to be examined more thoroughly, and then planned for accordingly, in order to achieve a successful implementation of the protocol. Therefore, the first element that needs to be addressed was the stakeholders' perspectives; in particular, the teachers' viewpoints on invisible disabilities. As Peterson (2006) explained, "Teachers and administrators, shaped by their own personal beliefs and experiences, often bring into the classroom misguided prejudices that influence their interactions with students" (p. 729).

Shannon, Scheon and Tansey (2009) further described the influences the stakeholders' misconceptions could impose, noting that, "unfavorable attitudes toward persons with disabilities contribute to the development, reinforcement and solidification of barriers that prevent full societal inclusion" (p. 12). Since the success in early identification of students with invisible disabilities and the provision of appropriate supports primarily is very likely to be contingent on the whole-hearted commitment of teachers; the amount of promotion and encouragement given to teachers by school administrators, regarding invisible disabilities, may need to be clarified. Thus, along with the establishment of an identification protocol for students with invisible disabilities, a continuous awareness program on invisible disabilities for school staff and other stakeholders may have to be developed simultaneously.

The second element requiring consideration was the determination of the extent of the problem. This included what types of invisible disabilities there are, along with their continuums of severity, and the appropriate supports that need to be provided for academic achievement and social acceptance by others in the school environment. Determination of an invisible disability

cannot simply be based on the Western Medical model that only used physical standards to verify disabilities. The mental, emotional, social and sensory connections or disconnections to the physical state of individuals need to be recognized and considered when defining what comprises invisible disabilities and determining the supports necessary for students with invisible disabilities to succeed in school. Consequently, as Miskovic and Gabel (2012) explained in their article, the social model for any disability identification should be used since:

The social model focuses attention on the structural features of society and illuminates the ways in which structural features determine who will and will not be fully included in all aspects of social life. Within the social model this structural exclusion, or the barriers to being included, are what disable people rather than their individual impairments. (p. 234)

The third element must address the diversity of First Nations in culture, language, geography and history. Because of these diversities, it may not be possible to design a ‘one-size fits all’ protocol for the early identification of students with invisible disabilities in First Nations’ schools. The differences amongst First Nations necessitates the development of a flexible identification process that includes the collection of foundational information on teachers’ perspectives, which are essential to building and maintaining the value of the identification process. As Anastasiou and Kauffman (2012) stated, “Meeting the learning needs of all children with disabilities requires thinking about the multifaceted needs of children and the demands of social inclusions” (p. 144).

Still, the importance of the identification of invisible disabilities was continually reinforced in the literature reviewed. If the status quo was allowed to continue, then less than

optimal outcomes would also continue without any positive changes to those outcomes for students with invisible disabilities and the concept of inclusion would remain illusionary for all stakeholders. As supported by Shah (2007), “The reality is that a great deal of change is required within ‘mainstream’ schools before disable children will actually experience inclusion” (p. 439). Not only does the change within ‘mainstream’ schools have to happen but eventually within those students with invisible disabilities. As Doubt and McColl (2003) explained:

The students seemed to aspire in assimilation rather than integration, attempting to adapt to an environment which demanded uniformity, achievement and perfection, rather than diversity—an environment in which they had limited potential for conformity and full participations. (p. 14)

Students with invisible disabilities likely will continue to seek and settle for the most stress free and non-confrontational existence possible, at least until they experience greater understanding, appreciation and acceptance. As this awareness of invisible disabilities increases, other related elements such as appropriate identification procedures, program adaptations, physical accommodations, and self-advocacy skills also will need to be developed. These elements are essential for students with invisible disabilities to reach their full potential and no longer accept the assimilation paradigm of the ‘mainstream schools’ as the best way to survive in a hostile environment.

As stated in this chapter, the literature review showed that students with invisible disabilities were poorly served by the mainstream education system. Students with invisible disabilities were not identified in timely and valid ways. Adaptations and accommodations for students with invisible disabilities were severely lacking due to the poor identification process

and teachers' lack of awareness surrounding invisible disabilities. The intent of this study was to establish an information baseline on teachers' knowledge and training regarding invisible disabilities in order to develop a protocol for early identification of students with invisible disabilities in First Nations schools.

Chapter 3 Research Methodology

Framework and Assumptions

In his article, Kovach (2010) stated:

Conceptual frameworks make visible the way we see the world. Within research, these frameworks are either transparent i.e., through form, or not, yet they are always present. The rationale for explicit representation of one's conceptual framework itself assists in illustrating the researcher's standpoint, thus giving the reader insight into the interpretative lens that influences the research. (p. 41)

The theoretical framework I used for this study was grounded theory. As I have neither outlined a tentative theory nor uncovered a closely related theory on the early identification of invisible disabilities in FN contexts that could be verified, I anticipated that a theory would emerge from the research findings. By searching for similarities, patterns or themes that surfaced from the participants' views, as expressed in their responses, I hoped to organize the data into meaningful categories. After analyzing that data, I expected to be able to design a process for the early identification of students with invisible disabilities in First Nation's schools.

Personal background. Because of my past involvement over many years in First Nations' schools in various capacities such as classroom teacher, resource teacher, student advocate, parental advisor, special education and administration facilitator, I have an established relationship of respect and trust with the communities and their members both in and out of the educational arena. I comprehend and appreciate the statement in Denzin and Lincoln (2005):

For indigenous and other marginalized communities, research ethics is at a very basic level about establishing, maintaining, and nurturing reciprocal and respectful

relationships, not just among people as individuals but also with people as individuals, as collectives and as members of communities, and with humans who live in and with other entities in the environment. (p. 97)

With this awareness of First Nations' sensitivities to past research transgressions, I planned to make every effort to avoid disenfranchising the school, staff, parents and community before the research began, during the research and after the research was complete. To achieve this goal, I followed closely the Code of Research Ethics (see Appendix A) developed by MFNERC based on the First Nations Centre's Considerations and Templates for Ethical Research and Practices (see Appendix B). I began my study only after consent had been received from Chief and Council or their designated representative (i.e., Education Director) (see Appendix C).

As I planned on conducting this research study at schools in two First Nations' communities which I have been connected to for over ten years, I believed that I and this study would be received more openly by the participants and the First Nations' community members than if I was someone simply conducting a research project from the 'outside'. I felt that I would be able to gather information that is more reflective of reality since I would be viewed as an insider and someone who is non-biased. This familiarity provided and promoted an atmosphere in which all teachers felt they could be more open and honest in the sharing of their feelings and attitudes on the topic of invisible disabilities as it related to their students. Other benefits to this familiarity were awareness of First Nations' cultures, languages and traditions and attentiveness to the historical and recent past experiences of First Nations with non-First Nations concerning schools and testing. With this background, I was better able to organize, analyze and deduce from the study's data, insights that led to a clearer understanding of teachers' perceptions of

invisible disabilities in FN communities and eventually on to how best to identify students with invisible disabilities in order to improve their academic success in First Nations schools.

At the same time, I took care when conducting the resource teachers' interviews to remain neutral and not to allow my previous work experience as a classroom or resource teacher to influence, in any way, the resource teachers' responses. Only their thoughts and opinions freely expressed to me in confidence were documented. During the analysis and interpretation of the data, I was vigilant that all the findings were based just on the participants' responses without my sway.

Type of Research

Qualitative research. I approached this research from a postmodern interpretivist perspective (Kroese, 2012) by deconstructing prevalent negative beliefs concerning individuals with invisible disabilities in order to right the social injustices of unfairness and intolerance that individuals with invisible disabilities experience, to varying degrees, on a daily basis. I also adopted a disability rights perspective (Parekh, 2015) of accepting individuals with invisible disabilities; not as less than normal, but as a variation of normal. Qualitative research methods were often considered the superior choice when these perspectives were involved (Finlay, 2006; Mack, Woodsong, MacQueen, Guest and Namey, 2005). Creswell (2009) further explained:

We conduct qualitative research because a problem or issue needs to be explored. This exploration is needed, in turn, because of a need to study a group or population, identify variables that can then be measured, or hear silenced voices. ... We also conduct qualitative research because we need a complex, detailed understanding of the issue. ...

We conduct qualitative research because we want to understand the contexts or settings in which participants in a study address a problem or issue. ... We use qualitative research

to develop theories when partial or inadequate theories exist for certain populations and samples or existing theories do not adequately capture the complexity of the problem we are examining. (p. 40)

This qualitative research included collected quantitative data. By using quantitative results to support or refute the qualitative findings, the findings of this study provided a clearer and more accurate answer to the question of the relationship between teachers' identification of students with invisible disabilities and provision of needed support.

The approach used in this qualitative study is derived from a pragmatic position. Despite pragmatism being strongly associated with mixed methods, that association is not exclusively restricted from other research aspects and methods. As Denscombe (2008) explained:

Nor is the mixed methods paradigm alone in its use of pragmatism as its philosophical underpinning. Pragmatism provides a recurrent theme underlying forms of research that can be traced back throughout the last century through the works of symbolic interactionists such as Dewey, Mead, Blumer, and Goffman (Cherryholmes, 1992; Maxcy, 2003), and there are aspects of pragmatism involved in grounded theory, ethnomethodology, conversational analysis, and discourse analysis of people such as Glaser, Strauss, Garfinkel, Cicourel, and Foucault (Guignon, 1991; Rorty, 1982, 1991). (p.275)

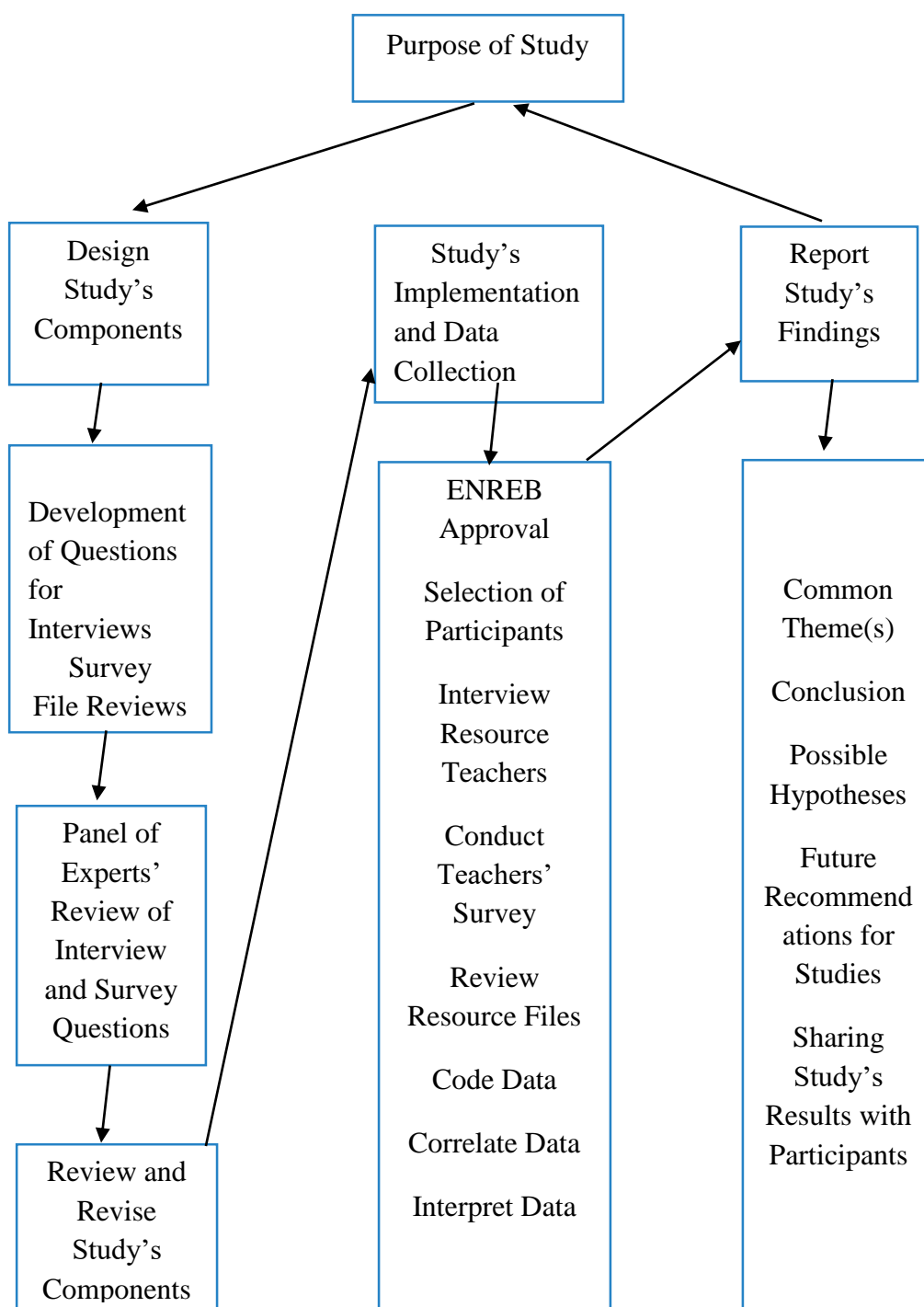
Using the pragmatic approach provided me the freedom to employ methods, techniques and procedures from both qualitative and quantitative research to explore deeply for more insightful information on the question of what is the relationship between teachers' identification of students with invisible disabilities and their provision of needed supports. As Johnson and Onwueguzie (2004) stated:

Pragmatically inclined philosophers and researchers also would suggest that we can reach some agreement about the importance of many (culturally derived) values and desired ends, such as, for example, preventing the dropping out of school by adolescents, reducing the use of illicit drugs by children and adolescents, finding effective teaching techniques for different kinds of students, educating children and adults (i.e., increasing their knowledge), helping to reduce discrimination in society, and attempting to eliminate or reduce mental, learning, and other disabilities. In other words, pragmatism takes an explicitly value-oriented approach to research. (p.17)

Overview of Research Design

The design of this qualitative study used the grounded theory approach in order to construct a possible theory that may assist in the early identification of FN students with invisible disabilities. Through a systematic process of designing and implementing the study, and collecting and evaluating data, a clearer understanding of possible themes related to early identification become clearer. This systematic process included a review of questions for the resource teachers' interview and the teachers' survey by a panel of experts, an adherence to all ethical guidelines and procedures, an organized delivery and collection of the interviews and surveys, coding and correlation of data, and interpretation and summarization of all data.

Design of Study



Ethics Approval

When the study's design was completed, I then followed the protocol as outlined by the University of Manitoba, to receive approval from the Education / Nursing Research Ethics Board (ENREB) (Appendix D) to conduct my study. In the request for approval, all the components of the study were described including dispersion of the study's findings and templates for cover letters detailing the study's purpose, protection of participants' confidentiality and for participants' approval and consent. The approval certificate was received November 2016. A change the design of the study involving the number of school participating and the removal of the student resource files review as one of the study's data collection methods was later requested and the amendment approval for those changes was received February 2016 (Appendix E). As the progress of the study was slower than anticipated, there was a third approval sought from ENREB for a time extension which was approved in October 2017 (Appendix F).

Participant Recruitment and Selection

As this qualitative study involved some quantitative methods so that comparisons and contrasts could be examined, the participant selection process was based on two prerequisites. The first requirement was the geographical location of the school where the participants were employed. The second condition was that schools have similar instructional staff numbers and student populations. A call for volunteer schools and their staffs was sent out to FN schools explaining the purpose and description of the study including the responsibilities of all those involved along with a tentative time line for the study.

Unfortunately, unanticipated difficulties can arise in any research study. In this study, the difficulty was obtaining the initial consent to begin my research from the Chiefs and Councils in a timely manner. This delay was the result of the Chiefs and Councils' extremely heavy

workloads (i.e., dealing with a wide range of responsibilities that include very major concerns such as housing, fuel shortages and flooding). Because of their limited time, Chiefs and Councils prioritized the issues and wherever possible delegated requests and decisions to their appropriated expert personnel (i.e., educational directors). As a result of these demands on the Chiefs' and Councils' time, my request for permission to conduct my study had to be forwarded on to the educational directors for approval. This meant that there was a long lapse of time before I could begin my research, as I had to resend all the paperwork to the First Nations' education directors for their approval (see Appendix C).

Initially, the participation of only two schools was planned for and required. But as the progression of the study unfolded, three schools from three different geographical regions and three different student populations volunteered to participate in this study on invisible disabilities. This required ENREB Amendment Approval (Appendix F) which was sought and received, as mentioned in the preceding section, before the data collection began.

The first school was situated in a remote northern Manitoba First Nations community. It could be reached year-round by air service but only by road during the winter. The school consisted of one main building with additional classroom space provided by portable huts in one location. The physical structure consisted of classrooms, a resource room, a gym, a non-functioning science lab, a computer room, a kitchen and an administrative office.

There were fifteen teachers, ten educational assistants, one resource teacher and one principal employed by the Band Council. All the educational assistants were from the community, while half of the teachers were from other areas in the province or from outside of Manitoba. Teachers from outside of the community fell into one of two categories. The first category was beginning teachers who were looking for teaching experience, while the second

category was made up of retired educators who, despite retiring in their home province, felt they still wanted to work in the classroom. The new teachers generally stayed for a year or two while the retired teachers tended to stay longer, for four or more years. The teachers from the community had all received their graduate degrees from one of Manitoba's universities via a specially designed program for individuals from First Nations' communities. The resource teacher was from the community and has been in that position for over ten years.

The school covered all grades, from Kindergarten to twelve. But the high school offered only the minimum, mandatory subjects required to meet the province's requirements for accredited graduation certificates. Because of this factor, the option for high school students to leave the community and attend other schools with more subject choices was afforded. Equipment, materials and resources were limited and very basic due to the funding agreement between INAC and Chief and Council. Internet services often were limited or not available for students and teachers to access.

The school's total student population was three hundred and thirty-six. Two thirds of the students, two hundred and twenty-six, were in the elementary and junior high grades. The remainder of the student population, one hundred and ten, was in high school. There has been a large on-going yearly drop-out rate between grade eight and grade nine. Of the overall student population, there were twenty-five students identified as high cost special needs according to INAC's guidelines; while there were another forty-five students who fell into INAC's low cost category (see Appendix G for INAC's specifications for high cost identification). The resource teacher coordinated all special needs services with both community agencies and outside agencies in accordance with INAC's administrative conditions. These duties limited her time providing direct student resource services to a small pull-out program.

The school had a formal referral protocol in its school policy. Unfortunately, the resource teacher had to continually deal with the issues of classroom teachers not wishing to adhere to it. When the referral protocol was followed, she proceeded with diagnostic services that led to services ranging from informal remediation to formal and alternative interventions. The community services that the resource teacher could access were extremely limited. The only regular support from an outside agency came from the Manitoba First Nations Education Resource Center (MFNERC). All clinical support that was needed had to be purchased through INAC's Special Education Plan (SEP).

The second school was in a more centrally located First Nations community in Manitoba. It could be reached year-round by both air and road. The school consisted of one main building. The physical structure consisted of classrooms, a resource room, a gym, a kitchen and an administrative office.

There were eleven teachers, five educational assistants, one resource teacher and one principal employed by the Band Council. All the educational assistants were from the community, while half of the teachers were from other areas of the province or outside of Manitoba. The teachers from outside of the community also fell into one of two categories. Like the first school, one of the categories was beginning teachers who were looking for work experience and who did not stay for a long period of time. However, the second category of teachers was different from the first school, in that these teachers were not of retirement age and wanted to work in a school within driving distance of a large urban center. The teachers from the community had all received their teaching degrees from one of Manitoba's universities via a specially designed program for individuals from First Nations' communities. The resource

teacher was from the community and had been in that position for over ten years, not only at this school, but also at several other First Nations' schools.

The school provided educational services from Kindergarten to grade nine. The only option for high school students was to leave the community and attend high school in the nearest urban center. Equipment, materials and resources were limited and quite basic due to the funding agreement between the INAC and Chief and Council. Internet services were generally good and the staff utilized technology as much as possible.

The school's total student population was two hundred. There has been a large on-going yearly drop-out rate in the junior high and high school grades. Of the overall student population at the school, there were twenty students identified as high cost special needs according to INAC's guidelines; while there were another thirteen students who fell into INAC's low cost category (see Appendix G for INAC's specifications for high cost identification). The resource teacher coordinated all special needs services with both in-community and outside agencies in accordance with the INAC's administrative conditions. The resource teacher was also the acting principal for a large portion of the year. These combined duties had severely limited her time in providing direct student resource services.

The school had a formal referral protocol in its school policy. Initially, the resource teacher had to continually deal with classroom teachers not wishing to adhere to it. But, over time, the teachers have accepted and now follow the school's referral protocol. After referral, the resource teacher proceeded with diagnostic services that led to educational services ranging from informal remediation to formal and alternative interventions. The community services that the resource teacher could access were extremely limited. The only regular support from an outside

agency came from the Manitoba First Nations Education Resource Center (MFNERC). All clinical support that was needed had to be purchased through INAC's Special Education Plan (SEP).

The third school was situated in a remote northern Manitoba First Nations community that has an all-season highway. Like the second school, it could be reached year-round by both air and road. The school consisted of one main building located separately from the other school building in the community. The physical structure consisted of several wings comprised of classrooms, a resource room, a life skills room, a gym, a computer room, a kitchen and an administrative office.

At this school there were twenty teachers, twenty educational assistants, three resource teachers and one principal employed by the Band Council. All the educational assistants were from the community as were the majority of the teachers. The teacher turnover at this school was very low. The teachers from the community had all received their undergraduate degrees from one of Manitoba's universities via a specially designed program for individuals from First Nations' communities. The resource teachers were from the community and only one of them was in her first year in the position of resource teacher.

This school was a middle years' school and only provided grades five to eight. When compared to many other First Nations' schools, the equipment, materials and resources were abundant due to the funding agreement between INAC and Chief and Council and to the combined efforts of school and community fund raising. Internet services were excellent and available for students and teachers to access.

The school's total student population was eight hundred. There continues to be a large yearly drop-out rate after the transition from this middle school. Of the overall student population, there were one hundred students identified as high cost special needs according to INAC's guidelines while there were another eighty students who fell into INAC's low cost category (see Appendix G for INAC's specifications for high cost identification). The resource teachers coordinated all special needs services with both inside and outside community agencies in accordance with the INAC's administrative conditions. Due to the large number of students, one on one direct service to special needs students by any of the resource teachers, was limited and these services generally fell into the category of problem solving with a teacher for a situation that had arisen with a student.

The school had a formal referral protocol in its school policy that was adhered to by the teaching staff. All diagnostic services were based on information collected by the resource teachers, and led to interventions ranging from informal remediation to formal and alternative interventions provided by teachers and parents. The community services that the resource teachers could access were limited but utilized as much as possible. The only consistent support from an outside agency came from the Manitoba First Nations Education Resource Center (MFNERC). All clinical support that was needed had to be purchased through INAC's Special Education Plan (SEP).

All ten of the teachers' questionnaire responses were used from this data collection. Interviews with the three resource teachers were conducted. To optimize the speed of return of the questionnaires, a chance at a draw for a prize was offered to the teachers.

Data Collection

For this study, concurrent data collection techniques from both qualitative and quantitative research methods were planned. This meant that the information was gathered simultaneously rather than qualitative data collected first followed by the quantitative data or vice versa. As one component of the data collection, participants were asked to complete a questionnaire (see Appendix H) with questions that enabled me to categorize a variety of variables such as ethnic affiliation, years teaching, previous interactions with disabled children, etc. In order to achieve this goal from the questionnaire, I attended carefully to the wording of the questions and the number of questions I asked.

The other components of the study, the review of students' resource files (see Appendix I) and resource teachers' interviews (see Appendix J) were to be done at the same time to collect both qualitative and quantitative information. This meant that, because of the timing of the collection of statements and statistics, this study can be considered a concurrent mixed method research project. Creswell (2009) defines concurrent mixed methods as:

The researcher converges or merges quantitative and qualitative data in order to provide a comprehensive analysis of the research problem. In this design, the investigator collects both forms of data at the same time and then integrates the information in the interpretation of the overall results. Also in this design, the researcher may embed one smaller form of data within another larger data collection in order to analysis different types of questions (the qualitative addresses the process while the quantitative, the outcomes). (p. 14)

Questionnaire.

To ensure that this study's questionnaire would be garner data that would provide insights into teachers' knowledge, training and attitudes regarding students with invisible disabilities, the questionnaire's development undertook specific steps to safeguard reliability and validity.

Questionnaire Development. In developing the questions on the classroom teachers' questionnaire, I drew on past experiences, both as a person with an invisible disability and as a teacher and a resource teacher working in FN communities. Based on the themes that emerged from the literature review and my experiences, both personally and professionally, I was able to determine what I needed to know, why I needed to know it, and what insights might be gained from the questionnaire. The purpose of this questionnaire was to ascertain the reasons for the lack of early identification of FN students with invisible disabilities and to explore why there has been an insufficiency of appropriate accommodations and adaptations for them. This meant that teachers' knowledge, skills, attitudes, practices and their perceptions of knowledge, skills, attitudes and practices had to be questioned. The selection of participants was inclusive - all classroom teachers, regardless of their age, education level, or years of experience were invited to complete the questionnaire.

The next step in development of the questionnaire, after defining the purpose and the participants, was selecting the measurement scale, scoring procedure and the data collection method. A rating continuum using a Likert-type scale was chosen because teachers' workloads and the demands on their time. I also decided that the most effective and confidential way of distributing and collecting the questionnaires was to personally visit the participating schools to distribute and collect them.

The third step was the drafting of the questions to be asked on the questionnaire. Following recommended guidelines for development of research questions (Diem, 2002), plain language was used. In addition, questions that were open-ended, too personalized or considered to be double-barreled were avoided. A balance of negative and positive answers was incorporated into the scale. Clear instructions for completion of the various sections were included. Finally, answer choices corresponded to the questions and a neutral answer choice were purposefully included on the scale. Upon completion, to establish content validity, a panel of experts from MFNERC's Special Education Team reviewed the questionnaire to determine if the questions being asked were in fact going to illicit answers directly related to the purpose of the study. The panel of experts stated they felt the questions on the questionnaire would bring forth answers clarifying teachers' knowledge, skills and attitudes regarding FN students with invisible disabilities. The last step, completing the cover letter (see Appendix K), explaining the purpose of the questionnaire and the teachers' option of not completing it if they chose not to, was then included along with the final copy of the questionnaire in my thesis proposal was sent to ENREB for approval.

Questionnaire Administration. The questionnaire consisted of fifty questions. At a general staff meeting, prior to the distribution of the questionnaire, I explained the intent of this research study, the confidentiality rules that I adhered to, the approval process followed, the types of data collected, and how the findings from the study would be shared. I answered any questions the teachers raised during the delivery of the questionnaires. I also explained, both in the cover letter and in person, that they had the right to not answer the questionnaire, should they choose to do so.

To ensure I received the answered questionnaires, I distributed and collected the questionnaires from each of the teachers after allowing time for completion during the scheduled staff meeting. Each teacher was also given an envelope to place his or her completed questionnaire in so he or she could then seal before it before returning it to me anonymously. Since I had previously obtained the support and approval from the Chief and Council or the Chief and Council's representative and the school administration, I felt it gave the teachers an added level of trustworthiness regarding my presence and my request for completing the questionnaire. I did not encounter any resistance to completing and returning the questionnaires.

The advantages of using a questionnaire for me as the researcher were:

1. it provided some insights in regards to direction of the interview questions with the resource teachers,
2. it allowed comparisons of the interviewees' answers and descriptive variables,
3. it provided some descriptive statistics that were used in the data analysis.

There were two disadvantages to consider when using a questionnaire and they were:

1. I would be unable to observe and record an individual's body language or facial or oral expressions in reactions to the questions,
2. I would be unable to probe why questions were answered as they were.

The advantages of utilizing the questionnaire method for data collection were considerable since I would be able to acquire a larger amount of useful data in timely fashion. By using the developed questionnaire, I was able to gather general baseline data such as educational background, teacher experience, gender, ethnic affiliation, and the teachers' views on adaptations and accommodations for students with special needs.

Review of student resource files. Unfortunately, this data collection component was removed from the study, with approval from ENREB (see Appendix E), out of consideration and respect for the resource teachers' concerns regarding student confidentiality. In the original research plan, a random selection from resource files of both the low and high cost students, during the same time frame as the resource teachers' interviews, was to be conducted. Once the selection had been done, parental cover letters and consent forms (see Appendix M) would be sent to the parents or legal guardians for their approval to be part of the study.

From the randomly selected group, information such as: (a) medical history, (b) teachers' referrals, (c) informal and formal assessments' observations and conclusions, (d) formal diagnose, and (e) remediation services provided by the classroom teacher or resource teachers would have been gathered. It was my intention to cross-reference this information with their cumulative files to further develop descriptive information such as: (a) specific marks in the subject areas, (b) promotion comments, and (c) teachers' anecdotal summary comments.

I felt the three advantages in conducting file reviews were:

1. the ability to gather supplementary details regarding the schools' students with visible and invisible disabilities,
2. the ability to obtain a fuller description, from previous years, of schools' histories regarding visible and invisible disabilities,
3. the ability to collect data on the students' past and current status and conduct deeper analysis of relationships between visible and invisible disabilities.

I also realized that the two disadvantages of the file review process were:

1. the considerable amount of time required to gather the appropriate signed consent forms by the students' legal guardians,

2. the considerable amount of time needed to read both the students' resource files and their cumulative files.

As a result of the removal of the review of the student resource files, the data from the two remaining components, the resource teachers' interviews and the teachers' questionnaires, were the only data sources used in this study.

Interview.

As with the questionnaire, steps to secure trustworthiness for the study's resource interview component were also undertaken.

Interview Questions Development. I scheduled interview dates and meeting times with the resource teachers to coincide with the distribution and collection of the teachers' questionnaires. This allowed me time to quickly review their colleagues' answers and make slight changes to the interview questions if I thought it was necessary. To add to the resource teachers' comfort, I let each one determine where they would like to have the interview take place. The resource teachers were also given cover letters and consent forms to complete prior to their interview taking place (see Appendix L).

The interview questions (see Appendix J) were developed with input from several sources: (a) background research on invisible disabilities (Mullins & Preyde, 2013; Stone, 2005), (b) my own personal experiences as a resource teacher, and (c) the teachers' responses on the questionnaires. The interview questions touched on the following topics: (a) knowledge about invisible disabilities, (b) personal definitions of disability and invisible disability, (c) experiences of teaching students with visible and non-visible disabilities, and (d) what types of adaptations and accommodations used for lesson design, lesson delivery, learning tasks, class assignments, and assessment methods and tools. The interview questions were formulated to gather data with

more depth than the questionnaire. I obtained the resource teachers' permission to audio record the interviews with the clear understanding that the recordings would be treated as confidential material. By having these audio recordings, I was able to review and compare them with my written interview notes for accuracy.

As the researcher in this study, I felt there were three advantages for conducting interviews with the schools' resource teachers. They were as follows:

1. it allowed me to establish deeper connections with the resource teachers,
2. it allowed me to gather more detailed information by asking questions that clarified responses, and
3. it allowed me to determine, from an insider's point of view, how the questionnaires' responses and interview responses were reflective of each other.

There was one disadvantage for using the interview method and that was because:

1. it required a longer period of time to complete the study because the interviews required more personalized attention and time.

Since there were more advantages than disadvantages and those advantages would provide me with more in-depth understanding of the resource teachers' thoughts, knowledge and experiences, I chose to conduct the interviews.

Data Analysis

Upon completion of the data collection, I began my analysis, looking for trends and re-occurring themes. Finally, when all data had been integrated and studied, I compiled the results in a draft report and sent the draft copies to the schools and band councils for their review. I also did follow-up school and community visits where I shared my findings with the participants and those community members interested. During those meetings, I asked for any feedback that they

thought should be added into the report. Final copies of the report were then sent to the school and band council for distribution to teachers, parents and community members.

For qualitative data component of my mixed methods study, I selected a grounded theory approach with the handling of the data proceeding in a hierarchical line. I began by tabulating the questionnaires' answers from each of the communities' schools separately. Then I combined the tabulations for an overall summary and record with both the separate and combined data on a summary sheet. I then transcribed the resource teachers' interviews and used open coding on the comments provided. Once the open coding was complete, I followed up with the axial coding to establish a possible central phenomenon as outlined by Creswell (2007).

In open coding, the researcher forms categories of information about the phenomenon being studied by segmenting information...In axial coding, the investigator assembles the data in new ways after open coding...identifies a central phenomenon...explores causal conditions...identifies the context and intervening conditions...delineates the consequences...In selective doing, the researcher may write a "story line" that connects the categories....Finally, the researcher may develop and visually portray a conditional matrix that elucidates the social, historical, and economic conditions influencing the central phenomenon. (p. 67)

With the development of a conditional matrix, I was able to formulate a theory from which I was able to construct possible implications.

For the quantitative data component, I began with a summarization of the number of participants by gender, age, ethnic group, educational training, and number of years of teaching experience, along with both professional and personal experiences with individuals who have

disabilities. I also included information on the geographical locations and ease of access to the world at large for the participants. Following that, I compiled a descriptive analysis of the data's variables and finally organized the results in tables with explanations and possible implications.

As the final step in the convergence of the data, I utilized concurrent triangulation and combined the findings from both the qualitative and quantitative data onto a matrix with the trends and themes (qualitative) on the vertical axis and the category and number (quantitative) on the horizontal axis. I also included further descriptions, explanations and possible implications based on the amalgamating of both types of data.

Qualitative Trustworthiness

A qualitative study could often be considered by some to be inferior to its counterpart, the quantitative study. But as numerous authors, such as Creswell (2007), Cohen and Crabtree (2006), and Gube and Lincoln (1998), have explained in great detail; a qualitative study's trustworthiness is the equal counterpart to quantitative study's validity and reliability. Therefore, it was essential when planning a qualitative study to design one that provides the maximum degree of trustworthiness through embedding: (a) creditability, (b) dependability, (c) transferability, (d) confirmability, and (e) authenticity throughout all the stages of the study. As Billup (2014) explained:

Trustworthiness, a concept adapted and promoted by Lincoln and Guba (1985), is considered the quintessential framework for evaluating qualitative research, but receives minimal attention from many institutional researchers, especially those predominantly oriented to quantitative methods...Four elements comprise the original trustworthiness framework: credibility (truth), dependability (consistency), transferability (applicability),

and confirmability (neutrality). Authenticity, a fifth element added since the original discussion, is endorsed by some qualitative researchers as an equally important evaluative element (Polit & Beck, 2011). (p.1)

By ensuring highest level of rigor, confidence in the trustworthiness of the study will be achieved. Therefore, upholding trustworthiness throughout this qualitative study was always of the utmost importance.

Credibility. One of the elements of trustworthiness, credibility, often is considered the most important factor in qualitative research (Shenton, 2004). Its purpose is to accurately measure how truthful the results of the research instruments were. In other words, were the findings from the study's measures accurate, beyond reproach, and thus able to provide the certainty necessary for confidence in the research results. As Cutcliffe and McKenna (1999) clarify:

Perhaps the most useful indicator of the credibility of the findings produced is when the practitioners themselves and the readers of the theory view the study findings and regard them as meaningful and applicable in terms of their experience. (p. 379)

In this study, unbiased sampling and triangulation were employed as methods for establishing creditability. Triangulation involves the collection of data from various sources. By using three different schools, with two different source groups at each school, and two different methods of data collection, not only did corroboration of findings occur, a wealth of comprehensive and rich data, which might otherwise have been missed, was collected. This was consistent with Creswell's recommendations (2007).

The selection of the FN schools and their staffs for participation in this study was strictly on a volunteer basis. I had no influence on the decision by the FN schools to participate. They may have chosen to be involved because of their interest in identifying students with invisible disabilities.

The triangulation of data was scaled down from the originally planned three sources to two sources. For one source, the resource teacher interviews, each resource teacher received a copy of the transcript of their interview for verification of the exactness of what was shared and to edit anything that was incorrect. All of the resource teachers were satisfied with the transcripts and no further revisions or second reviews for verifications were needed. The second source, teacher questionnaires, used quantitative validation methods prior to the comparison with the resource teacher interviews.

Dependability. Since this study was the first of its kind for First Nations' schools in Manitoba, the best approach was to follow the prototype model for dependability. A prototype model meant that all aspects of the study were recorded in precise detail so that replication of the study can be done exactly with confidence. The prototype model often used when the measure was only used once with the study's participants. As this project involved a one-time only measure, I followed the prototype model and fully documented all details of the study. As Shenton (2004) clarifies:

In order to address the dependability issue more directly, the processes within a study will be reported in detail, thereby enabling a future researcher to repeat the work, if not necessarily to gain the same results. Thus, the research design may be viewed as a 'prototype model'. Such in-depth coverage will also allow the reader to assess the extent

to which proper research practices have been followed. So as to enable readers of the research report to develop a thorough understanding of the methods and their effectiveness, the text will include sections devoted to:

- (a) the research design and its implementation, describing what was planned and executed on a strategic level,
- (b) the operational detail of data gathering, addressing the minutiae of what was done in the field, and
- (c) reflective appraisal of the project, evaluating the effectiveness of the process of inquiry undertaken. (p.71)

This study followed the prototype model criteria, as outlined above, from beginning to end.

Transferability. The degree of generalization that can be derived from a study's findings would be described as transferability. Transferability could also fall under the umbrella of trustworthiness. As Billups (2014) explained:

While the goal of qualitative research is not to produce results which are statistically generalizable, the intent is to produce findings which other researchers can interpret for similar settings, even to the point of applying the research design for their own purposes. (p.3)

One possible outcome of this research study may be further research by others on the topic of FN students with invisible disabilities. Again, to that end, every aspect of the design, implementation and completion of the study have been detailed.

Confirmability. Another element of trustworthiness is confirmability. It refers to the extent that the results of the study could be corroborated by others; or as Tobin and Begley (2004) have explained, confirmability...

...is concerned with establishing that data and interpretations of the findings are not figments of the inquirer's imagination, but are clearly derived from the data. (p.392)

As I adhered to these research guidelines for trustworthiness, a documented paper trail on all aspects of the study, in precise detail, was maintained. Consequently, future researchers can replicate the methodology for the selection of participants and data collection to determine if the results would be the same as in this initial study.

Authenticity. To meet the qualitative study's criteria for authenticity, the researcher must be honest, impartial and objective in describing the participants' experiences. All views expressed need to be respected and documented by using ethical and appropriate methods. Milne (2005) clarifies: "A focus on authenticity would not only ensure that our methods of collecting data are pristine but that our data is also faithful to the constructions of all stakeholders" (p.3). Billups (2014) concurs:

The intended value of a study, the implied benefit to many stakeholders, and the assurance that as many voices as possible were considered are all issues that must be addressed when presenting the findings (p.4)

Fairness is the key component to authenticity and was constantly present throughout the study.

Quantitative validity and reliability

One component of this study, the teachers' questionnaires, was quantitative in nature and necessitated that validity and reliability were present.

Validity. Heale and Twycross (2015) define validity “as the extent to which a concept is accurately measured in a quantitative study” (p. 66). To ensure measure accuracy, there must be no variations to any portion of a study. Any variation can bring into question the validity of that study. Variation refers to any form of deviation from the original design of the study. Some of the most common deviations are:

- (a) any undocumented alterations to the study’s design,
- (b) involvement of more than one researcher,
- (c) any selection bias regarding who participants, and
- (d) length of time it takes to complete the study.

In this study, alterations with respect to timing and one data source (students’ files) were documented and ENREB approval was obtained, only one researcher was involved, and the researcher knew of no selection bias.

However, for one component of the study, the questionnaire, I needed to focus on three particular threats to validity: (a) face validity, (b) content validity and (c) construct validity. Both face validity and content validity concerns, with respect to the questionnaire, were addressed through the use of MFNERC’s Special Education panel of experts. They reviewed the questionnaire for how well it covered the concept the study was purporting to investigate along with how well the questionnaire measured what it was intended to measure. However, construct validity could be a limitation as the term “invisible disabilities” remains poorly defined and contested as determined from the literature review for this study.

Confounding was another subcategory of internal validity and appears when there is a change to a dependent variable because of the manipulation of another variable. This manipulation could include the any form of deviation from the design of the study and is often the result of there being more than one examiner in a study. Since there was only one examiner in this study, who followed the same First Nations protocol agreement established with each of the communities prior to the commencement of the project, there were no changes to the delivery and collection of the questionnaires.

Another subcategory of internal validity is selection bias. This was of minimal concern for two reasons. I had no input into the hiring of teachers to work at the schools and I also had no influence on which schools participated in the study. Therefore, internal validity was not at risk because there was no selection bias influencing this study.

History is another threat to internal validity. There was a possibility that historical influences such as residential schools, deficiencies in funding by the government, poor infrastructure, or high migration of teachers might influence the outcome of the questionnaire. These events still have an effect, to varying degrees, on all First Nation individuals including the teachers employed at the schools. This means that there may be some questionnaire responses that were affected by historical incidents.

A final internal validity subcategory is maturation. Maturation refers to changes in the participants during the research project. This study's design as a one-time data collection event eliminated the mortality issue. Also, this project did not involve any instrument change, compensation for participation, or direct interactions between the participants and the researcher during the questionnaire session.

External validity. When considering the external validity of the questionnaire component of the study; consistency, meaning dependability and uniformity are the important factors. Despite the fact that the First Nation schools selected were in different geographical locations and were from different cultural and linguistic tribes, the schools can be considered classic representatives of the educational institutions found in Manitoba because many variables (i.e. geography, accessibility, language, services, culture, etc.) were encompassed in those two schools. Unfortunately, while the data and the summary findings from the data from this project can be considered most relevant to First Nations' schools in Manitoba, how the results relate to other First Nations' students with invisible disabilities in other parts of Canada may be questioned as this project was conducted only in Manitoba First Nations' communities and on a limited scale.

Reliability. Reliability is just as essential as validity in every research study. Reliability is defined by Heale and Twycross (2015) as "the consistency of the measure" (p. 66). So, to ensure that there was consistency in the measure used for this study's questionnaire, the split half technique was employed. I divided the questions in the questionnaire into two groups, odd and even numbered, and then computed the scores for the two sets to check the correlation score between them. Due to time constraints and concerns for validity consistency, the project had only one questionnaire form.

Although this was a qualitative study, one source of results came by way of the teachers' questionnaire, which was quantitative in nature. Therefore, validity and reliability had to be considered when reviewing the data.

Protocols, Procedures, Permission, Ethical Considerations

I wanted the participants in this research project to feel safe and comfortable. In order to achieve that, I took every measure to ensure that confidentiality was maintained throughout entire study. It was of utmost importance to me that confidentiality was respected at all times. As Mack, Woodsong, MacQueen, Guest, and Namey (2005) state in their field guide,

Whenever we conduct research on people, the well-being of research participants must be our top priority. The research question is always of secondary importance. This means that if a choice must be made between doing harm to a participant and doing harm to the research, it is the research that is sacrificed. (p. 8)

As the sole researcher, I was the only one to carry out the collection, storage and interpretation of the data. All data, field notes and back-up copies were locked in my office until completion of the research project. Then, the storage of materials from the study followed the agreements with the Education Directors.

The Education Directors from each of the three communities participating in this study agreed to the following conditions without requests for amendments to or alternatives for the storage of data. These conditions were that all data, consent forms and other materials, whether electronic or hard copy, related to the study and the communities be kept for a maximum of one year following final completion of the research project and the publication of the final report locked in my home office. At that time, all paper data including consent forms, questionnaires, transcripts of interviews, file review analysis, researcher's notes, etc. will be shredded and

burned. The electronic data, including audio-cassettes and memory sticks, will be destroyed by smashing them with a hammer and then all the remnants will be incinerated.

The letters of invitation to participate included: (a) background information explaining the reasons behind the study, (b) an explanation of the importance of the study, including what and how the data would be collected, (c) permission and approval letters, and (d) assurances about how confidentiality would be honored and how the study's findings would be shared. They were faxed to all the First Nations' schools serviced by MFNERC in late November 2015. This was in keeping with the study's timeline in Chapter 3. In January 2016, an amendment approval was sought and received from Research Ethics and Compliance (see Appendix E). As a result of waiting for the amendment approval, the data collection began at the beginning of February, 2016, when all the consent forms were completed from the three First Nations schools participating in the study.

Although the participating schools had agreed to all the study's components: the teacher questionnaire, the resource teacher interviews and student resource file reviews, the researcher felt there was a degree of concern surrounding the use of data gleaned from the resource files. When the researcher spoke with the resource teachers to confirm dates for interviews, they expressed some concerns relating to information contained in the resource files and parents' fears and apprehensions, despite confidentiality laws and protocols. The three schools who agreed to the study's three components may have agreed because of their past professional work experience with the researcher through MFNERC. To alleviate this trepidation for the resource teachers, their schools and communities, the researcher sought approval to eliminate the resource file review from the project from the ethics board. At the same time, the researcher also included the request to increase the number of participating schools from two to three for this research

project. This adjustment was also granted. Research Ethics and Compliance approved both changes in the amendment approval letter (see Appendix E).

As this was an educational research study, the Chiefs and Councils deferred the final decision regarding participation to their Education Directors. Once the Education Directors gave their consent (see Appendix C), the study's information and consent letters were circulated to the resource and classroom teachers. It became apparent early on in the study's progression that amendments were needed. So, I again sought and received approval for changes to the study (see Appendix E). Once all the approvals had been obtained, I met with administrators from the three schools, their resource teachers, and the classroom teachers to explain the purpose of the study, to reaffirm how I would collect and store the data and to answer any questions that arose. Then, arrangements for data collection from the three schools were finalized. The data collection started in late February 2016 and finished in early May 2016.

The study's design followed the guidelines developed by the Manitoba First Nations Education Resource Centre (MFNERC) to safeguard the rights of First Nations (see Appendix A). MFNERC's research guidelines are adapted with permission from the First Nations Centre's (2007) *Considerations and Templates for Ethical Research Practices* (see Appendix B) and clearly define the protocols to be honored by researchers, all of the stakeholders' responsibilities, ownership rights of all data and subsequent reports, and long term storage plans for all of the research data and reports. I based my behavior in conducting my research on MFNERC's recommended templates on ethical conduct, including all presentations with the communities' leaderships and their schools' administrations.

As mandated by the University of Manitoba, I also sought and received approval for this study from Research Ethics and Compliance Committee (see Appendix D). Upon receiving this approval, letters of interest in participating in the study were distributed to the First Nations' schools serviced by MFNERC. The information and consent letters were then sent for approval to those schools' Chiefs and Councils and Education Directors who had shown interest.

Timeline to Complete Study's Steps

Steps	Date	Activity
1	November 2015	Obtained formal research approval from Research Ethics Compliance Sent out call to schools who might be interested in participating this study
2	November 2015 December 2015	Collected consent forms from Education Directs Arranged dates for any information or pre-research collection meetings
3	December 2015	Third school requested to participate in this study
4	January 2016	Amended the research proposal with Research Ethics and Compliance to remove the Review of Student Resource Files from study and to include the third school
5	February 2016	Received amendment approval from Research Ethics Compliance Collected consent forms from resource teachers Set dates for collection of research data from resource teachers and classroom teachers
6	March 2016 April 2016 May 2016	Conducted resource teachers' interviews Distributed and collected the classroom teachers' questionnaires

Steps	Date	Activity
7	June 2016 July 2016 August 2016	Transcribed resource teachers' interviews Verified accuracy of transcriptions Coded transcriptions and analysis Tabulated results from the teachers' questionnaires Analyzed the tabulated results Triangulated the data from the resource teachers' interviews and the teachers' questionnaires Summarized the results
8	September 2016 October 2016 November 2016	Wrote, revised and edited the study's report Applied for and received an extension deadline from Research Ethics Compliance for completion of the study (see Appendix F) Continued with revisions on the study's report
9	December 2016	Submitted to advisory committee for their approval
10	February 2017	Submitted to external reviewer for approval Submitted to U of M for approval
11	March 2017	Shared research report with the three participating schools and presented copies of the research report to the stakeholders

Costs

The costs for this research project covered refreshments and snacks for the school teaching staff during the initial meetings at which the purpose of the study was explained, questions were answered, the study's questionnaires were distributed and collected; the follow-up meetings where the findings and recommendations from the study were shared and finally, at any community meetings requested to share the study's conclusions. An opportunity to win a

draw prize for handing in a completed questionnaire was also provided to the teachers. These costs were covered by the researcher.

Chapter 4 Research Data and Analysis

Introduction

In this chapter, the information from the resource teachers' interviews and the teachers' questionnaire will be presented and analyzed. The methodology design chosen for this project was grounded theory using a mixed methods approach and the study's data collection procedures were both explained in the previous chapter. As outlined in chapter three, the initial procedural steps regarding the approval acquisition from ENREB (see Appendix D) for the research, letters of invitation to participate, consent from educational authorities and resource teachers were carried out as planned.

Prior to obtaining Research Ethics and Compliance's approval (see Appendix D), a panel of experts from MFNERC's Special Education Unit reviewed and critiqued the teachers' questionnaire to ascertain that the questions would elicit the responses relevant to the study's purpose. Based on the panel's recommendations, revisions were made where necessary and, once the review was completed, the questionnaire, along all other pertinent papers and forms, was sent to the ethics board for final approval. Only when that approval was received, did the research project begin by sending of the letters of invitation to participate in this research project on invisible disabilities to First Nations schools.

However, what was not planned or anticipated was the keen interest of a third school. In the initial design for this research study, the researcher had intended to invite only two First Nations' schools to participate. But after showing such a strong disappointment at not being part of the study the researcher allowed the third school to participate in the study too. This change was approved by ENREB (see Appendix F). So instead of two, there were three First Nations'

schools with varying geographical locations, differing student populations, and differing numbers of teaching staff involved in the study.

The school without an all-seasons access road was the first to have both the resource teacher interview and teacher questionnaires completed. This school's resource teacher also had extensive personal experience with disabilities as her adopted son has FASD without many of the physical characteristics. The second school to complete the data collection process was the smallest of the three schools. This school's resource teacher had limited personal experiences with disabilities and those experiences had been only in professional situations. The largest school was the last to finish the resource teacher interviews and the classroom teacher questionnaires. Two of school's resource teachers each had over fifteen years of experience in the resource program. They also had extensive experience with various disabilities through work and personal circumstances. One of these two resource teachers' personal experiences with disabilities extended as far back as childhood memories because of relatives with severe disabilities that required extensive clinical services and supports. The second resource teacher also had experiences with family and friends with various disabilities that were not solely physical in nature. The third resource teacher had worked in the resource position for less than a year, but had over ten years of experience as a classroom teacher. She, too, had had some personal experience with disabilities, although to a much lesser degree than her either of her colleagues.

Of these three schools, only the third school had a majority of classroom teachers who were under the age of thirty-five with under ten years of teaching experience. At both the first and second schools, the age of the majority of classroom teachers was over forty-five years and

with ten or more years of teaching experience. At all three schools, at least fifty percent of employed teachers were of First Nations affiliation.

Resource Teachers' Interviews

The researcher met privately with each resource teacher for interviews at his or her school. There were eight questions (see Appendix J) covering the following topics: (a) defining disability terminology, (b) types of disabilities, (c) experience with disabilities of any type, (d) adaptations and accommodations for all types of disabilities, (e) early identification of struggling students with invisible disabilities and, (f) how to help both teachers and student deal with invisible disabilities. Signed written consent for the interviews to be recorded and permission to contact them for follow-up communication, should any questions regarding clarification of their statements be required, was obtained from all resource teachers prior to the interviews. The interviews were conducted during the same time frame as the teachers' questionnaires in each of the schools. The follow-up school visits for the sharing of the final reports was scheduled at the convenience of the schools and their communities in the late fall of 2016.

After the interviews were completed, transcriptions were made from the audio recordings. Each resource teacher received a copy of his or her own transcription to check for accuracy and edit any errors. Once confirmation for the accuracy of the transcribing was received, open coding was used to form categories of information contained in the transcripts. Six categories developed from the initial coding: (a) no definitive definition of either visible or invisible disabilities, (b) two types of educational training (i.e., formal and informal), (c) the implementation of adaptations and accommodations (i.e., strategies, practice, availability), (d) personal opinions on topic of individuals with invisible disabilities, (e) reasons for student referrals, and (f) supports for increasing classroom teachers' awareness of invisible disabilities.

Upon completion of the open coding, axial coding then followed. From it, four themes emerged when further analyzing the resource teachers' interview data. These themes were: (a) the complexity surrounding the definition of invisible disabilities, (b) identification of students with invisible disabilities, (c) adaptation and accommodation strategies employed by teachers working with students with invisible disabilities, and (d) professional development to increase classroom teachers' awareness and knowledge on the topic of invisible disabilities. These four themes were also identified in the teachers' questionnaire responses.

Summary of resource teacher interviews. All five resource teachers, Agnes, Bernice, Donna, Ethel and Frances (pseudonyms), from the three schools took part in the interviews. Their years of experience in the position of resource teacher/resource coordinator ranged from less than one to ten plus years. Work and life experiences involving any type of disabilities also varied greatly amongst these five resource teachers: from close personal family or friends' circumstances to situational or chance encounters. Throughout all of the interviews, it was observed that the resource teachers' background wealth of experiences provided them with a deep understanding and appreciation for students with disabilities especially invisible ones and the difficulties they encountered. One resource teacher, Donna, described her personal experience of visiting a close relative with profound disabilities in St. Amant Centre in Winnipeg,

There was lots of quadriplegics and you had people screaming in there. It kind of scared me but it kind of intrigued me too. A nurse came there and said we're going to take and she has to go to school. Where does she go to school? I have questions. And then she said do you want to come? I said yeah I want to come. Well you can come with ..., okay I'll come So we went to this big room with a set of tables it was very clean. And

we went and they had all sorts of things that we use in the resource or the classroom, the manipulatives and everything. I was like wow and I saw these teachers in there. The helpers, the nurses and there was three, four maybe around. They were so nice to her. They treated her like a human being not somebody with a disability. Like this is somebody's child. You know this is somebody's heart. You know let's take care of this heart. And that just made me wow. You know like they teach her like they teach me. By singing they would raise their hand, you know things like that. And it just did something to me.

Yet, at the same time, there was a nuance within the resource teachers' opinions that seemed contradictory to the expertise they had gained from their experiences. This nuance was reflected in their opinions on their knowledge of disabilities, regardless of category, and their lack of confidence in their skills for working effectively with students who have invisible disabilities, that seemed almost self-effacing. Another resource teacher, Ethel, when asked if she felt she had received sufficient training on invisible disabilities at first said,

No, not at all, not at that time. But I do now.....after I finished my graduate in special education and I continued on to my masters, I took courses in counseling. From then on going through those courses I figure that anxiety [and] other mental disorders are a part of a disability that kids have. They have to deal with this daily and we don't even know it, it's invisible, we don't know it and they're suffering and tormented by that.

They expressed doubts in their capabilities in meeting the needs of the students with invisible disabilities and the need for more training and professional development for themselves. Another

resource teacher, Frances, shared an example of one her experiences where she was left feeling overwhelmed because she could not meet the needs of a student and his teacher,

One time there was this boy that takes Ritalin, he's in the classroom and this teacher came up to me, 'I'm so tired of this boy, I need help.' I didn't know what she wanted from me. I think she wanted me to take that boy but I couldn't take him. I have other students here. That's what the teachers are doing to me, they want me to take students that are low academic and they just want me to take them. They don't want nothing to do with them.

Perhaps, this was because of their experiences with a wide range of disabling conditions, the diverse characteristics within and across disabilities, and the magnitude of the challenge of teaching students with visible and invisible disabilities in FN schools. Bernice summed up her uncertainty and challenges involving invisible disabilities by first identifying in order to provide the appropriate services when she stated, "I just don't know because it's so hard to say if there are (disabilities) unless I'm trained in it." Frances, gave a valuable example of learning and skill growth over time that she experienced working with students with all kinds of disabilities,

"When I first became a teacher, I didn't know how to take care of the students that were...the low learners. I had a hard time with them. But then I got to know. For example, there was going to be a boy coming to school here with Downs Syndrome and I got ready for him. I got everything ready, I got the room ready, I got an EA ready."

Despite the varying work and life experiences amongst the resource teachers, the first theme: the complexity surrounding the definition of invisible disabilities was strikingly evident. All the definitions given were as different as the resource teachers themselves. There was no one

common definition for any of the terms, invisible disability, visible disability or disability. When asked to give a definition for an invisible disability, three resource teachers struggled with the task. The resource teachers with the most personal experiences demonstrated more awareness on the topic. As Agnes stated, “It’s hidden but you can see it. If you know the student like someone in your family, you can notice it right away.” While Bernice explained, “It’s a term that is new to me. It is something that I can’t say what it is.” And Donna described, “Invisible disability if I was a regular (if I wasn’t a teacher, wasn’t in special ed.), I wouldn’t know. As a teacher working with kids every day that are so diverse and we catch on. And you [don’t see it] but the teacher in you knows.” Ethel defined, “Invisible disability could be something; for example, the child doesn’t have the physical features but shows other symptoms of FASD. That could be an invisible disability because the features are not there, we don’t know what’s wrong with the child, but we know that there is something.” And Frances expounded, “Nobody can quite see it “.

Surprisingly, even when I asked the resource teachers to define the term visible disabilities there was little agreement. Donna said, “Somebody in a wheelchair. Somebody who’s using crutches, somebody using a walking stick.” Ethel stated, “it’s what we can see, what we can determine through assessment”. Inconsistency in the definition for the term disabilities was evident again by the statements from the resource teachers. Donna said, “Is blue sticker in my car because I have a passenger who uses that,” Frances said, “He can’t go around doing things for himself.” There was no overall, solid conformity on any of the terms, disabilities, visible disabilities or invisible disabilities, just wisps of commonalities such as the necessity of teachers really knowing their students in order to appreciate that they were experiencing difficulties. Agnes said, “Maybe it’s because they don’t talk to the parents. They’re scared to talk to the parents. I know some teachers don’t, they leave it alone and they’ll come to me and say, ‘That’s

your job.” Donna said, “...come out from your text books. Get out of the box. Listen to this one (student) and if it’s a red flag ask the senior teachers.” In addition, the feeling that teachers preferred to concentrate on curriculum and outcomes rather than on their students’ difficulties was expressed when Frances stated, “They have to really focus on the students; they have to try to find out what’s wrong”. The resource teachers believed the classroom teachers needed to increase their awareness of, and appreciation for, the limitations experienced by individuals with all types of disabilities and the impacts of those limitations.

The responses regarding the second theme, the identification of students with invisible disabilities, was more consistent amongst the resource teachers. They believed that there were students with invisible disabilities in their schools who had either not been identified or had been identified incorrectly under the umbrella of unspecified learning difficulties. It was felt that the number of unidentified students with invisible disabilities was greater than anyone thought. Resource teacher 4 went so far as to state. “I think one out of every ten students have some kind of invisible disability in our student population because they come across me.”

The resource teachers stated that the majority of student referrals fell into one of two classifications: academics and behavior. They thought that such students were not achieving academic success, primarily indicated by below grade level academic performances in reading and writing, and that their academic difficulties led them into various forms of inappropriate conduct during class instruction and work time. Ethel explained, “When they refer the students, it’s always the behavior I hear about and sometimes it’s remedial, mainly reading and writing.” Resource teacher 4 noted that the teachers say, “They’re (students) defiant, they’re not working, they’re not listening to me.” Frances said, “Yes, behaviors mostly... Many times when I get referrals the teacher will say, ‘I don’t think she knows how to read.’”

After having expressed the need for classroom teachers to get to know their students, the resource teachers then felt that this could lead to stronger relationships with the students; where disclosure of their invisible disabilities might be made because they truly trusted their classroom teachers. Ethel explained, “when you talk to the child and he or she comes to you and if there’s trust there they disclose and that’s how I know that there are invisible disabilities within each child, a lot of children in this school.” Without that trust with the classroom teachers, many students with invisible disabilities experience negative feelings that they do share with their resource teachers as described by Agnes, “Some kids tell me ‘nobody understands me’. Some of the kids come here just to talk and then they leave.”

As the resource teachers shared their views on invisible and visible disabilities, the third theme, adaptation and accommodation strategies employed by teachers working with students with invisible disabilities became a major point of concern. The resource teachers expressed the opinion that classroom teachers generally were reluctant to employ, or limited their employment of adaptive and accommodative methods in their daily instructional programming practices for their students. Although none of the resource teachers speculated on the reasons for that, they were not hesitant to share what they felt were important adaptation and accommodation strategies that could and should be utilized in the classroom to provide an inclusive environment for students with invisible disabilities. For example, Frances said, “Get the students to roam around, sit comfortably where they want to learn during reading time ...do learning centers.” Donna stated, “They just need chill out time because the florescent lights are bugging them.”

The fourth theme, professional development to increase classroom teachers’ awareness and knowledge on the topic of invisible disabilities arose from ideas and suggestions stated by the resource teachers. They felt that teacher training such as MFNERC’s RISE (Resource

Inclusive Special Education) university programs should cover more than just ADHD or FASD. Frances said, “We took a course, it’s called Exceptional Children, those ones we were told that there’s going to be FASD and ADHD and all that. But HIV was coming out [and] it was never mentioned how to take care of them.” They stated that there should be more coverage on both visible and invisible disabilities including their presenting characteristics and what types of accommodations, adaptations and strategies should be utilized by all teachers. Conferences, workshops, resource and special education meetings and school in-services were some of the suggestions made by the resource teachers. Agnes said, “Have a workshop at the beginning of the year.” Ethel stated, “There should be in-services for the teachers to make them aware of what it is and the characteristics that usually show on a person.” Bernice said, “Come August, before school starts to sort of refresh the teachers in accommodations and making adaptations.”

Teachers’ Questionnaires

The procedure for the delivery of the teachers’ questionnaire (see Appendix H) was the same in all the schools. The teachers’ questionnaires were distributed with a letter of explanation about the study, the questionnaire, and an envelope for the completed questionnaire. Once the teachers returned their questionnaires in the sealed envelopes, they were given a raffle ticket for an appreciation draw. Unfortunately, during this time at the third school, there was a community crisis occurring that severely impacted not only the community members but also the teaching staff. Its effect was reflected in the number of teachers’ questionnaires returned. Only half of the number of distributed questionnaires came back despite the strong support and encouragement from the school’s principal.

Response rate. Of the forty-two teacher questionnaires handed out, twenty-seven were completed and returned. At the first school eleven questionnaires were distributed and eight were

returned, resulting in a 72% response rate. Eleven questionnaires were distributed at the second school and nine were returned, resulting in an 82% response rate. At the last school, twenty questionnaires were given out and ten were returned, resulting in a 50% response rate.

Combining the all the returned questionnaires, the response rate was 67%. However, disappointing the returning numbers of teacher questionnaires was, vital data can be drawn from those classroom teachers' responses that can provide insights into the teachers' knowledge and awareness pertaining to disabilities.

Summary of classroom teachers' questionnaires. After receiving the completed questionnaires from the three schools, I recorded and tabulated the questionnaires' answers, first by the individual schools, and then by combining the collective totals. The data was recorded and tabulated and separately for each school. Then, average scores were calculated using the three schools' combined data.

The first summary chart, Table 1, from the teachers' questionnaire Part I, displays the results of the participants' demographics for each of the schools. Included in the participant demographics was years of teaching experience, ethnicity and age, and the level of education the teachers had completed. Two of these schools had an almost even mix of FN and non-FN teachers while the third school had a staff of nearly all FN teachers. It is interesting to note that all three schools had older mature teachers with ten plus years of experience. This raises the question of how actively these teachers sought information on current trends in education regarding best practices via professional journals, workshops, training or university courses. If they have not, they may be limiting, unknowingly, their pool of choices for skills, strategies and techniques that would benefit their students.

The next two charts, Table 2, Term “Disability”, and Table 3, Term “Invisible Disability”, break down the participants’ responses for Part II of the teachers’ questionnaire. As in Part I, all the data reported on these charts was compiled separately for each school and then averaged.

Table 2: Term “Disability” looks at how the term disability was defined by the teachers. From the data collected, there was no particular definition with which all the teachers could agree one hundred percent. The definition that framed the term disability as any limitations, either internally or externally, that prevents an individual’s ability to perform had the highest agreement amongst the three schools at ninety-two percent. Surprisingly, the school 1 teachers were the only staff to indicate that the definition of disability was more closely tied to barriers than to personal health features.

Table 3: Term “Invisible Disability” looks at how the term invisible disability was defined by the teachers. The three schools indicated that two of the definitions were of equal quality in describing the term invisible disability despite the fact that one definition centered on an individual’s ability to perform while the other definition included the descriptors of lack of appearance linked with cognitive issues. Based on the results displayed in Table 3: Term, “Invisible Disability”, the teachers from the three schools associated the lack of a disability’s visible features or characteristics with the lack of appropriate cognitive functioning. It also seemed that the teachers from the three schools considered neurological conditions to be the least preferred descriptor for invisible disabilities of the four definitions from which the teachers had to choose.

*Table 1**Part I, Participants' Demographics (questions 1, 2, 3 & 4)*

	Years of Teaching Experience	Ethic Affliction	Age Affiliation	Level of Education Completed
School 1	75% 10 years & over	50% FN	100% 35 years & older	100% Bachelor Degree & more
School 2	67% 10 years & over	44% FN	66% 35 years & older	77% Bachelor Degree & more
School 3	80% 10 years & over	90% FN	90% 35 years & older	100% Bachelor Degree & more
Three Schools Combined	74% 10 years & over	61% FN	85% 35 years & older	93% Bachelor Degree & more

Table 2

Term "Disability" (questions 5, 6, 7 & 8)

	Physical or mental condition that limits a person's movements	Disadvantage or handicap , especially one imposed or recognized by the law	A restriction in the ability to perform a normal activity of daily living which someone of the same age is able to perform	Any limitation, either internally or externally, that prevents an individual's ability to perform
School 1	75% agree	100% agree	100% agree	100% agree
School 2	100% agree	75% agree	88% agree	75% agree
School 3	80% agree	70% agree	50% agree	100% agree
Three Schools Combined	85% agree	82% agree	79% agree	92% agree

Table 3

Term “Invisible Disability” (questions 9, 10, 11 & 12)

	Any limitation, either internally or externally, that prevents an individual’s ability to perform	Any disability that is not immediately apparent to another person	A hidden neurological condition that present significant challenges to learning, interacting with others, regulating mood and thinking patterns	An absence in appearance difference from other individuals, but with cognitive issues
School 1	100% agree	100% agree	88% agree	100% agree
School 2	100% agree	100% agree	88% agree	100% agree
School 3	90% agree	80% agree	80% agree	90% agree
Three Schools Combined	97% agree	93% agree	85% agree	97% agree

Table 4

Disabilities Working Experience (questions 13, 14, 15 & 16)

	Officially identified and funded with visible disabilities	Not officially identified and not funded with visible disabilities	Officially identified and funded with invisible disabilities	Not officially identified and not funded with invisible disabilities
School 1	100% agree	100% agree	100% agree	87% agree
School 2	67% agree	87% agree	77% agree	67% agree
School 3	80% agree	90% agree	90% agree	80% agree
Three Schools Combined	82% agree	92% agree	89% agree	78% agree

Table 4: Disabilities Working Experience, reports the extent of teachers' first hand working experiences with students who fall into one of four groupings. The categories involved combinations of official and unofficial identification with funded or not funded visible and invisible disabilities. The results show that sixty-seven to one hundred percent of the teachers stated that they had experience working with students who had identified as having visible or invisible disabilities who were either funded or not funded.

Table 5: Types and Categories of Disabilities, reports the teachers' views involving the relationship between definitions of terms and types of disabilities. As can be seen in this table, only school 1's teachers were in total agreement (one hundred percent) that visible disabilities fell into the physical category while the teachers from the other two schools were significantly less adamant on that point. There also seemed to be a reaffirmation of teachers' views of the relationship between invisible disabilities and cognitive disabilities as first noted in Table 3: Term "Invisible Disability". The teachers' responses indicated an inclination towards a cognitive impairment being a necessary component for having the classification of an individual with an invisible disability.

In Part III of the teachers' questionnaire, participants categorized selected visible and invisible disabilities. The results are recorded on Table 6: Categorization of Disabilities. The tabulation of data was done for each individual school and each school assigned a different color for ease of reporting. However, it was felt that any percentage less than sixty (60%) was not

Table 5

Types and Categories of Disabilities (questions 17 & 18)

	Majority of visible disabilities fall into the physical category	Majority of invisible disabilities fall into the cognitive disability category
School 1	100% agree	87% agree
School 2	63% agree	87% agree
School 3	60% agree	80% agree
Three Schools Combined	74% agree	85% agree

Table 6

Part III, Categorization of Disabilities: (questions 19 to 32 inclusive)

School 1

Invisible Disability (60% or more)	Neither Invisible nor Visible (50/ 50)	Visible Disability (60% or more)
	Deafness	Blindness
	Autism	Dyslexia
	Oppositional Deviant	ADD/ADHD
	Diabetes	Down Syndrome
	Attachment Disorder	Asthma
	Crohn's Disease	Food Allergies
		Chronic Fatigue Syndrome
		Brain Trauma
		Epilepsy

School 2

Invisible Disability (60% or more)	Neither Invisible nor Visible (50/ 50)	Visible Disability (60% or more)
Food Allergies	Deafness	Blindness
Diabetes	Dyslexia	ADD/ADHD
Chronic Fatigue Syndrome	Oppositional Deviant	Down Syndrome
Brain Trauma	Asthma	Autism
	Epilepsy	
	Attachment Disorder	
	Crohn's Disease	

School 3

Invisible Disability (60% or more)	Neither Invisible nor Visible (50/ 50)	Visible Disability (60% or more)
Deafness	Dyslexia	Blindness
ADD/ADHD	Oppositional Deviant	Down Syndrome
Diabetes	Asthma	Autism
Chronic Fatigue Syndrome	Food Allergies	
Brain Trauma	Epilepsy	
Crohn's Disease	Attachment Disorder	

Three Schools Combined Results:

Invisible Disability (60% or more)	Neither Invisible nor Visible (50/ 50)	Visible Disability (60% or more)
No agreement	Oppositional Deviant & Attachment Disorder	Blindness & Down Syndrome

significantly definitive to be placed in any other category than ‘neither invisible nor visible’ as no specific descriptors were given for each of the disabilities listed for the participants to use in their decision making.

It should be noted that out of all the chosen visible and invisible disabilities to categorize, the only agreed upon visible disabilities were Down Syndrome and blindness. The only other agreement amongst the teachers was that oppositional defiant and attachment disorder could be considered either visible or invisible disabilities. It was interesting to see how several disabilities fell into more than one category, confirming the lack of clear universal criteria for defining visible and invisible disabilities.

In the Part IV, the questionnaire researched teachers’ views on the identification of students with visible and invisible disabilities along with the teachers’ feelings on how their workload was affected when providing adaptations and accommodations for students with disabilities. These data are displayed in the Table 7: Teachers’ Disabilities Identification and Table 8: Teachers’ Invisible Disabilities Identification. Table 9: Adaptations/Accommodations summarizes the participants’ views concerning adaptations/accommodations in regard to whether the invisible disabilities caused participants’ workload to increase more than visible disabilities.

For two of the four questions contained in Table 7: Teachers’ Disabilities Identification, the teachers’ responses were not surprising. The teachers indicated that it is easier to identify students with visible disabilities than invisible disabilities and that they required no assistance in identifying students with visible disabilities. But the surprise was that two thirds of the teachers felt they could also identify students with invisible disabilities without any assistance.

Table 7

Part V, Teachers' Views on Identifying Students with Disabilities: (questions 33, 34, 35 & 42)

	Easier to identify students with visible disabilities than with invisible disabilities	Can identify students with visible disabilities without assistance from others	Can identify students with invisible disabilities without assistance from others	There are fewer students with invisible disabilities than there are students with visible disabilities
School 1	100% agree	100% agree	75% agree	62% agree
School 2	100% agree	88% agree	44% agree	77% agree
School 3	100% agree	80% agree	80% agree	60% agree
Three Schools Combined	100% agree	89% agree	66% agree	66% agree

Table 8

Part IV, Teachers' Views Regarding Students with Invisible Disabilities: (questions 36, 37, 39, 44 & 45)

	Are more “at risk” than students with visible disabilities	Have an easier time in school because they blend in with the general student population	Can use their invisible disability to their advantage more easily than students with visible disabilities	Need to be officially identified before any adaptations/ accommodations/ modifications to lesson plans and learning environment are made	Often use their invisible disabilities as an excuse for not completing assignments
School 1	75% agree	38% agree	50% agree	87% agree	63% agree
School 2	50% agree	77% agree	77% agree	77% agree	77% agree
School 3	100% agree	60% agree	70% agree	60% agree	80% agree
Three Schools Combined	75% agree	58% agree	66% agree	75% agree	73% agree

Still another surprise was that well over two thirds of the teachers believed there were less students with invisible disabilities than students with visible disabilities. As so many participants expressed these sentiments, there should not be much doubt as to why teacher skepticism has been the reaction expressed towards students who have been declared to have an invisible disability.

Perhaps Table 8: Teachers' Invisible Disabilities Identification displayed best the teachers' views on invisible disabilities. Collectively, the majority of teachers felt it was necessary for an official identification to be made before any adaptations or accommodations be implemented along with the opinion that students use their invisible disabilities as an excuse for getting out of assigned work.

In Table 9: Teachers' Views Regarding Accommodations/Adaptations, the teachers' responses to the questions indicated strong agreement at all three schools concerning the ease of implementing accommodations/adaptations, the amount of extra preparation time caused by the accommodations/adaptations, and the added stress placed on the teachers because of the additional effort and time. The teachers expressed the belief that it was easier to provide accommodations (52%) / adaptations (26%) for students with invisible disabilities than for students with visible disabilities. One inference from these two questions' is that three quarters of teachers experienced difficulties in delivering the accommodations and adaptations that are so necessary in inclusive classrooms.

Table 9

Part IV, Teachers' Views Regarding Accommodations / Adaptations: (questions 38, 40, 41, 43 & 46)

	Is easier to accommodate students with invisible disabilities than students with visible disabilities	Takes extra time to prepare lessons for students with invisible disabilities	Adds more stress to teachers' workloads when having to adapt/accommodate the environment for students with invisible disabilities as well as for students with visible disabilities	Is much easier to adapt and/or modify lesson plans for students with visible disabilities than for students with invisible disabilities	Can achieve academic success without any adaptations /accommodations if they just work more intensely at the assigned tasks
School 1	50% agree	87% agree	86% agree	75% agree	37% agree
School 2	56% agree	88% agree	100% agree	88% agree	56% agree
School 3	50% agree	70% agree	70% agree	70% agree	60% agree
Three Schools Combined	52% agree	82% agree	85% agree	74% agree	51% agree

It must also be remembered that these teachers had previously stated they wanted an official diagnosis of an invisible disability, before they would provide the accommodations and adaptations (see Table 8: Teachers' Views Regarding Students with Invisible Disabilities, 87%). And just over half (51%) these teachers held the opinion that students could achieve academic success without accommodations and adaptations, if they would simply work harder on their assigned tasks.

In the last section, Part V of the teachers' questionnaire, information on the participants' exposure to training for working with students who have invisible disabilities was collected and summarized in Table 10: Teacher Training/Exposure to Invisible Disabilities. The majority of teaching staff at all three schools indicated that they felt they had less than adequate education on the barriers students with invisible disabilities face in the school environment (76%) and less than adequate awareness on the types of adaptations or accommodations that would help offset those barriers (83%). These two findings could explain why the resource teachers reported a lack of willingness by the teachers to incorporate adaptations and accommodation in their work plans.

The last two questions in Part V explored the participants' personal life experiences and professional work experiences with individuals who have disabilities in the context of different environments, both inside and outside of school. The data is presented in Table 11: Personal Experience with Visible and Invisible Disabilities. The data were recorded and tabulated separately for each school and then averaged.

Table 10

Teacher Training / Exposure to Invisible Disabilities: (questions 47 & 48)

	Awareness of difficulties students with invisible disabilities face in acquiring an education	Awareness of invisible disabilities regarding adaptations / accommodations for students with invisible disabilities
School 1	60% less than adequate	70% less than adequate
School 2	89% less than adequate	100% less than adequate
School 3	80% less than adequate	80% less than adequate
Three Schools Combined	76% less than adequate	83% less than adequate

Table 11

Personal Experience with Visible and Invisible Disabilities: (questions 49 & 50)

	Individuals with visible disabilities outside the school setting	Individuals with invisible disabilities outside the school setting
School 1	60% adequate & more than adequate	50% less than adequate
School 2	46% adequate & more than adequate	67% less than adequate
School 3	60% adequate & more than adequate	40 % less than adequate
Three Schools Combined	55% adequate & more than adequate	52% less than adequate

The teachers' responses for the two questions in Table 11 revealed that half or close to half the questionnaire's respondents identified themselves as having more than adequate experience with individuals with visible disabilities (55%) and invisible disabilities (48%) outside of the classroom. The resource teachers attributed their knowledge and understanding of working with students with invisible disabilities to personal experiences outside of the classroom. Thus, lack of or limited personal experiences with individuals with disabilities might be another factor directly connected to the teachers' reluctance to provide accommodations and adaptations.

Convergence of data. In the original design of this study, concurrent triangulation, using resource teacher interviews, teachers' questionnaire and review of students' resource files was to be utilized. But out of respect of the resource teachers' concerns for sensitivity regarding the protection of confidentiality for their students, the review of students' resource files was deleted from this study with ENREB approval (see Appendix E). However, a comparison from the two remaining data sources was conducted. Any correlations between classroom teachers' responses in the questionnaire and the four themes identified by the resource teachers were studied for their possible relationships.

Trustworthiness. Since this study involved both qualitative and quantitative information, the framework for qualitative and quantitative applications concerning the data was checked.

Qualitative credibility. I believe that internal creditability of this study was not compromised as there was no deviation from the design or delivery of the study's components and procedures in the collection of data. There was also no bias in this study, as the researcher had no influence over the school's administration or staff in agreeing to participate in this study

and no influence regarding participants' security of job positions in relationship to their participation in the study. Because this study was a one-time data collection event, there was no issue of maturation affecting the study's creditability. However, a subcategory of reliability, the history factor, may or may not have influenced some of the participants' responses in the teachers' questionnaire responses. But if any teachers had negative experiences from the past they had the option of not participating in the study without fear of reprisals from anyone.

With respect to external credibility, where consistency of dependability and uniformity are the standards, all three participating First Nations schools would be considered as classic representatives of the FN educational institutions found in Manitoba because of all the possible variables i.e. geography, accessibility, language, service, culture, etc. Although the three schools were located in central and northern Manitoba with none from the southern part of the province, one school did have as easy access to a large urban center as would any southern First Nations community. Therefore, I consider the external credibility to be intact.

Qualitative dependability. The guidelines for qualitative dependability were adhered to throughout all of the resource teachers' interviews. Every interview was conducted in a location of the resource teacher's choice as the time it took place. Permission for recording the interview was requested and granted by all the resource teachers. The recorded interviews were then transcribed. All transcripts were checked, double checked and then confirmed accurate by the interviewees' as accurate prior to the coding process. Once approval for accuracy had been given by the resource teachers, the transcripts were coded for commonalities of thoughts, views and opinions first, followed by categorizing and coding for reoccurring themes. To effectively assess the process of the study, the coding of the transcripts was conducted by the researcher in a

reflective and evaluative manner. The method of data collection from the resource teachers can be replicated easily by another researcher, at any time.

Qualitative transferability. As stated previously, none of the three participating schools were geographically located in southern Manitoba. But two of the schools did have the same accessibility options as any southern FN community. Despite the fact that all FN communities are considered unique and individual from one another, there are enough shared historical and present day experiences and similar on-going educational, social and economic issues that this study's results would be similar if different but similar settings were selected to replicate this study.

Qualitative confirmability. All five resource teachers felt there were several issues involving disabilities with which the teachers were having difficulties. They were: (a) defining what was a disability, (b) the complexities of identification, (c) adaptations and accommodations and (d) professional development. These views were supported by using the triangulation method on the data collected from the teachers' questionnaires and comparing it to the resource teachers' interviews.

Qualitative authenticity. I have presented all the data collected from both the resource teachers' interviews and the teachers' questionnaires without altering any of the responses. By respecting all the participants' views and differing perspectives through honestly recording and reporting the responses without changing any answers, the fairness or authenticity of this study remains intact.

Quantitative validity and reliability. To facilitate the questionnaire's construct and content validity, a volunteer panel of experts from MFNERC's Special Education Unit

reviewed questions the appropriateness of the questions on the questionnaire in relationship to the study's focus. This volunteer panel of experts were each given a copy of the teacher's questionnaire and asked to review and critique each of the fifty questions. They were asked to give their opinions on the wording in relationship to glean as the honest and unbiased views held by the teachers. The panel members were asked to do this review independently of each other, and to write any additional thoughts, comments or concerns regarding any of the questions. When done, they returned the reviewed questionnaires to me. Other than a few minor changes to the phrasing of words, the experts were unanimous in their views that the questionnaire would draw out the information on classroom teachers' mindset regarding invisible disabilities in FN schools.

Following the questionnaire review by the panel of experts, a trial run was also conducted. For this trial run, another volunteer group of non-project participants from MFNERC's Service Delivery Unit were asked to answer the questionnaire first and also comment on the appropriateness of the questions being asked. The questionnaires were distributed to the volunteers who then returned the completed questionnaires. It was at this time that I asked for their comments concerning the appropriateness of the questions. The members of the volunteer group were also unanimous in their opinions on the questions and the topic of invisible disabilities. They were consistent in expressing the view that they had not previously heard of the term invisible disabilities and definitely not in relationship for FN students and that the questions were very thought provoking, giving them pause to question their mindsets surrounding disabilities and working with FN students in the classroom.

The delivery and collection of the questionnaire data from the participants was consistent for all three schools and never deviated in any fashion from the original design.

Then, to verify internal consistency of the data collected from the three schools, the split half method was employed. The questionnaire was divided into odd and even numbered questions after assigning coding numbers according to each of the Likert scale categories used. The assigned coded numbers were then entered into an Excel Reliability Calculator (Siegle, 2002) to obtain the Cronbach's Alpha, Split –Half Correlation and the Spearman-Brow Prophecy. Each half of the questionnaire was tabulated as an individual part first and then as overall whole with all five parts in order to check the reliability of the questionnaire.

The Excel Reliability Calculator was used because of the many opinions of research statisticians on what method is the best and most applicable to use (i.e., Cronbach's Alpha is not designed for Likert scales, Spearman-Brown is not as accurate as Cronbach's Alpha, Split Half Correlation is necessary with a Likert scale, etc.). Since the Excel Reliability Calculator gave calculations for all three, it was utilized to better assess how the questionnaire had covered the constructs (i.e., participants' demographics, knowledge of and job experience with disabilities, categorizations of disabilities, identification of and adapting and accommodating for students with disabilities and educational training on and personal experience with disabilities. By having the Cronbach's Alpha, Split-Half Correlation and the Spearman-Brown Prophecy calculations, a more complete appraisal of the questionnaire's reliability was gained. Thus, with this broader view of reliability provided, a greater confidence in this study's measurement tool for reliability was achieved.

The calculation results for the odd numbered half of the questionnaire for parts I, III & IV were in the acceptable to good range while the even numbered half for parts III & IV were acceptable to good range also (see Table 12: Teachers' Questionnaire Part I, Table 14: Teachers' Questionnaire Part III, & Table 15: Teachers' Questionnaire Part IV). The poor

results for Part II and Part V (see Table 13: Teachers' Questionnaire Part II & Table 16: Teachers' Questionnaire Part V) need to be reviewed to determine if more questions are required in those areas, or if reworking the wording of the questions would suffice. The last calculation (see Table 17: Teachers' Questionnaire Whole Half Questionnaire) regarding the overall reliability of the questionnaire was acceptable to good. This final tabulation afforded the researcher confidence that the data collected from the questionnaire was reliable.

Table 12

Teachers' Questionnaire Part I

Part I Odd Numbered Questions		Part I Even Numbered Questions	
Cronbach's Alpha	0.772486772	Cronbach's Alpha	0.207373272
Split-Half (odd-even)		Split-Half (odd-even)	
Correlation	0.665642918	Correlation	0.116237167
Spearman-Brown		Spearman-Brown	
Prophecy	0.799262448	Prophecy	0.208266076
Mean for Test	7	Mean for Test	5.62962963
Standard Deviation for		Standard Deviation for	
Test	2.27710017	Test	1.543160493
KR21	8.75	KR21	10.58064516
KR20	8.915343915	KR20	10.97004608

Table 13

Teachers' Questionnaire Part II

Part II Odd Numbered Questions		Part II Even Numbered Questions	
Cronbach's Alpha	0.334264143	Cronbach's Alpha	0.404267019
Split-Half (odd-even)		Split-Half (odd-even)	
Correlation	0.300191264	Correlation	0.507344993
Spearman-Brown		Spearman-Brown	
Prophecy	0.461764776	Prophecy	0.673163736
Mean for Test	20.51851852	Mean for Test	21.40740741
Standard Deviation for		Standard Deviation for	
Test	2.973592046	Test	2.883660987
KR21	14.1104561	KR21	16.27119762
KR20	14.1623746	KR20	16.29605191

Table 14

Teachers' Questionnaire Part III

Part III Odd Numbered Questions		Part III Even Numbered Questions	
Cronbach's Alpha	0.681906373	Cronbach's Alpha	0.63731977
Split-Half (odd-even)		Split-Half (odd-even)	
Correlation	0.744773258	Correlation	0.676433305
Spearman-Brown Prophecy	0.853719249	Spearman-Brown Prophecy	0.806991012
Mean for Test	38.96296296	Mean for Test	28.2962963
Standard Deviation for Test	7.426087557	Standard Deviation for Test	5.759467663
KR21	3.771224068	KR21	4.194400794
KR20	3.85223372	KR20	4.276845036

Table 15

Teachers' Questionnaire Part IV

Part IV Odd Numbered Questions		Part IV Even Numbered Questions	
Cronbach's Alpha	0.729766804	Cronbach's Alpha	0.64676297
Split-Half (odd-even)		Split-Half (odd-even)	
Correlation	0.653770674	Correlation	0.435520051
Spearman-Brown Prophecy	0.790642481	Spearman-Brown Prophecy	0.606776688
Mean for Test	31.33333333	Mean for Test	31.55555556
Standard Deviation for Test	5.944184833	Standard Deviation for Test	5.265775827
KR21	4.763102725	KR21	5.82413179
KR20	4.819214742	KR20	5.95753768

Table 16

Teachers' Questionnaire Part V

Part V Odd Numbered Questions		Part V Even Numbered Questions	
Cronbach's Alpha	-0.15746873	Cronbach's Alpha	0.49113082
Split-Half (odd-even)		Split-Half (odd-even)	
Correlation	-0.07362186	Correlation	0.325503076
Spearman-Brown Prophecy	-0.1589456	Spearman-Brown Prophecy	0.491138922
Mean for Test	6.888888889	Mean for Test	6.296296296
Standard Deviation for Test	1.930905244	Standard Deviation for Test	2.224689988
KR21	11.03311258	KR21	7.465631929
KR20	11.56438558	KR20	7.555432373

Table 17

Teachers' Questionnaire Whole Half Questionnaire

Part VI Odd Numbered Questions		Part VI Even Numbered Questions	
Cronbach's Alpha	0.769801039	Cronbach's Alpha	0.671761773
Split-Half (odd-even)		Split-Half (odd-even)	
Correlation	0.756067005	Correlation	0.671204032
Spearman-Brown Prophecy	0.861091294	Spearman-Brown Prophecy	0.803258033
Mean for Test	112.5555556	Mean for Test	108.2962963
Standard Deviation for Test	14.27594022	Standard Deviation for Test	11.30655272
KR21	2.952108069	KR21	3.981804086
KR20	3.020782382	KR20	4.148984019

Comparison between Resource Teachers' Interviews and Classroom Teachers' Questionnaires

When comparing the demographics of the classroom teachers who answered the questionnaire with the resource teachers interviewed, the following similarities were discerned:

That the majority of teachers from both groups, resource and classroom teachers, and all three schools:

- had over ten years of teaching experience, even the first-year resource teacher had at least ten years of working in the classroom environment,
- were of First Nations Affiliation,
- were 35 years of age and older, and
- had a Bachelor Degree or more in Education.

Then after reviewing the findings from the questionnaire within the framework of the four themes that had arisen from the resource teachers' interviews, the following similarities and differences were detected.

1. Theme 1, involving the complexity surrounding the definition of invisible disabilities, and the identification of students with invisible disabilities:
 - the complexity surrounding the definitions of invisible and visible disabilities, that was expressed by the resource teachers, also was present in the teachers' questionnaires, as indicated by all the participants selecting multiple and varied definitions covering a wide range of disability aspects including physical, cognitive, and emotional abilities and limitations
2. Theme 2, concerning the identification of students with invisible disabilities showed a difference between the resource teachers' views and those of the classroom teachers, especially with respect to dealing with the "risk factors" for students with invisible disabilities:
 - only school 2's classroom teachers indicated that they felt they could identify students with invisible disabilities without assistance from others,
 - the teaching staff at schools 1 (75%) and 3 (80%) expressed significantly more confidence in their abilities to identify students with invisible disabilities without outside assistance,
 - the teachers at schools 1 (75%) and 3 (100%) felt that students with invisible disabilities were more "at risk" than students with visible disabilities, while school 2's teachers saw no difference in the risk factor, and
 - the majority of all three schools' teaching staffs believed that there were less students with invisible disabilities than students with visible disabilities, and that those students with invisible disabilities often used their invisible disabilities as an excuse for unfinished assignments.

3. Theme 3, relating to the adaptation and accommodation strategies employed by teachers working with invisible disabilities identified in the resource teachers' interviews was again supported by the data from the classroom teachers' questionnaire:

- the majority of classroom teachers in all three schools indicated that students with invisible disabilities ought to be officially identified prior to any adaptations or accommodations being implemented,
- the resource teachers also agreed that, as much as clinically possible, students with invisible disabilities should be officially identified, especially if that would assist in the students' eligibility for post-secondary and other funding supports,
- over half the classroom teachers at schools 2 (56%) and 3 (60%) expressed the view that students with invisible disabilities could achieve academic success without any adaptations or accommodations if they just worked more intensely on their assigned tasks,
- because of their more extensive knowledge of disabilities, resource teachers expressed more empathic views concerning the difficulties students with invisible disabilities experienced when there were no adaptations or accommodations and understanding that no amount of intensity or focus by those students would allow them to achieve success,
- the majority of classroom teachers, at all three schools, did not see any differences in the ease or amount of extra time needed to making adaptations and accommodations for students with visible or invisible disabilities,

- the resource teachers also agreed that regardless of the type of disability, visible or invisible, adapting and accommodating would always take time initially, but would become easier as time went on,
 - the majority of classroom teachers at all three schools also agreed that it caused them extra stress and increased their workloads when they had to adapt or accommodate for students with invisible disabilities, as well as for the students with visible disabilities,
 - all of the resource teachers' views regarding adaptations and accommodations were counter to those of the classroom teachers regarding this point - the resource teachers felt that once the appropriate adaptations or accommodations were implemented, the workload actually becomes lighter as a result of students experiencing less frustration that would otherwise erupt as unacceptable classroom behaviors,
 - the majority of classroom teachers, at all three schools, agreed that it was easier to make adaptations and accommodations for students with visible disabilities than for students with invisible disabilities, and
 - the resource teachers' opinions differed from the classroom teachers' in that they did not view selecting and implementing adaptations or accommodations for students with invisible disabilities as any more difficult as doing that for students with visible disabilities.
4. Theme 4, pertaining to professional development to increase classroom teachers' awareness and knowledge on the topic of invisible disabilities, also brought forth agreement between the resource teachers and the classroom teachers that more preparation concerning students with invisible disabilities was desperately needed:

- the majority of classroom teachers, at all three schools, felt that their awareness of all aspects affected by invisible disabilities was less than adequate, based on both personal experience and educational preparation,
- the resource teachers believed that their awareness and knowledge of invisible disabilities was more than the classroom teachers but only adequate at a minimal to moderate level,
- the resource teachers credited their personal experiences more than their educational preparation for their better adequacy in understanding students with invisible disabilities, and
- the resource teachers felt strongly that more university courses and professional development workshops on invisible disabilities should be made available to classroom teachers to increase their awareness and teaching skills.

Relationship between Resource Teachers' Interviews and the Teachers' Questionnaires

It was apparent from the questionnaire and interview data collected that the resource teachers' personal and informal assessments of the learning environments for students with any type of disability, especially invisible ones, are filled with both physical and attitudinal obstacles, making it extremely difficult for those students with invisible disabilities to successfully navigate school. Identification, whether officially or unofficially, of students with invisible disabilities was extremely difficult because the opinions or views on what characteristics and which category any disability falls under are as varied as the educators involved. This point was clearly shown when looking at the categorization chart in Part III indicating the randomness of placement for the chosen samples of disabilities. There was no predictable or uniform consistency to the classroom teachers' responses in the categorization of the disabilities listed.

This point was also reinforced by the various descriptions the resource teachers gave for the defining the term invisible disability during their interviews.

It was interesting to see how personal experiences outside of the school environment with individuals who had any type of disability affected the majority of resource teachers' confidence levels along with their personal framework and willingness to try adaptations and accommodations, as well as their resilience not to be deterred by unsuccessful interventions. This framework of willingness and resilience seemed to be much less evident in the classroom teachers. Possibly vision and mission statements would best address the concerns of the willingness to try adaptation ad accommodation and of sustaining the resilience to keep trying other interventions when one fails until a successful one is found. These statements would provide the mindset and also the framework for advancing the creation of the school's protocol for the early identification of students with invisible disabilities.

It seemed that, generally, the classroom teachers had much less personal experience with individuals with disabilities than did the resource teachers. Unfortunately, the questionnaire did not ask for suggestions from the classroom teachers about the types of professional development that they might like to receive to assist them in cultivating a much richer understand of the effects of invisible disabilities. However, the resource teachers indicated that they would like more training on invisible disabilities and were very willing to present ideas on how that training could be delivered to all the teachers.

Delimitations

Since I was unable to find any previously completed research related to any aspect of invisible disabilities linked to education in First Nations' schools, I designed my study's structure based, in part, on my twenty plus years of teaching in First Nations' communities experience. As a classroom teacher in a FN school, I worked with students who functioned well outside the classroom but were unsuccessful in their academics regardless of their efforts I observed them putting into their assigned tasks. They were experiencing barriers that I was not able to see or understand at that time. Unfortunately, at that time invisible disabilities were not even a paradigm in either the education or health fields.

Then as a resource teacher in a FN school, I constantly received referrals for students were experiencing difficulties in achieving academic success. The descriptions of students' presenting problems were similar to what I had encountered as a classroom teacher. The referrals often detailed the students as exhibiting to various degrees and combinations some, if not all, of the classic characteristics such as: sensory issues, receptive and expressive struggles, inattentiveness, inappropriate conduct and even poor cognitive abilities associated with many of today's accepted disabilities. Yet, none of the students qualified for extra support services because they did not fully meet the funding criteria set out by INAC.

My personal experiences as a person with an invisible disability also contributed to the focus and design of this study. Because as an individual who received a late identification of an invisible disability, I realized the importance and impact of early identification in a student's life and that many FN students with invisible disabilities were being identified and therefore not receiving the necessary support services to aid in their academic careers.

Along with the design delimitation, the selection of the location of the schools, student population, community supports, and access to external support systems were also part of this study. The freedom to choose the schools that were involved base on geographical location, school size, supports within the community and supports obtainable outside the community, allowed comparisons to be made using the study's findings. Further delimitations also involved the design and length of the study and the First Nations protocol as developed by MFNERC for researchers conducting studies in First Nations' communities on which I based my conduct for this study. Being the lone researcher, I needed a study design that was manageable in size, yet, would provide data resulting valuable insights concerning identification of invisible disabilities.

Limitations

The two major limitations to this study were time and sample size. Although the time schedule was very tight, it was workable. However, as often happens in First Nations' communities, unforeseen events such as severe storms, community member's death, etc. occurred that necessitated the rearranging of plans and schedules. The original design of the study involved a smaller sample size of participants. But with the addition of the third school, the sample size was increased. Unfortunately, as a result of an unexpected and extremely traumatic event in one community, the response rate for the teachers' questionnaires was lower than I had anticipated. Still as this was the first study conducted concerning FN students with invisible disabilities important information was gleaned despite the sample size was not large.

As described previously in this chapter, the development and completion of this study included successfully meeting the challenges of respecting protocols of two cultural different perspectives, the First Nations' and ENREB's. Receiving the appropriate approval by following the proper protocols of First Nations and ENREB was as important as determining the type of

study to conduct, the individual components of the study, its data collection methods along with maintaining trustworthiness and dependability. In the following chapter, Chapter 5, recommendations for the development of an early identification protocol for students with invisible disabilities in First Nations schools, based on the data from this study, will be discussed.

Chapter 5 Conclusion

One reason for selecting the grounded theory approach for this study was flexibility. The choices that such flexibility offered, not only in the choice of strategies for collecting data from qualitative and quantitative research sources, but also in the categorization of variables arising from the data, provided the freedom to delve deeper into the identification of FN students with invisible disabilities. Grounded theory also afforded a method of systematically analyzing the data in a manner that would allow hypotheses to be developed that explained the studied findings and thereby ascertain the issues that need to be addressed prior developing a protocol for identifying FN students with invisible disabilities.

The aim of the study was to identify the factors concerning FN students with invisible disabilities. These factors included both professional and personal influences on the teachers' perception of invisible disabilities and their impact on the teachers' attitudes. Further factors included how the teachers' attitudes affected their abilities to identify, plan and implement the appropriate programming necessary for First Nations' students with invisible disabilities to achieve academic success. The advantages of early identification, along with timely and appropriate supports, benefit students with invisible disabilities, as well as their teachers and parents, and the communities in which they live (Shealey, Lue, Brooks and McCray, 2005; Wingert & Kantrowitz, 1997). All First Nations schools need to develop a systematic protocol for the early identification of students with invisible disabilities and the implementation of effective supports. Only when a complete picture of the underlying factors, regarding the connection between invisible disabilities and the provision of appropriate teaching services in First Nations schools is developed, can a functional protocol be developed. As the data in this study emphasizes, any protocol for identifying students with invisible disabilities needs to be

flexible enough so that adjustments can be made based on many elements including the teachers': (a) knowledge, (b) educational training, (c) personal attitudes regarding all disabilities, and especially invisible disabilities, and (d) cultural beliefs and practices.

It was through the delimitations of work and personal experience along with the school selection criteria, that the study's design was able to document some essential underpinnings of teachers' and resource teachers' awareness and knowledge concerning invisible disabilities. Despite this study's limitations of time and size in terms of the number of participating schools and teachers, the importance of uncovering the relationships between visible and invisible disabilities, teachers' beliefs and attitudes, teachers' educational knowledge, training and life experiences was such that it demands not only immediate attention, but also long overdue action. Even though the number of participating schools, teachers and resource teachers was small, the data and findings were sufficient.

All research on the generic term, disabilities, continues to verify the fact that early intervention is preferable to later remediation and that early intervention is based on early identification (O'Shaughnessy, Lane, Gresham & Beebe-Berger, 2003; Mainemer, 1998). Yet, research on any practices, methods, or strategies for early identification and assessment of students with invisible disabilities in FN communities was, and continues to be, exceedingly rare and difficult to find. Invisible disabilities, including all their related sub-themes, are issues that need to be investigated in-depth and without delay in order to identify and assist all students with invisible disabilities, so they can reach their full academic potential.

Discussion

As discussed in Chapter 2, definitions for the term disability were many and varied depending on the mindset of the sources for the definitions. The definition for the term invisible disability was extremely difficult to find, and the inconsistencies in competing definitions that were found are as diverse as the definitions are for the term disability. The variations in the definitions of the term invisible disabilities created and sustained difficulties in accurately identifying students with invisible disabilities. The five resource teachers in this study had five different descriptions for the term invisible disability. One resource teacher defined it as “hidden but can still see it.” While another resource teacher stated, “I’m not really sure if I understand what invisible disabilities means or what to look for or what it looks like.” The third resource teacher described invisible disability as, “you, you don’t see it, but the teacher in you knows, you can read your kids.” The fourth resource teacher explained, “The child doesn’t have the features but show symptoms of FASD. That could be an invisible disability because the features are not there, we don’t know what’s wrong with the child, but we know that there is something.” And the last resource teacher described invisible disability using an example, “if I take off these (glasses) I can’t see far, but if I put these on they’re perfect, that’s invisible to me.”

Unfortunately, it was not university course work on the topic of invisible disabilities but their personal and job experiences that provided the resource teachers with the majority of their background knowledge on invisible disabilities. The five resource teachers agreed that the universities dealt with the disability topic, but said they did not specifically address the topic of invisible disabilities in their course work. A resource teacher summarized the training, “We took a course, it’s called *Exceptional Children*.”

The results from the teachers' questionnaire also supported the view that there is no consistency or conformity in defining the terms invisible disability and disability. The questionnaire offered four diverse definitions for each term but close to one hundred percent of the participants agreed with all four of the proffered definitions despite the differences. This finding confirms what was stated in the literature, that there is an enormous complexity in defining an accurate and appropriate definition for invisible disabilities.

Identification of students with invisible disabilities was the second theme that arose in both the resource teachers' interviews and the classroom teachers' questionnaires. Although the resource teachers, with their extensive experience, felt they could identify students with invisible disabilities more easily than their fellow staff members, the resource teachers wanted to have access to clinicians with expertise in the area of identifying invisible disabilities for verification. Interestingly, on the questionnaire, one hundred percent of the classroom teachers indicated that it is easier to identify students with visible disabilities than students with invisible disabilities. Yet at the same time, three quarters (seventy-five percent) of the classroom teachers stated that they could identify students with invisible disabilities without any assistance. They also indicated that they felt there were fewer students with invisible disabilities than students with visible disabilities.

These last two findings were interesting and contradictory in nature. Later in the questionnaire, the classroom teachers indicated that their teacher training on the awareness of invisible disabilities (seventy-five percent) and their experience individuals with invisible disabilities (fifty-two percent) were less than adequate. The classroom teachers indicated much less concern for acquiring confirmation on the identification of students with invisible disabilities than did the resource teachers.

The study's results relating to the third theme, the provision of adaptations and accommodations for students with invisible disabilities, showed a differing of opinions between the resource teachers and the classroom teachers. The resource teachers felt that classroom teachers could do more, when it came to utilizing adaptation and accommodation strategies for students with invisible disabilities. However, the reason for this lack of implementation of adaptations and accommodations by the classroom teachers may be found in the questionnaire's question 44. In that question, the classroom teachers (seventy-five percent) expressed their belief that an official identification of disability needed to be made before adaptations and accommodations could be implemented. Another possible explanation for the lack of implementation of adaptations and accommodations by classroom teachers arose in their response to question 43 on the questionnaire. Eighty-five percent of the classroom teachers confirmed that more stress is added to their workloads when they have to make adaptations and accommodations. The classroom teachers also indicated (seventy-seven percent) that it was much easier to adapt and accommodate for students with visible disabilities than for students with invisible disabilities. Perhaps the underlying reason for this response was because of inadequate training, as eighty percent of the classroom teachers concurred that they had less than adequate training on adaptations and accommodations for students with invisible disabilities.

The fourth theme, the provision of professional education and training to teachers on how to work with students who have invisible disabilities, revealed complete agreement between the resource and classroom teachers on the significant lack of awareness or knowledge regarding the topic of invisible disabilities and students with invisible disabilities. The classroom teachers (seventy-eight percent) declared that they had less than adequate teacher training on invisible disabilities. The resource teachers agreed that more training was needed by everyone and that is

was only through personal and work experiences, including post graduate training, resource teachers' meetings and special education in-services that they had been prepared them to deal effectively with students who had invisible disabilities.

As mentioned previously, the complexities involving all aspects of invisible disabilities were numerous and varied. The data collected from the study's two components, the questionnaire and the interview, often seemed to be contradictory i.e., all of the resource teachers each expressed uncertainty in their ability to identify students with invisible disability while two-thirds of the classroom teachers stated that they could identify students with invisible disabilities without any assistance. This current of contradictions continued throughout the study's findings i.e., three quarters of classroom teachers surveyed said that despite having less than adequate awareness of difficulties students with invisible disabilities face yet half of those same teachers believed that students with invisible disabilities could achieve academic success without any adaptations/accommodations if those students worked more intensely t the assigned tasks. As a result of the complexities surrounding the findings, close attention and great care was taken with first with the interpretations and then

Recommendations

As a result of this study's findings, I have made several recommendations for future research, educational development for teachers, and effective practices in FN schools.

Future research. The first recommendation is that more research on teaching students with invisible disabilities in FN communities needs to be conducted. Future studies should involve not only educators, but also the students and their parents in order to truly gather a comprehensive picture of the hurdles faced by students with invisible disabilities daily in

educational environments. Although there were stiff ethical regulations regarding research studies involving underage students, every effort must be made to include their perspectives, as it is those very students who will benefit the most from having well informed and well educated teachers.

The second recommendation deals with increasing the understanding of teachers' rationales for categorizing disabilities. As teachers' perceptions of students with disabilities, especially invisible disabilities, influenced the school environment including academic success and social acceptance, the importance of ascertaining which characteristics or factors impact the teachers' definitions of various disabilities should be clarified. Therefore, any future studies on categorizing disabilities as visible or invisible should be conducted with one of two options. The first option could be to include a short descriptive definition with disability related terms so that all the participants were categorizing the disabilities based on the same definition. The second option could be to have the participants indicate what they used as the deciding factor in their categorization of each disability term. Either method could provide more in-depth information on what factors teachers used to determine how they categorize students with disabilities.

Also, the importance of the FN school administrators' knowledge about invisible disabilities must be stressed, as their unwavering support in the early identification of students with invisible disabilities is imperative for the development of an appropriate protocol. Therefore, the third recommendation was for research into how FN school administrators could better facilitate their teaching staffs' acquisition of knowledge on invisible disabilities. This component would be essential for drafting, developing, promoting and sustaining a protocol for identifying students with invisible disabilities.

Educational development for teachers. The fourth recommendation involves a revamping of the post-secondary institutions' delivery of education training to future teachers. The information from this study's resource teachers' interviews and classroom teachers' questionnaires strongly suggested that all education faculties need to include courses on invisible disabilities and to mandate those courses as compulsory. These courses should cover the complexities of defining the term invisible disabilities, adversities experienced because of invisible disabilities, complications in identifying students with invisible disabilities and, finally, the intricacies of flexible adaptations and accommodations. Without this knowledge, classroom teachers will remain oblivious to the obstacles hindering students with invisible disabilities from achieving academic success.

Effective practices in FN schools. Until the previous four recommendations come into being, the issue of developing an early identification protocol for FN students with invisible disabilities remains mired in a wasteland of educators' confusion and inconsistencies. Nevertheless, there are some recommended steps that can be taken which would at the very least lessen the daily hardships many FN students with invisible disabilities face. Until such time as a protocol is established, the resource teachers need to take on the leadership role in implementing these initial steps in their schools.

In the leadership role, resource teachers must practice strong advocacy for those students who have been, and have yet to be, identified with invisible disabilities; mentoring classroom teachers on increasing their knowledge regarding invisible disabilities while training them to constantly look for any signs that a student that may have an invisible disability. Acting as an advocate for students has always been an action that resource teachers seem to naturally practice on a regular basis and therefore would not be another new responsibility added to their already

heavy workload. But, mentoring classroom teachers to be watchful for students who might possibly have invisible disabilities, and then implementing adaptations and accommodations (both pre and post formal identification) would add considerably to the numerous demands of the resource teachers. Still, it is important that this takes place and for that reason it is the fifth recommendation of this study.

As part of the leadership role, planning appropriate professional development workshops is essential for: (a) improving awareness and knowledge of invisible disabilities, (b) identifying students with invisible disabilities, and (c) strategies to implement to reduce barriers for students with invisible disabilities. Along with the workshops, information memos can be distributed and discussed on various invisible disabilities, possible characteristics or hints that students have that invisible disabilities and what strategies will best support those students with that invisible disabilities on a regularly basis as part of staff meetings. Further professional development can focus on strategies for working effectively to achieve not only academic, but also social and emotional success with students with invisible disabilities.

Finally, the following four recommendations are for practices that could be considered essential for early the identification of invisible disabilities and need to be incorporated into the schools' protocols. These practices are universal and are applicable to all FN schools and their students. But until FN schools have their own protocols for the early identification of students with invisible disabilities, these practices, at the very least, need to be implemented immediately.

1. Yearly vision screenings for Kindergarten, and Grades 1, 3,5,7,9 and 11 students.
2. Yearly hearing screenings for Kindergarten, and Grades 1,2,4,6,8,10 and 12 students.
3. Yearly Irlen screenings for Kindergarten and Grade 1 students.

4. Yearly phonological skills screenings covering: (a) phonological awareness, (b) phonological memory, and (c) rapid naming for Grade 1 students.

When any one of these physical attributes, vision, hearing, light sensitivity, and phonological skills are not functioning properly in a student, the resulting long term impact on educational success, social acceptance and emotional well-being for that student can be catastrophic. Yet without some outward indication such as a white cane or hearing aid, a classroom teacher would not recognize the invisible disability.

Summary

It is clear in this study that the resource teachers were more conversant on the existence of invisible disabilities, and the struggles students with those invisible disabilities had in trying to achieve academic success, than the classroom teachers. The resource teachers also recognized their own shortfalls in the early identification process for invisible disabilities and expressed the strong need for more appropriate assessments for invisible disabilities along with access to clinicians who were qualified to identify students with invisible disabilities. The classroom teachers seemed to be less knowledgeable about invisible disabilities than the resource teachers.

The data collected and information gleaned from the results of this study confirm that teachers working in First Nations schools have a lack of awareness and knowledge about invisible disabilities. Therefore, the impact on early identification of students with invisible disabilities and the implementations of appropriate supports for those students is negative. Unfortunately, a protocol for early identification of students with invisible disabilities is not likely in the foreseeable future. At least not until all teachers in FN schools have a substantial

increase in their awareness and knowledge of all aspects surrounding invisible disabilities in the educational environment.

To begin the process of developing a protocol for early identification of students with invisible disabilities, FN schools need to establish an educational committee of representatives from all stakeholders: teachers, administration, parents, community members, community agencies representative and, especially, students. The committee should be tasked to create their school's own frame of reference for the terms visible and invisible disabilities in order to build their protocol. Once this has been done, the next step is to draft an overview on tasks and responsibilities. But since this is an enormous undertaking and the scope of it can easily confuse and stall the development progress, the presence of the school's resource teacher on the committee is necessary because of the direct connection the resource teacher has with referred students and INAC's funding guidelines.

Hopefully, every overview would include such basic elements as: (a) regular screenings for vision, hearing, Irlen and phonological awareness, (b) parental questionnaires for student background information, (c) student self-identification check sheets, (d) glossary of invisible disabilities common or most frequent presenting characteristics associated with invisible disabilities. Other elements considered vital in aiding teachers to identify students with invisible disabilities, and to program, adapt or accommodate appropriately for them, would be determined by the FN school's educational committee. One last component crucial to the protocol, is the professional development of teachers which would assist in expanding their awareness and knowledge on invisible disabilities and would expand their bank of teaching strategies to use when working with students who have invisible disabilities.

Based on this study's results, any FN school wanting to develop and initiate a protocol for early identification of students with invisible disabilities is facing a massive undertaking. But the rewards of doing so would be considerable not only for the students but also for their families and communities. Students with invisible disabilities would thrive academically, socially and emotionally. Schools would then truly and fully become inclusive environments for all students.

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Appendix A: Code of Research Ethics

On the following pages is a copy of the Code of Research Ethics that the Manitoba First Nations Education Resource Centre recommends as a template for researchers to adhere to when conducting studies involving First Nations Communities in Manitoba.

Code of Research Ethics

(with permission from Manitoba First Nations Education Resource Centre)

On this day of the month of , in the year of , the Band and Council appointed a Research Committee (community leaders, Elders, educators, and other professionals) to develop a draft of principles and guidelines to protect individual and community data and information, as well as intellectual and cultural knowledge.

All members of the Research Committee share an understanding that research on community issues affects local policy and planning, and it should contribute to the well-being of the community in which research is being conducted. These factors contribute to First Nation control of information and surveillance as tools for effective health planning and advocacy.

The Research Committee members include .

The Research Committee's work resulted in a draft Code of Research Ethics to protect their people's rights and assert the ownership, control, access, and possession principles.

The draft Code of Research Ethics was reviewed and ratified by the Band and Council on .

Researchers are expected to respect and follow the principles and protocols set out in the Code of Research Ethics to ensure the highest standards of research appropriate to the (First Nation).

Research must acknowledge and respect the beliefs, culture, traditions and practices of the (First Nation).

The Code of Research Ethics seeks to ensure that the right of ownership of the community's knowledge and heritage rests with the (First Nation).

The purpose of this code is to establish the framework for principles and procedures that will govern all research and data collection activities involving the (First Nation), whether involving human subjects or not, and all research regarding materials, wherever located, of which the (First Nation) has a claim of intellectual, cultural, or other ownership, legal or equitable.

This code outlines the obligations and responsibilities of each partner in a research project (community, external researchers, and community-based researchers) through all phases including research design, implementation, data collection and analysis, and the dissemination of information.

The (First Nation) has designed this code as a tool to assist in the protection and well-being of its members and the community in research activities, and to facilitate cultural self-determination and preservation.

It is recognized and respected that the right of self-determination of the (First Nation) includes the authority and jurisdiction to make decisions about research in their community. It also assumes ownership, control, access, and possession over information in the course of, and resulting from, research activities.

The community and individual community members should be strengthened by the benefits of the research. Research should assist the community in learning about the well-being of their people, in taking control and management of their information, and in the promotion of ethical practices and effective program planning.

The (First Nation) promotes strengthening the social, cultural, physical, and spiritual well-being of its community and fulfilling its traditional responsibility of caring for its members.

The following guiding principles will be observed throughout the research process:

The (First Nation) recognizes the highest standards of research practice and will ensure the principles of ownership, control, access, and possession (OCAP) be respected.

The (First Nation) must be involved as a full partner in all aspects of the research. Feedback, input, consultation, and participation in the analysis, interpretation, and communications should always characterize the research partnership.

Research should support the transfer of skills to members of the (First Nation) and increase the capacity of the community to manage its own research.

Mutual respect is important for successful partnerships.

All research must respect (First Nation) local laws, regulations, and protocols.

All research partners must show respect for the language, traditions and standards of the (First Nation) on which they seek to conduct research to ensure ethical research practices. All researchers are encouraged to familiarize themselves with the cultures and traditions of local communities.

The research must respect the privacy and dignity of the people in the community.

The (First Nation) authorities must approve data collection in their communities through written permission.

Informed consent must be obtained from each individual and the community participating in the research prior to collecting personal information.

Researchers must provide information about the purpose and nature of the research activities to the individuals and/or community participating in the research. They should also explain the

potential beneficial and harmful effects of the research on individuals, the community, and the environment.

Confidentiality of information must be respected and assured. Participant information will remain anonymous whenever possible when the results are reported.

All data collected belongs to the (First Nation) and must be returned as grouped (aggregate) results.

The First Nation will participate, as much as possible, in fact-finding and data analysis, allowing the community to determine which issues should be addressed and how.

All research results, analysis, and interpretations must be reported to the First Nation to ensure accuracy and avoid misunderstanding.

The strengths, culture, expertise, language, and traditional norms of the community must be respected and drawn upon wherever possible. The incorporation of relevant traditional knowledge into all stages of research is encouraged.

Definitions

Access: First Nations people must have access to information and data about themselves and their communities, regardless of where the information and data are currently held. The principle also refers to the right of First Nations communities and organizations to manage and make decisions regarding access to their collective information.

Community: A community is a population that may share cultural, social, political, health, or economic interests but is not limited to a particular geographic location.

Control: The aspirations and rights of First Nations to maintain and regain control of all aspects of their lives and institutions including research and information. The principle of *control*

declares that First Nations, their communities, and representative bodies are within their rights in seeking to control research and information management processes that affect them. This includes all aspects of research projects such as research policy, resources, review processes, the formulation of conceptual frameworks, and data management.

Ownership: The notion of ownership that refers to the relationship of a First Nation community to its cultural knowledge, data, and information. The principle states that a community or group owns information collectively in the same way that an individual owns his or her personal information. It is distinct from stewardship or possession (see Possession).

Possession: Possession and safekeeping of data also implies guardianship. While *ownership* identifies the relationship between a people and their data in principle, the idea of *possession* or *stewardship* is more literal. Although not a condition of ownership, possession (of data) is a mechanism by which ownership can be asserted and protected. When data owned by one party is in the possession of another, there is a risk of breach or misuse. This is particularly important when trust is lacking between the owner and possessor.

Research institution: A research institution is a recognized institution or organization (academic, government, non-profit), whose primary objective is to undertake research for the purposes of advancing knowledge, facilitating policy-making, or creating strategies and solutions to problems and conditions relevant to the study population.

Research: Research is the use of systematic methods to investigate, gather, and analyze information for the purposes of discovering or interpreting phenomena, proving or disproving a hypothesis, critically evaluating concepts or practices, or otherwise adding to knowledge and insight in a particular discipline or field of knowledge.

Obligations of the Partners

Community Partner

The First Nation community partner has the following obligations:

First and foremost, to represent the interests, perspectives, and concerns of community members and of the community as a whole.

To ensure that research is conducted in accordance with the highest standards, both methodologically and from a First Nations cultural perspective.

To communicate the results of the research to other communities, and to share ideas as well as program and service development for mutual benefit and involvement.

To serve as the guardian of the research data during and/or after completion of the project.

To offer the external and community researchers the opportunity to continue data analyses before the data is offered to new researchers.

Community-Based Researcher

Community-based researchers are people employed within the community.

In addition to the obligations listed for the external research partners, the community researcher is obliged

To provide a link between the research project team and other community members, and provide relevant, timely information on the project.

To place the needs of the community as a first priority in any decision where the community researcher's dual roles of community member and researcher may be in conflict.

In situations where a research project is promoting healthy lifestyles or practices, to promote the intervention objectives of the project by working closely with community health, social, and/or education professionals.

To be stewards of the data until the end of the project if requested or appropriate.

External Research Partner

External researchers usually include consultants, people working at research institutions, or other organizations involved in research (e.g., universities, federal or provincial governments, non-profit organizations, or for-profit companies).

External researchers should strive to

Do no harm to the community.

Ensure active participation by the community in the research process and to promote it as a community-owned activity.

Ensure the research's design, implementation, analysis, interpretation, reporting, publication, and distribution of its results are culturally relevant and in compliance with the standards of competent research.

Undertake research that will contribute something of value to the community.

Ensure that new skills are acquired by community members, such as research design, planning, data collection, storage, analysis, interpretation, and so on.

Be stewards of the data until the end of the project if requested or appropriate.

Promote the dissemination of information to society at large, if desired and appropriate, through both written publications and oral presentations.

Be involved in any future analysis of the data after the data is returned to the community, if requested.

Abide by any local laws, regulations, and protocols in effect in the community or region, and to become familiar with the culture and traditions of the community.

Advocate and address health, social, or other issues that may emerge as a result of the research, as part of their respective roles as researchers and community representatives.

Ensure that the community is fully informed in all parts of the research process including its outcomes through publications and presentations, and to promptly answer questions that may emerge regarding the project and its findings.

Communicate equally with the other partners in all issues arising in the project.

Ensure that research carried out is done in accordance with the highest standards, both methodologically and from a First Nations cultural perspective.

Support the community by providing resources as a matter of priority (e.g., research funding to support community research coordinator).

Abide by their own professional standards, their institution's guidelines for ethical research, and general standards of ethical research.

Operational Procedures

Partnership

Full and Equal Participation: The community, external researchers, and community-based researchers are full and equal partners in all aspects of the research process.

Accountability: The principal investigators representing all partners are fully accountable for all decisions in the research project, including the decisions of subordinates.

Community at Large

Expertise and Knowledge: The strengths, culture, expertise, language, and traditional norms of the community must be respected and drawn upon whenever possible.

Consultations: The research design and data analysis should as much as possible incorporate broad participatory community input in the areas of priorities, interventions, and future directions of the research. A determination of the extent of community consultation should take into account the relevant cultural considerations and the type of research involved.

Capacity Development: Sound participatory research will endeavour to transfer new skills to the community and, where possible, enhance local benefits that may result from research. Meaningful capacity development is reciprocal, since researchers gain invaluable knowledge from the community (e.g., cultural, traditional, and holistic knowledge). Meaningful capacity development involves the transfer of resources to the First Nation for community economic and institutional development.

Confidentiality: The confidentiality of all information received from research participants must be assured. All personal information will be made anonymous whenever possible. Research protocols will be developed and reflected in a research agreement to ensure confidentiality of collected data. In an agreement, if confidentiality cannot be guaranteed, the research participants must be informed of the possible consequences of this factor before becoming involved in the research.

Participants

Voluntary Participation: Participation in any research activity is voluntary for all community members.

Informed Consent: The *informed consent* of participants must be obtained before any research is started. People must not be subjected to undue pressure or influence when approached to participate in the research process.

Full Disclosure: An interactive process should be used to obtain informed consent, where a brief, comprehensive, and reader-friendly written document, that provides contextual information on the problem and the proposed intervention, is accompanied by a verbal explanation from the researcher. The objectives of the research should be stated in the context of the local benefits that are expected to accompany increased knowledge as a result of research. Researchers should clearly identify the sponsors of the research, the source of financial support, and the principal investigators. A description should be provided of any potential harmful effects of the research to people, the community, or the environment.

Withdrawal: An individual participant has the right to withdraw from the research process at any point. If this occurs, all information already collected on the person should be destroyed or returned to the person.

Research Data

Data Collection: The data collection process should be in accord with community values and norms, and competent and ethical research practice.

Ownership: The community or group owns the research information collectively in the same way that a person owns his or her personal information. This is distinct from stewardship or possession.

Data Storage: The storage of raw data acquired in the research project should be negotiated among all partners before the start of the project and renegotiated during the project as priorities

change. There is a preference for local community storage if capacity exists and confidentiality requirements can be met. All grouped data results must be returned to the community free from any personal details.

Analysis: All partners should review research results, analysis, and interpretations for accuracy and appropriateness, and approve these prior to any public release or publication.

Secondary Data: Community secondary data generated through analysis of general population databases (e.g., provincial hospital and physician databases) should be governed by a data-sharing protocol. This protocol between the community and the database steward (e.g., provincial government) embodies the relevant principles of this code. The community should negotiate ownership, control, and access provisions based on the circumstances of the analysis.

Access: First Nations should have access to their data, as reaffirmed by the OCAP principles. However, communities must ensure that the proper protections are in place regarding who has access to the data.

Communications

Research Process: The community at large should have access at all times to descriptions of the research objectives and methods.

Anonymity: Research results will be presented in a grouped manner such that individuals cannot be identified. In some instances, an individual or community may request that their statements be specifically attributed to them. In this case, the wishes of the individual and community should be respected.

Priority of Communications: The community will be the first to receive research results and the first invited to provide input and feedback on the results. The results should be returned in a

format that is language appropriate and accessible to the community. All communications will be respectful of the community and presented in a beneficial, non-harmful manner.

Preparation of Communications: It is part of the shared responsibility of the researchers to prepare communications for the community and society at large. All partners must jointly make guidelines about the publication and distribution of all or parts of the research results. Ideas for specific communications (e.g., articles in scientific journals; oral presentations at meetings; oral or written presentations to community health professionals, Band Council, or community at large; or educational materials) must be initially presented to all research partners and the code's designated representative. All research partners (community researchers, community partners, and external researchers) must approve the final version of the communication before use or submission.

Language: Communications directed to the community, such as research summaries, should be written using accessible, community-friendly language and in an appropriate format. Where required by the community, materials should also be provided in the language of the community.

Research Results: No results or data are released or disseminated without approval from all parties.

“Right to Dissent” on Communications: In the event of a disagreement among the partners regarding a written or oral communication about the research results, the partner who disagrees must be invited to submit their own interpretation of the same data, which will accompany the main communication. All partners agree to not distribute the communication until the alternative interpretation is added, provided that the disagreeing partner(s) does not unduly delay the distribution process. An alternative approach to the issue of disagreement is that best efforts will

be made to reach consensus regarding the interpretation of results for publication. In the event that a reasonable measure of consensus cannot be reached, no publication will be released.

Appendix B: Considerations and Templates for Ethical Research Practices

On the following pages is a copy of Considerations and Templates for Ethical Research Practice that the Manitoba First Nations Education Resource Centre used as a guideline in its development of a template for researchers to adhere to when conducting studies involving First Nations Communities in Manitoba.

Considerations and Templates for Ethical Research Practices

1. Introduction

The introduction identifies the First Nation community or organization, the jurisdiction and types of activities (i.e., research) affected by the Code. It briefly summarizes the obligations and responsibilities of those undertaking research within the jurisdiction. It may be appropriate to identify the formal status of the Code (e.g., date of adoption by a band council resolution).

The introduction also provides background information about the development of the Code, the reason it was developed, who was involved, the underlying principles and intended uses. Any sources (including templates) used in the Code's development should be referenced.

It may identify an individual(s), committee or group to be a representative(s) responsible for the Code as a contact. The representative(s) may also specifically be given responsibility to fully oversee the community based research, including documentation of approved projects.

Sample text:

At the _____ First Nation meeting on _____, the Band and Council appointed a Working Group of community leaders, elders, educators and other professionals to develop a draft of principles and guidelines to protect individual and community data and information, as well as intellectual and cultural knowledge. The Working Group's work resulted in a draft Code of Research Ethics to protect their people's rights and assert the OCAP principles, which is self-determination applied to research.

The draft Code of Research Ethics was reviewed and ratified by the Band and Council on _____. All members of the Working Group share an understanding that research on community issues impacts on local policy and planning, and should contribute to the well-being of the community in which research is being conducted. These factors contribute to First Nation control of information and surveillance as tools for effective health planning and advocacy.

Community-based participatory research acknowledges that there must be respect for the beliefs, culture, traditions and practices of the _____ First Nation. The Code of Research Ethics seeks to ensure that the right of ownership of the community's knowledge and heritage rests with the _____ First Nation. Researchers are expected to respect and follow the principles and protocols set out in the Code of Research Ethics to ensure the highest standards of research appropriate to the _____ First Nation.

The Working Group members include: _____.

2. Purpose

Under this heading, the purpose of the Code is established. This may include information on what the Code will address as well as identifying the objectives of the Code.

Appendix A - Template for a Code of Research Ethics 12 Sample text:

The _____ First Nation has designed this Code as a tool to assist in the protection and wellbeing of its members and the community in research activities, and to facilitate cultural self-determination and preservation.

The purpose of this Code is to establish the framework for principles and procedures that will govern all research and data collection activities involving the _____ First Nation, whether involving human subjects or not, and all research regarding materials, wherever located, of which the _____ First Nation has a claim of intellectual, cultural, or other ownership, legal or equitable.

This Code outlines the obligations and responsibilities of each partner in a research project (community, external researchers and community-based researchers) through all phases including research design, implementation, data collection and analysis, and the dissemination of information.

3. Policy Statement

The policy statement identifies the rationale for the Code and the research policy goals it pursues. These can include community and individual benefit, community empowerment through capacity development (research expertise), cultural development and preservation, and other community interests. It also serves to inform the public of the community's policies for the regulation of research. It should reflect the attitudes, beliefs, values, principles and cultural traditions of the First Nation towards research. The principles of OCAP or self-determination in the area of research may be key concepts in the policy statement.

Sample text:

It is recognized and respected that the right of self-determination of the _____ First Nation includes the authority and jurisdiction to make decisions about research in their community, and also to assume ownership, control, access and possession over information in the course of, and resulting from, research activities. The community and individual community members should be strengthened by the benefits of the research. Research should facilitate the community in learning about health and the well-being of their people, in taking control and management of their information, and in assisting in the promotion of healthy lifestyles, practices and effective program planning. The _____ First Nation promotes strengthening the social, cultural, physical and spiritual well-being of its community and fulfilling its traditional responsibility of caring for its members.

4. Guiding Principles

The guiding principles encompass the fundamental values. They express the standards, rights and values of the First Nation with respect to research activities. They should reflect the aspirations of the community and can help to create awareness among researchers and community members. Researchers must observe and be respectful of the guiding principles set

out in the Code throughout all processes of research. The principles can be used to help contextualize, or if necessary, interpret other sections of the Code. The principles provided in the template are general in nature and, as with other sections, will likely need to be revised to reflect local realities and perspectives.

Sample text:

a) The _____ First Nation recognizes the highest standards of research practice and will ensure the principles of OCAP (Ownership, Control, Access, and Possession) will be respected. OCAP is self-determination applied to research.

Ownership: The notion of ownership refers to the relationship of a First Nations community to its cultural knowledge/data/information. The principle states that a community or group owns information collectively in the same way that an individual owns his or her personal information. It is distinct from stewardship or possession (see Possession).

Control: The aspirations and rights of First Nations to maintain and regain control of all aspects of their lives and institutions include research and information. The principle of “control” asserts that First Nations, their communities and representative bodies are within their rights in seeking to control research and information management processes that impact them. This includes all stages of research projects, and more broadly, research policy, resources, review processes, the formulation of conceptual frameworks, data management and so on.

Access: First Nations people must have access to information and data about themselves and their communities, regardless of where these are currently held. The principle also refers to the right of First Nations communities and organizations to manage and make decisions regarding access to their collective information.

Possession: While “ownership” identifies the relationship between a people and their data in principle, the idea of “possession” or “stewardship” is more literal. Although not a condition of ownership, possession (of data) is a mechanism by which ownership can be asserted and protected. When data owned by one party are in the possession of another, there is a risk of breach or misuse. This is particularly important when trust is lacking between the owner and possessor.

b) The _____ First Nation must be involved as a full partner in all aspects of the research. Feedback, input, consultation and participation in the analysis, interpretation and communications should always characterize the research partnership.

c) Research should support the transfer of skills to members of the _____ First Nation and increase the capacity of the community to manage its own research.

d) Mutual respect is important for successful partnerships.

e) All must respect _____ First Nation local community laws, regulations and protocols.

- f) All research partners must show respect for the language, traditions and standards of the _____ First Nation on which they seek to conduct research to ensure ethical research practices. All researchers are encouraged to familiarize themselves with the cultures and traditions of local communities.
- g) The research must respect the privacy and dignity of the people in the community.
- h) The _____ First Nation authorities must approve data collection in their communities through written permission.
- i) Informed consent must be obtained from each individual and the community participating in the research prior to collecting personal information.
- j) Researchers must provide information about the purpose and nature of the research activities to the individuals and/or community participating in the research. They should also explain the potential beneficial and harmful effects of the research on individuals, the community and the environment.
- k) Confidentiality of information must be respected and assured. Participant information will remain anonymous whenever possible when the results are reported.
- l) All data collected belongs to the _____ First Nation and must be returned as grouped (aggregate or de-identified) results.
- m) The First Nation will participate, as much as possible, in fact-finding and data analysis, allowing the community to determine which issues should be addressed and how.
- n) All research results, analysis and interpretations must be reported to the First Nation to ensure accuracy and avoid misunderstanding.
- o) The strengths, culture, expertise, language and traditional norms of the community must be respected and drawn upon wherever possible. The incorporation of relevant traditional knowledge into all stages of research is encouraged.

5. Definitions

Definitions are useful in clarifying the meaning of certain terms to avoid any misunderstanding.

Sample text:

Community: A community is a population that may share “cultural, social, political, health, or economic interests”, but is not limited to a particular geographic location.

Research: Research is the use of systematic methods to investigate, gather and analyze information for the purposes of discovering or interpreting facts, proving or disproving a

hypothesis, evaluating concepts or practices, or otherwise adding to knowledge and insight in a particular discipline or field of knowledge.

Research methods that are commonly used at the community level include: surveys (phone or mail), needs assessments and public opinion polls; interviews; focus groups or talking circles (informal discussions with a group of experts in a particular discipline or field); and case studies (re-examining existing information).

Research institution: A research institution is a recognized institution or organization (academic, government, non-profit), whose primary objective is to undertake research for the purposes of advancing knowledge, facilitating policy-making, or creating strategies and solutions to problems and conditions relevant to the study population.

6. Obligations of the Partners

In this section, the obligations of the partners are established. The template uses the typical example of three partners (community, community-based researchers and external researchers) but may be adapted to reflect other situations. The First Nation or organization would be the community partner. Community based researchers are individuals employed within the community. They can also be referred to as co-investigators. External researchers typically include consultants and people working at research institutions or other organizations involved in research (e.g., universities, federal or provincial governments, health authorities, non-profit organizations and for-profit companies).

The template is general in terms of content. It may be useful to add more precise and detailed obligations for specific projects (e.g., training, hiring and reporting or accountability requirements). These may be incorporated into the Code itself or other documents related to the project.

Sample text:

External Research Partner

- To do no harm to the community.
- To involve the community in active participation of the research process and to promote it as a community-owned activity.
- To ensure the research's design, implementation, analysis, interpretation, reporting, publication and distribution of its results are culturally relevant and in compliance with the standards of competent research.
- To undertake research that will contribute something of value to the community.
- To ensure that new skills are acquired by community members, such as research design, planning, data collection, storage, analysis, interpretation and so on.

- To be stewards of the data until the end of the project if requested or appropriate.
- To promote the dissemination of information to society at large if desired and appropriate through both written publications and oral presentations.
- To be involved in any future analysis of the data after the data is returned to the community, if requested.
- To abide by any local laws, regulations and protocols in effect in the community or region, and to become familiar with the culture and traditions of the community.
- Within their respective roles as researchers and community representatives, to advocate and address health, social or other issues that may emerge as a result of the research.
- To ensure that the community is fully informed in all parts of the research process including its out- comes through publications and presentations, and to promptly answer questions that may emerge regarding the project and its findings.
- To communicate equally with the other partners in all issues arising in the project.
- To ensure that research carried out is done in accordance with the highest standards, both methodologically and from a First Nations cultural perspective.
- To support the community by providing resources as a matter of priority (e.g., research funding to support community research coordinator).
- To abide by their own professional standards, their institution's guidelines for ethical research and general standards of ethical research.

Community-Based Researcher

In addition to the obligations listed for the external research partners, the community researcher is obligated:

- To provide a link between the research project team and other community members, and provide relevant, timely information on the project.
- To place the needs of the community as a first priority in any decision where the community researcher's dual roles of community member and researcher may be in conflict.
- In situations where a research project is promoting healthy lifestyles or practices, to promote the intervention objectives of the project by working closely with community health, social and/or education professionals.
- To be stewards of the data until the end of the project if requested or appropriate.

Community Partner

- First and foremost, to represent the interests, perspectives and concerns of community members and of the community as a whole.
- To ensure that research carried out is done in accordance with the highest standards, both methodologically and from a First Nations cultural perspective.
- To communicate the results of the research to other communities, and to share ideas as well as program and service development for mutual benefit and involvement.
- To serve as the guardian of the research data during and/or after completion of the project.
- To offer the external and community researchers the opportunity to continue data analyses before the data are offered to new researchers.

7. Operational Procedures

This section further lays out the roles of the partners and establishes ground rules and formal expectations in all aspects of the research process. The community should consider creating an addendum to the Code or an agreement with specific researchers for specific projects to address issues such as the selection of a data storage site, determination of target audiences for reports, data analysis procedures, publication of results, a communications strategy and release policies, authorship on publications and activities to improve community capacity in research.

Sample text:

Partnership

Full and Equal Participation: The community, external researchers and community-based researchers are full and equal partners in all aspects of the research process.

Accountability: The Principal Investigators representing all partners are fully accountable for all decisions in the research project, including the decisions of subordinates.

Community at Large

Expertise and Knowledge: The strengths, culture, expertise, language and traditional norms of the community must be respected and drawn upon whenever possible.

Consultations: The research design and data analysis should as much as possible incorporate broad participatory community input in the areas of priorities, interventions and future directions of the research. A determination of the extent of community consultation should take into account the relevant cultural considerations and the type of research involved.

Capacity Development

Sound participatory research will endeavour to transfer new skills to the community and, where possible, enhance local benefits that may result from research. Meaningful capacity development is reciprocal, since researchers gain invaluable knowledge from the community (e.g., cultural, traditional and holistic knowledge). Meaningful capacity development involves the transfer of resources to the First Nation for community economic and institutional development.

Confidentiality

The confidentiality of all information received from research participants must be assured. All personal information provided by individuals will be made anonymous whenever possible. Research protocols will be developed and reflected in a research agreement to ensure confidentiality of collected data. In an agreement, if confidentiality cannot be guaranteed, the research participants must be informed of the possible consequences of this before becoming involved in the research.

Participants

Voluntary Participation: Participation in any research activity is voluntary for all community members.

Expressed Informed Consent: The informed consent of participants providing information to the research project must be obtained prior to the use of any information- gathering technique. Individuals must not be subjected to undue pressure or influence when approached to participate in the research process.

Full Disclosure: An interactive process should be used to obtain informed consent, whereby a brief, comprehensive and reader-friendly written document, which provides contextual information on the problem and the proposed intervention, is accompanied by a verbal explanation from the researcher. The objectives of the research should be stated in the context of the local benefits that are expected to accompany increased knowledge as a result of research. Researchers should clearly identify the sponsors of the research, the source of financial support and the principal investigators. A description should be provided of any potential harmful effects of the research to individuals, the community or the environment.

Withdrawal: An individual participant has the right to withdraw from the research process at any point. If this occurs, all information already collected on the individual should be destroyed or returned to the individual.

Research Data

Data Collection: The data collection process should be in accord with community values and norms, and competent and ethical research practice.

Ownership: The community or group owns the research information collectively in the same way that an individual owns his or her personal information. This is distinct from stewardship or possession.

Data Storage: The storage of raw data acquired in the research project should be negotiated among all partners before the commencement of the project and renegotiated during the project as priorities change. There is a preference for local community storage if capacity exists and confidentiality requirements can be met. All de-identified grouped data results must be returned to the community.

Analysis: All partners should review research results, analysis and interpretations for accuracy and appropriateness, and approve these prior to any public release or publication.

Secondary Data: Community secondary data generated through analysis of general population databases (e.g., provincial hospital and physician databases) should be governed by a data-sharing protocol. This protocol between the community and the database steward (e.g., provincial government) embodies the relevant principles of this Code. The community should negotiate ownership, control and access provisions based on the circumstances of the analysis.

Access: First Nations should have access to their data, as reaffirmed by the OCAP principles. However, communities must ensure that the proper protections are in place regarding who has access to the data.

Communications

Research Process: The community at large should have access at all times to descriptions of the research objectives and methods.

Anonymity: Research results will be presented in a grouped manner such that individuals cannot be identified. In some instances, an individual or community may request that their statements be specifically attributed to them. In this case, the wishes of the individual and community should be respected.

Priority of Communications: The community will be the first to receive research results and the first invited to provide input and feedback on the results. The results should be returned in a format that is language appropriate and accessible to the community. All communications will be respectful of the community and presented in a beneficial, non-harmful manner.

Preparation of Communications: It is part of the shared responsibility of the researchers to prepare communications for the community and society at large. All partners must jointly make guidelines about the publication and distribution of all or parts of the research results. Ideas for specific communications (articles in scientific journals; oral presentations at meetings; oral or written presentations to community health professionals, band council, or community at large; or educational materials) must be initially presented to all research partners and the Code's designated representative. All research partners (community researchers, community partner and external researchers) must approve the final version of the communication before use or submission.

Language: Communications directed to the community, such as research summaries, should be written using accessible, community-friendly language and in an appropriate format. Where required by the community, materials should also be provided in the language of the community.

Research Results: No results or data are released or disseminated without approval from all parties.

“Right to Dissent” on Communications: In the event of a disagreement among the partners regarding a written or oral communication about the research results, the partner who disagrees must be invited to submit their own interpretation of the same data, which will accompany the main communication. All partners agree to not distribute the communication until the alternative interpretation is added, provided that the disagreeing partner(s) does not unduly delay the distribution process. An alternative approach to the issue of disagreement is this: best efforts will be made to reach consensus regarding the interpretation of results for publication. In the event that a reasonable measure of consensus cannot be reached, no publication will be released.

8. Evaluation of New Research Applications

Communities may wish to develop processes for the handling and evaluation of external applications for research that may be received without solicitation. This process can be tailored to the specifics of each community, and should consider:

- *establishing a mechanism to make the community’s Code of Research Ethics available to interested research partners;*
- *setting up a screening body that can conduct a preliminary evaluation of the research proposal prior to a wider community consultation or committee review. Some First Nation organizations, such as the FNC (www.naho.ca/fnc), may provide advice or information support;*
- *developing a list of written requirements or a standardized form(s) to be completed by the researchers submitting the proposal. The form could require the following types of information presented in plain language: names, titles, affiliations, contact information and credentials of researchers, a summary description of the proposed research in plain language, proposed funding sources, a time frame for the project and reporting of results, and expected outcomes, including the benefits to the community and contributions to the advancement of knowledge in the subject area;*
- *if appropriate, arranging a meeting between the researchers and the screening body to present the proposal verbally;*
- *establishing a series of considerations or a formal review or scoring tool to aid in the evaluation of the proposal;*
- *setting a time period for the screening body (e.g., ____days) to make a decision and the method of decision (consensus, majority vote);*

- *devising an appropriate method to seek wider community consultation if a proposal is approved by the screening committee;*
- *establishing a time frame to provide the final decision to the researcher as a result of the community consultation; and,*
- developing a process for identifying any specific conditions the community has for participation (e.g., changes to the protocol, resources for a local coordinator, local steering committee), and negotiating these as needed.

i Adapted from: Mi'kmaq College Institute, Mi'kmaq Ethics Watch: Principles and Guidelines for Researchers conducting Research With and/or Among Mi'kmaq People (Antigonish, Nova Scotia, 1999) p.1 and; First Nations Regional Longitudinal Health Survey, First Nations Centre, First Nations Regional Longitudinal Health Survey (RHS) Code of Ethics (Ottawa: National Aboriginal Health Organization, 2004). ii First Nations Regional Longitudinal Health Survey, First Nations Centre, First Nations Regional Longitudinal Health Survey (RHS) Code of Ethics, p.3. iii Adapted from: Association of Canadian Universities for Northern Studies, Ethical Principles for the Conduct of Research in the North (Ottawa: Author, 2003), p. 5; Kahnawá:ke Schools Diabetes Prevention Project, KSDPP Code of Research Ethics; First Nations Centre, First Nations Regional Longitudinal Health Survey (RHS) Code of Ethics, pp. 3-4 and; Mi'kmaq College Institute, Mi'kmaq Ethics Watch: Principles and Guidelines for Researchers Conducting Research With and/or Among Mi'kmaq People, p.3. iv World Health Organization, Indigenous Peoples and Participatory Health Research: Planning and Management - Preparing Research Agreements (www.who.int/ethics/indigenous_peoples/en/print.html).

Template for a Collaborative Agreement

Project title _____

THIS COLLABORATIVE RESEARCH AGREEMENT is made this ____ day of ____, 2006.

BETWEEN:

Principal Researchers(s)

Name(s): _____

Supporting Agency _____

Address: _____

Telephone: _____

Facsimile: _____

Email: _____

AND

_____ First Nation Community

Contact person(s): _____

Organization: _____

Address: _____

Telephone: _____

Facsimile: _____

Email: _____

The principal researchers, as named, and the _____ First Nation agree to conduct the named collaborative research project in accordance with the guidelines and conditions described in this document.

1. Purpose of the Research Project

This section should describe the general topic that is being researched, and also the purpose of doing the research (e.g. to increase awareness/understanding, enhance well-being, improve programs, etc.). A statement of purpose is usually fairly brief (2-5 sentences) and not too specific.

Sample text:

The purpose of this research project, as discussed with and understood by the _____ First Nation in the community of _____, is to investigate _____.

The results of this research may be used to _____.

2. Scope of the Project

This section provides a more specific and detailed description of the project. It should cover the following areas: • Specific research objectives or question(s); • Types of information that will be gathered (e.g. statistics, interviews, etc.);

Sample text:

The project has the following objectives and/or aims to answer the following questions: _____.

In order to meet the objectives or answer the questions stated above, the following types of information will be gathered: _____.

3. Methods and Procedures

This section describes how research data will be gathered, recorded, analyzed and reported. Issues that should be addressed in this section are listed below. Involvement of First Nation community members in the project is addressed in this section, but a separate section could be created to deal with that issue since it is usually an important consideration for communities.

- *Research (or data-gathering) methods; depending on the nature of the project, these might include: collecting information/statistics from databases; collecting environmental samples; conducting surveys, interviews or focus groups;*
- *The extent or amount of data to be obtained should be specified (e.g. statistical variables, number of interviews/surveys, number of samples, etc.) and explained;*
- *The role of community members in the research (or data-gathering) phase (as participants in inter- views, etc. and/or as paid researchers, fieldworkers or guides);*
- *Procedures for obtaining consent (individual or collective) must be described in detail; • Methods to be used for recording and storing data;*
- *Procedures for ensuring confidentiality and security of data; • Methods of analysis or interpretation of data to generate findings and conclusions;*
- *Opportunity for community members or community researchers to participate in data analysis, or to verify the results of the analysis;*
- *Preparation of the final report; will community members have an opportunity to revise and approve it before it is finalized?*
- *Format for presenting findings to the general public and the community (e.g. article, final report, presentation, etc.)*

Sample text:

Data will be gathered using the following methods or procedures: _____

The amount of data that is required for this project is _____

This number/amount is required because _____

Community members will assist or participate with the data-gathering phase in the following ways: _____

Individual consent to participate in the project will be obtained in the following way: _____

Participants have the right to withdraw from the project at any time for any reason. In this case, that participant's data will be destroyed.

Research data will be stored in the following ways: _____

The following persons will have access to research data: _____

Confidentiality of research data (if desired) will be ensured in the following ways: _____

Data will be analyzed or interpreted through the following methods: _____

Community researchers/participants will participate in the analysis of data, or the verification of results, in the following ways:

The final research report will be submitted to the community for review and approval.

Research findings will be presented to the community in a language and format that is clear and comprehensible to community members.

Research findings will be presented to the community in the following formats:

Research findings will be presented to the general public and/or any other audience in the following formats:

4. Expected Outcomes, Benefits and Risks

This section sets out the expected outcomes and benefits of the research project. It is important to be clear and honest about expected benefits for both the researchers and the community. Benefits for the principal researchers may include financial gain (from publication, etc.) or indirect financial benefit through enhancement of professional status (to an individual or research institution). Benefits to the community may include the generation of information that will support future funding applications or that will enhance community programs/services; education and/or training for community members; or direct financial compensation to community researchers and/or participants.

Risks to the community as a result of the project should also be considered, as should any measure that could be taken to minimize those risks. These may include: environmental impacts; invasion of personal or collective privacy; portrayal of the community in a negative way and; disruption of other important community projects or issues.

Sample text:

The expected outcomes of this research project are:

The project will benefit the principal (external) researchers in the following ways:

The project will benefit the community (individually or collectively) in the following ways:

The project poses the following risks to the community:

Measures that will be taken to minimize these risks are:

5. Obligations and Responsibilities

This section is not specific to a particular research project. It describes general obligations and responsibilities of each partner (community, external researchers and community-based researchers) in a community-based research project through all phases including research design, implementation, data collection and analysis and the dissemination of information.

External Research Partner

- To do no harm to the community.
- To involve the community in active participation of the research process and to promote it as a community-owned activity.
- To ensure the research's design, implementation, analysis, interpretation, reporting, publication and distribution of its results are culturally relevant and in compliance with the standards of competent research.
- To undertake research that will contribute something of value to the community.
- To ensure that new skills are acquired by community members, such as research design, planning, data collection, storage, analysis, interpretation and so on.
- To be stewards of the data until the end of the project if requested or appropriate.
- To promote the dissemination of information to society at large if desired and appropriate through both written publications and oral presentations.
- To be involved in any future analysis of the data after the data is returned to the community, if requested.
- To abide by any local laws, regulations and protocols in effect in the community or region, and to become familiar with the culture and traditions of the community.

- Within their respective roles as researchers and community representatives, to advocate and address health, social or other issues that may emerge as a result of the research.
- To ensure that the community is fully informed in all parts of the research process, including its out- comes through publications and presentations, and to promptly answer questions that may emerge regarding the project and its findings.
- To communicate equally with the other partners in all issues arising in the project.
- To ensure that research carried out is done in accordance with the highest standards, both methodologically and from a First Nations cultural perspective.
- To support the community by providing resources as a matter of priority (e.g., research funding to support community research coordinator).
- To abide by their own professional standards, their institution's guidelines for ethical research and general standards of ethical research.

Community-Based Researcher

In addition to the obligations listed for the external research partners, the community researcher is obligated:

- To provide a link between the research project team and other community members, and provide relevant, timely information on the project.
- To place the needs of the community as a first priority in any decision where the community researcher's dual roles of community member and researcher may be in conflict.
- In situations where a research project is promoting healthy lifestyles or practices, to promote the intervention objectives of the project by working closely with community health, social and/or education professionals.
- To be stewards of the data until the end of the project if requested or appropriate.

Community Partner

- First and foremost, to represent the interests, perspectives and concerns of community members and of the community as a whole.
- To ensure that research carried out is done in accordance with the highest standards, both methodologically and from a First Nations cultural perspective.
- To communicate the results of the research to other communities, and to share ideas as well as program and service development for mutual benefit and involvement.
- To serve as the guardian of the research data during and/or after completion of the project.

- To offer the external and community researchers the opportunity to continue data analyses before the data are offered to new researchers.

6, Funding

This section identifies funding sources and sets out the responsibilities of all partners with respect to funding requirements.

Sample text:

The principal researchers have acquired funding and other forms of support for this research project from these sources:

The funding agencies have imposed the following criteria, disclosures, limitations and reporting responsibilities on the principal researchers:

The community partner has the following responsibilities with respect to funding requirements*:

*In most cases, responsibility to fulfill funding and reporting requirements falls primarily to the principal researchers, so this may not be applicable.

7. Dissemination of Results

This section should identify all the stakeholders (e.g. communities, the academic sector, funding bodies, professional bodies, government departments, etc.), to which research results will be disseminated. The methods for dissemination should also be described.

You may want to consider the degree of control that the community has over future publication or dissemination of research results.

Sample text:

Research results will be disseminated to the following stakeholders: _____

Research results will be disseminated in the following manner: _____

Any future publication or dissemination of research results, beyond what is described in this agreement, shall not be undertaken without consultation with the _____ First Nation community.

8. Data Ownership and Intellectual Property Rights

The data gathered or produced through the research project is distinct from the research results. The First Nation community should clearly affirm ownership of its data, as well as any

associated intellectual property rights. Conditions of data stewardship and use of data after completion of the research project should be considered by the community, but do not need to be specified in the research agreement since this is an internal protocol to be determined at the community's discretion.

Sample text:

The individual owns his or her personal information while the _____ First Nation owns the collective data.

The _____ First Nation retains all intellectual property rights (including copyright), as applicable, to the data offered under this agreement.

Access and stewardship of the collective data are negotiated and determined by the First Nation.

9. Communication

Guidelines for internal and external communication should be established in this section. 'Internal communication' means communication between research partners names in this agreement, while 'external communication' refers to communication about the project to other interested parties such as the media.

Sample text:

Communication on all aspects of the research, including progress reports to the community, will be ensured in the following ways: _____

In the case of media inquiries during or after the project, designated spokespersons are:

The community will be the first to receive research results and the first invited to provide input and feedback on the results. The results should be presented in a format that is language appropriate and accessible to the community. Results will not be released without the approval of the community.

At the end of the study, the research partners agree to participate in community meetings to discuss the results and their implications.

10. Dispute Resolution

This section sets out the process for addressing concerns or resolving disputes related to the implementation, interpretation or release of research data and/or findings.

Sample text:

In the event that a dispute arises out of or relates to this research project, both parties agree first to try in good faith to settle the dispute by mediation administered by an agreed upon neutral party before resorting to arbitration, litigation or some other dispute resolution procedure. A mediator will assist the parties in finding a resolution that is mutually acceptable.

If a dispute cannot be resolved to the satisfaction of both parties, the research project may be terminated according to the terms described below.

11. Term and Termination

This section notes the duration of the project and sets out the course of action to be followed if either party to the agreement wishes to terminate the research project.

Sample text:

This agreement shall have an effective date of _____ and shall terminate on _____.

This agreement may be terminated by the written notification of either party.

i Adapted from: World Health Organization, Indigenous peoples and participatory health research: Preparing research agreements, Annex B: Example of a research agreement concluded between CINE and an indigenous community in Canada (www.who.int/ethics/indigenous_peoples/en/print.html) and; Masuzumi, B., and Quirk, S, Dene Tracking. A participatory research process for Dene/Métis communities: Exploring community-based research concerns for Aboriginal northerners (Yellowknife, NT: Dene Nation, 1993) p. 14-16.

Template for a Data-Sharing Protocol

THIS DATA-SHARING PROTOCOL is made this _____ day of _____, 2006.

BETWEEN:

_____ (First Nation community or organization)

AND

_____ (Research partner(s) or organization)

1.Introduction

In general, the introduction provides some background information leading to the development of the Data-Sharing Protocol. What is the purpose of the Data-Sharing Protocol and why is it necessary? The introduction should identify the parties to the agreement, their names, titles, contact information and the names of their organizations. It may also include relevant policy statements, a mission statement, or guiding principles.

Sample text:

The _____ First Nation promotes meaningful partnerships through working in collaboration with the _____ (research partner(s) or organization).

The _____ First Nation has agreed to enter into an agreement whereby the _____ (research partner(s) or organization) is authorized to use the _____ data (record level or aggregate data) from the _____ (name of past research conducted), as set out in this Agreement. This Data-Sharing Protocol will maintain the values, principles and protect the rights of the First Nation. This Protocol should not be used for any other purpose.

2. Definitions

Relevant definitions may be included in this agreement for clarification of certain terms.

Sample text:

Information sharing:

The exchanging, collecting, using or disclosing of personal information by one organization with another organization for certain purposes, including First Nations, government bodies, educational institutions, non-profit organizations, etc. The sharing may be carried out using any transmission method and may take place over any time period.

Data linkage or data profiling:

This is a computerized use of personal data obtained from a variety of sources, including personal information banks, to merge and compare files on identifiable individuals or categories of individuals for administrative purposes. This linkage or profiling generates a new body of personal information. These pages can be photocopied to be shared or re-used as necessary.

Appendix C - Template for a Data-sharing Protocol

Personal information:

Recorded data or information that is related to an identifiable individual. Record level data: Information that is specific to an individual or group of individuals, whether or not the person is identifiable by name.

Aggregate data:

Aggregate data includes data collected from several sources that do not reveal the identity of any individual. It is collective data meant for developing statistics or for planning based upon that data (e.g., combining demographic data about clients from all primary care providers in a service area generates aggregate data about client characteristics).

3. Purpose

The purpose and reason for the data-sharing agreement should be identified. If individual data records are being shared, the applicable federal, provincial and territorial legislation regulating the use and release of individual client information should be specified (e.g., freedom of

information and protection of privacy acts, health information acts or other community protocols, such as a Code of Research Ethics or Privacy Code). The purpose of the data-sharing arrangement must be understood and formally agreed to by those entering into it.

Sample text:

The purpose of this Data-Sharing Protocol is to:

- a) summarize the conditions and arrangements for data or information collection and sharing;
- b) set out the fundamental principles and obligations that organizations must adhere to when they collect, use, store and disclose personal information about members of the First Nation;
- c) describe why data or information is being shared, how and when data will be collected and shared, and by whom;
- d) protect individual and community interests, information and privacy;
- e) maintain appropriate standards and prevent misunderstandings over responsibilities; and,
- f) clarify issues of data ownership, control and access, intellectual property, aggregate data, confidentiality, use of information and further disclosure.

This Protocol provides a framework for the use of data that supports First Nations principles of OCAP in relation to research, and supports the data needs and capacity of the _____ First Nation and the _____ (research partner(s) or organization), with respect to the use of information for planning, advocacy, and determining community priorities and trends.

Ownership: Refers to the relationship of First Nations to their cultural knowledge/data/information. The principle states that a community or group owns information collectively in the same way that an individual owns his or her personal information.

Control: The principle of “control” asserts that First Nations people, their communities and representative bodies are within their rights in seeking to control all aspects of research and information management processes that impact them. First Nations control of research can include all stages of a particular research project from conception to completion. The principle extends to the control of resources and review processes, the formulation of conceptual frameworks, data management and so on.

Access: First Nations people must have access to information and data about themselves and their communities, regardless of where it is currently held. The principle also refers to the right of First Nations communities and organizations to manage and make decisions regarding access to their collective information. This may be achieved in practice through standardized, formal protocols.

Possession: While “ownership” identifies the relationship between a people and their data in principle, possession or stewardship is more literal. It refers to the physical control of data. Although not a condition of ownership per se, possession is a mechanism by which ownership can be asserted and protected.

4. Information to be Shared

Within the protocol, it is important to describe in detail the data to be shared.

Sample text:

[Record level or aggregate] data from the _____ First Nation will be shared for the purposes of this agreement.

The data to be shared consists of

_____.

5. Use of Data or Information

The agreement should clearly identify how the data or information shared under the arrangement will be used. For what purpose(s) are the data going to be used? It may state that the data will only be used for the stated purpose(s) and may not be used for any other purposes (further disclosure), without the explicit written approval, in advance, of the First Nation. The research partner(s) may not release the data for any purpose, unless agreed to in advance by all parties, and provided it is not in violation of provincial, territorial or federal legislation.

Sample text:

The research partner(s) will use the data for the purposes of

The research partner(s) will only use the data for the stated purpose(s) and the data may not be used for any other purposes (further disclosure) without the explicit written approval, in advance, of the _____ First Nation. The research partner(s) may not release the data for any purpose unless agreed to in advance by all parties, and provided it is not in violation of provincial, territorial or federal legislation.

6. Mechanism for Information-Sharing

The methods of data-sharing need to be identified. Some mechanisms for sharing include electronic transfer over a secure network or electronic transfer through password-protected external disks.

Sample text:

The data-sharing will involve electronic transfer over a secure network. Data matching and linkage will be used. (Note: this is only an example; your community may use a different mechanism for sharing.)

7. Data Ownership

The agreement should address control and access to data by the requesting party. The requesting party may be deemed custodians or stewards of the data under the conditions defined in the agreement and, depending upon the specifics of the project, may receive either individual records or aggregate data. Users may be expressly prohibited from use of the data in the pursuit of any commercial or income-generating venture, either publicly or privately.

Sample text:

The _____ First Nation owns the collective data. Access and stewardship are negotiated and determined by the First Nation.

8. Publication and Dissemination

Depending upon what kind of information you have allowed the research partner(s) to access, you may decide to specify that you are a co-author or a partner in the research project, particularly if the information is very sensitive. This may allow you to shepherd the information and retain some rights to the publication without sacrificing the integrity of the research results.

Sample text:

The research partner(s) will not release data received as part of this agreement to other local or research institutions or organizations without express written agreement from the _____ First Nation. Other interested research institutions or organizations shall contact the First Nation directly.

9. Data Security and Confidentiality

The data steward must maintain confidentiality and protect the data in a manner consistent with clearly defined principles, and according to formal and rigorous data protection standards and methods. The data steward will be responsible for upholding the principles, standards and methods. Custodians of data with personal identifiers must agree and take all steps necessary to ensure its privacy and security as described in relevant freedom of information and privacy acts, health information acts, or other legislation as well as their institution's protocols and community protocols, where applicable. If either party deems security and confidentiality inadequate, the stewardship should be revoked in favour of a more secure steward or destruction of the data.

Integrity and security of the data must be maintained by instituting regulatory controls, such as ensuring that only authorized users have access to the data and that electronic systems are properly maintained and managed.

Sample text:

All employees, agents and representatives of the _____ First Nation and the research partner(s) who will come in contact with data must take an Oath of Secrecy by completing and signing the standardized form. The First Nation shall record and document the names of all persons who have taken the oath and the date the oath was taken.

The following is an example of an Oath of Secrecy.

I _____, do solemnly swear (or affirm) that I will faithfully and honestly fulfill my duties as an employee/contractor of the _____ in relation to its participation in the _____ research study. I swear (or affirm) that I will protect the privacy of individual respondents, communities and First Nations collectively, and maintain the confidentiality of all research data and related information pursuant to the policies, rules, regulations and instructions provided to me by _____ and the _____ First Nation. I will respect the _____ First Nation Code of Research Ethics and the provisions of the protection agreement. I will not, without due legal authority, disclose or make known any matter or thing that comes to my knowledge by reason of my work on the _____ research study. I will not release data or statistical outputs without appropriate authorization from regional authorities.

I understand that maintaining confidentiality is critical to the credibility of the research and of the organizations taking part in the research, and that a breach of confidentiality may result, among other things, in the immediate termination of my contract and legal action against me for damages.

The _____ First Nation and the research partner(s) will each provide, for their own offices, all necessary equipment, supplies and policies to ensure the confidentiality of the survey data, including but not limited to:

- a lockable storage room and lockable filing cabinet; • password protection for computers containing confidential data or information;
- controlled and restricted access, by lock and/or computer password, of all data or information, either hard copy or electronic; and,
- a firewall or similar software or hardware to protect the data or information that is stored on a computer that has access, directly or indirectly, to the Internet or any other type of data-sharing networks.

The _____ First Nation and the research partner(s) will ensure that at all times the data or information is either directly supervised by one of its employees or agents, or that it is safely locked in a secure cabinet.

10. Retention and Disposal of Information

The agreement should specify how long the shared data are kept or stored. Also, terms should be identified regarding the disposal of the data once the agreement has expired or been revoked. The data may be returned to the source or destroyed by the recipient, either physically or electronically.

Sample text:

The _____ (research partner(s)) will store and maintain the data in a manner that ensures its use remains consistent with the terms and conditions of this agreement. Upon expiration or revocation of this agreement, the _____ (research partner(s)) will immediately and permanently remove and destroy all copies, both physically and electronically, of the data provided under this agreement in accordance with relevant laws and policies (e.g., band bylaws and policies or government laws).

11. Intellectual Property

Although this may not be consistent with some First Nations perspectives, intellectual property arising from research in Canada is normally vested in the organization(s) that conducts the research. As a result, in situations where data is provided to an organization that may conduct further research, it may be important to specify in an agreement that the First Nation retains all intellectual property rights (including copyright), as applicable, to the data offered under this agreement, and this agreement constitutes only a license to acquire and use these data products. Furthermore, it may be specified that no title or rights be conveyed by this agreement.

Sample text:

The _____ First Nation retains all intellectual property rights (including copyright), as applicable, to the data offered under this agreement, and this agreement constitutes only a license to acquire and use these data products. Furthermore, this agreement does not convey title or rights.

12. Duration and Renewal

A clause should include information on when the agreement will come into effect (e.g., the date of signing by the last of the parties), as well as how long the agreement will remain in effect. There can also be terms set out for renewal, extensions or amendments to the agreement, if necessary.

Sample text:

This agreement will commence on and come into effect from the date of signing by the last of the parties, and will remain in effect for the duration of five (5) years. This agreement may be renewed, extended or amended with the written consent of both parties at least sixty (60) days prior to the expiration of the agreement. Notwithstanding paragraph 12.1, either party shall be entitled to terminate this agreement in the event the other party fails to fulfill any of its

obligations as stipulated in this agreement by providing a written notice to the other party sixty (60) days prior to termination. Data access privileges are terminated immediately. At the end of the notice period all copies of the data will be removed and destroyed, as described in section 10.

13. Expiration or Revocation of the Agreement

There should be a clause outlining the terms for the expiration or revocation of the agreement.

Sample text:

Upon expiration or revocation of this agreement, the research partners will immediately and permanently remove and destroy all copies, both physically and electronically, of the statistical outputs provided under this agreement in accordance with federal laws and Treasury Board Policy or any other federal government policy. (This refers to statistical outputs that may or may not be the subject of the agreement.) In exceptional circumstances, such as discovery of repeated misuse or distortion of the statistical outputs, the _____ First Nation will advise the research partner(s) in writing of the inappropriate action and provide the them with sixty (60) days to correct the said inappropriate action. In the event that the research partner (s) does not correct the said inappropriate action within the sixty (60) day period, the research partner's license to use the statistical outputs may be revoked by the _____ Band Council on behalf of the _____ First Nation. Upon revocation, all copies of the statistical outputs will be removed and destroyed.

14. Signing Authorities

The agreement should identify signing authorities, contact names, titles, addresses and phones numbers of the parties involved. The agreement should be signed and dated by the authorized representative of each party. This information is also used to allow the public to direct notices to the appropriate party.

IN WITNESS whereof, this agreement has been executed on behalf of the parties by their duly authorized representatives:

_____	_____
Name and Title	Date
_____	_____
Witness	Date
_____	_____
Name and Title	Date
_____	_____
Witness	Date

i Adapted from: Assembly of First Nations, Template for a Community Code of Ethics in Research and Data Sharing Protocols (Ottawa: Author, 1999) and; First Nations Regional Longitudinal Health Survey, First Nations Centre, First Nations Regional iiAdapted from Information Management, Access and Privacy Alberta Government Services, Freedom of information and protection of privacy: Guide for Developing Personal Information Sharing Agreements (Alberta: Government of Alberta, October, 2003). iiiAdapted from First Nations Regional Longitudinal Health Survey, First Nations Centre, First Nations Regional Longitudinal Health Survey Data Protection and Stewardship Protocol (Ottawa: National Aboriginal Health Organization, March, 2004)

Appendix C: Consent Letters, School Administration Approval

This appendix displays the template for requesting permission to conduct this research study and to acquire informed written consent from the appropriate representative in order to conduct this research study.

Consent Letters, School Administration Approval



UNIVERSITY
OF MANITOBA

Faculty of Education

Research Project Title: Identifying First Nations Students with Invisible Disabilities

Principal Investigator: Gina Schall, Ph.D. Student, Faculty of Education, University of Manitoba.

Research Supervisor: D. Rick Freeze,

This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

Dear Director of Education/ Principal *this will be adapted for the appropriate recipient.

My name is Gina Schall and I am a Ph.D. student at the University of Manitoba in the Faculty of Education. I have worked for the Manitoba First Nations Education Resource Centre for the past 15 years within the special education unit. My thesis advisor is Dr. Rick Freeze in the Faculty of Education. I am writing this letter to inform you of my research study and to request your approval for your school's participation in this study. I am conducting research on developing a protocol for early identification of First Nations students with invisible disabilities. I believe that by early identification of students with invisible disabilities many barriers and issues that arise preventing the students' academic success can be avoid.

The purpose of this study is to establish a baseline of teachers' knowledge and understanding regarding First Nations' students with invisible disabilities including types of invisible disabilities, presenting indicators of invisible disabilities, their impact on students' academic achievements and what types of accommodation and adaptations work best to help students with invisible disabilities.

Please know that this study is not an evaluation of any specific First Nations schools/staffs, special inclusive education programs or education organizations. It is an opportunity for participants to share their knowledge and experiences, and contribute to providing overall recommendations for developing a protocol for early identification of students with invisible disabilities in First Nations schools in Manitoba in order to provide the most appropriate learning environment to all students.

All the teaching staff are considered to be eligible research participants regardless of the number years of teaching experience. Participation is voluntary and declining to participate will have no negative consequences on your staff, school, or community. I will ask the participants to complete an anonymous survey. The school's resource teachers who agree to participate will be interviewed and the interviews will be audiotaped with a digital recorder. The study also involves a review of randomly selected student resource files for the possibility of an invisible disabilities impacting student achievement. Informed written consent will be obtained from the parents / legal guardians before any review of the files is done. Names of individuals, schools or communities will NOT appear anywhere in the results. Confidentiality will be insured by not identifying individual students, teachers, parents, community members or individual schools or communities in the dissemination of the results of the study. Pseudonyms will be used for names of people, places and identifying information.

Teachers' Survey: As the surveys are anonymous, by the completion and return of them will be considered as consent by those participants. All data collected in the surveys will be treated as private and confidential. No names will be required anywhere on the survey. The surveys will be given out with unmarked envelopes into which the completed surveys will be place and then sealed by each participant before being returned to either myself or the resource teacher from whom I will collect any envelopes that have been turned into him/her. Only I will tabulate, record and store the data.

Resource Teachers' Interviews: Before being interviewed, the resource teacher(s) will sign a consent forms agreeing to participate. Participation is voluntary and declining to participate will have no negative consequences. The consent form will also include agreeing to audio taping the initial interview and any future interviews if necessary for further clarification of data collected. The consent form will clearly indicate the right to voluntarily withdraw from the study at any time without fear of reprisal along with a guarantee of confidentiality and anonymity at all times. All data collected from the interview will be treated as private and confidential.

The interview will be no longer than one hour and will take place in a location selected by the resource teacher i.e. resource room, resource teacher's home, etc. I will be the only person to do the transcribing of the audio tape and will provide a copy of the written transcript of the interview for the resource teacher to review any revision necessary. I will contact the resource

teacher after the transcription review and revision if further clarification is needed. All data will be encrypted by me.

Student resource file reviews: Signed written consent by the parents/ legal guardians will be obtained prior to the file review. All data collected in this study will be treated as private and confidential. If the parent / legal guardian does not sign the consent form, no data will be collected from their child's school resource file. The consent form will clearly indicate the right to voluntarily withdraw from the study at any time without fear of reprisal along with a guarantee of confidentiality and anonymity. The central theme of the research is also included in these forms along with any known or anticipated risks and benefits to the potential research participants. Selection of the student resource files will be done randomly i.e. every fourth file. No names will be used in the information recorded and all data will be coded by me. I will be the only one with the code key. Pseudonyms will be used for names of people, places and identifying information.

All data will be kept in a locked desk drawer in my home office located at [REDACTED], Manitoba. Electronic data will be stored only on an encrypted memory stick which will also be kept with the all the other data in a secure and locked desk drawer in my home office. All data will be kept for a maximum of one year following final completion of the research project and the publication of the final report. At that time all paper data including consent forms, surveys, transcripts of interviews, file review analysis, researcher's notes, etc. will be shredded and burned. The electronic data including audio cassettes and memory stick will be destroyed by smashing them with a hammer. All the remnants will then be incinerated.

There will be no financial remuneration for participating in this study. Participation in this study is voluntary, and declining to participate will have no negative consequences. Participants are not obligated to answer any questions in this study that they do not want to, and are free at any time to withdraw simply by telling me that they wish to do so. Their data will then be removed from the study.

All participants will have the opportunity to review, add to or revise change the information they provide in their interviews and will also receive a summary of the findings at the completion of the study. All participants can withdraw at any time during the research by either phoning [REDACTED] or emailing me. I will then remove and destroy their data from the events in which they had been involved. All participants and schools in First Nations communities will receive this summary no later than Winter, 2016 and will be sent by either email, or mail, whichever they prefer. Results from this study will be shared through my dissertation along with presentations at meetings in each of the two schools' communities meetings and may also be disseminated through presentations at educational and scholarly conferences and through publication in academic journals. Chief and Council and the participating schools will also receive copies of the final results. Any community members who

wish to receive a copy can contact me either by phone [REDACTED] or email and I will forward a copy to them.

I currently am employed, in the Special Education Unit with the Manitoba First Nations Education Resource Center. In no way will the services to your local school be affected in any way by your participation or refusal to participate in this project. This research is not part of my work at the MFNERC and is a separate project undertaken through the Department of Education at the University of Manitoba.

The University of Manitoba may look at your research records to see that the research is being done in a safe and proper way. This research has been approved by the Education Research Ethics Board at the University of Manitoba. If you have any concerns or complaints about this project you may contact the Human Ethics Secretariat at 474-7122, or by e-mail at Margaret_Bowman@umanitoba.ca., and or my advisor Dr. Rick Freeze at [REDACTED]

If you agree to approve this research study please sign this form and return it to me. Thank you and I look forward to working with you on this exciting and important project.

Sincerely,

Gina Schall

School Administration Consent Form

Your signature on this form indicates that you agree to the research study taking place in your school. In no way does this wave your legal rights nor release the researchers, sponsor, or involved institutions from their legal and professional responsibilities.

These are the minimum standards for conducting research, however with research with First Nation communities I believe there are additional responsibilities, which I will also adhere to. In this study I will ensure that First Nations voices and perspectives are front and center. In the study I will honor and respect sacred knowledge(s), observe cultural protocols. I believe it is important that the study benefit the communities and education systems directly involved in the study. For me, this study is about working towards a better future for all First Nations learners.

The University of Manitoba may look at the research records to see that the research is being done in a safe and proper way. This research has been approved by the Education and Nursing Research Ethics Board at the University of Manitoba. If you have any concerns or complaints about this project you may contact the Human Ethics Coordinator (HEC), Margaret Bowman at 474-7122.

I understand that:

- the purpose of this research study is to assist in developing an early identification protocol for First Nations students who have invisible disabilities so as to provide appropriate supports for achieving academic success.
- all information will be kept confidential and that will be total anonymity for all participants.
- that there will be no risk to the participants and that any participant can withdraw at any time during this study by contacting the researcher through phone [REDACTED] or email and his/her data will be removed from the study and destroyed.
- the study's report will be presented at a community meeting when it is finished.
- a final report will be given to Chief and Council, the school and to any community members who request one.

I give my approval for this described research project, Identifying Invisible Disabilities of First Nations Students, to be conducted in _____ School.

Signature of Authority: _____ Date: _____

Signature or Researcher: _____ Date: _____

Appendix D: Research Ethics and Compliance Approval

Appendix D is the photocopy of Research Ethics and Compliance Approval for this research project.

Research Ethics and Compliance Approval



Research Ethics and Compliance
Office of the Vice-President (Research and International)

Human Ethics
208-194 Dafoe Road
Winnipeg, MB
Canada R3T 2N2
Phone +204-474-7122
Fax +204-269-7173

APPROVAL CERTIFICATE

November 26, 2015

TO: **Gina Schall** (Supervisor: Richard Freeze)
Principal Investigator

FROM: **Zana Lutfiyya, Chair**
Education/Nursing Research Ethics Board (ENREB)

Re: **Protocol #E2015:091**
"Identifying First Nations Students with Invisible Disabilities"

Please be advised that your above-referenced protocol has received human ethics approval by the **Education/Nursing Research Ethics Board**, which is organized and operates according to the Tri-Council Policy Statement (2). **This approval is valid for one year only.**

Any significant changes of the protocol and/or informed consent form should be reported to the Human Ethics Secretariat in advance of implementation of such changes.

Please note:

- If you have funds pending human ethics approval, please mail/e-mail/fax (261-0325) a copy of this Approval (identifying the related UM Project Number) to the Research Grants Officer in ORS in order to initiate fund setup. (How to find your UM Project Number: <http://umanitoba.ca/research/ors/mrt-faq.html#pr0>)
- if you have received multi-year funding for this research, responsibility lies with you to apply for and obtain Renewal Approval at the expiry of the initial one-year approval; otherwise the account will be locked.

The Research Quality Management Office may request to review research documentation from this project to demonstrate compliance with this approved protocol and the University of Manitoba *Ethics of Research Involving Humans*.

The Research Ethics Board requests a final report for your study (available at: http://umanitoba.ca/research/orec/ethics/human_ethics_REB_forms_guidelines.html) in order to be in compliance with Tri-Council Guidelines.

Appendix E: Research Ethics and Compliance Amendment Approval

A copy of the amendment approval from Research Ethics and Compliance is contained in this appendix.

Research Ethics and Compliance Amendment Approval



Research Ethics and Compliance
Office of the Vice-President (Research and International)

Human Ethics
208-194 Dafoe Road
Winnipeg, MB
Canada R3T 2N2
Phone +204-474-7122
Fax +204-269-7173

AMENDMENT APPROVAL

February 9, 2016

TO: **Gina Schall** (Supervisor: **Richard Freeze**)
Principal Investigator [REDACTED]

FROM: **Zana Lutfiyya, Chair**
Education/Nursing Research Ethics Board (ENREB)

Re: **Protocol #E2015:091**
"Identifying First Nations Students with Invisible Disabilities"

This will acknowledge your Amendment Request dated February 9, 2016,
requesting amendment to your above-noted protocol.

Approval is given for this amendment. Any further changes to the protocol must
be reported to the Human Ethics Coordinator in advance of implementation.

Appendix F: Research Ethics and Compliance Renewal Approval

A copy of the renewal approval from Research Ethics and Compliance is contained in this appendix.

Research Ethics and Compliance Renewal Approval



Research Ethics and Compliance
Office of the Vice-President (Research and International)

Human Ethics
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Phone +204-474-7122
Fax +204-269-7173

RENEWAL APPROVAL

October 31, 2016

TO: Gina Schall (Advisor: Rick Freeze)
Principal Investigator [REDACTED]

FROM: Zana Lutflyya, Chair
Education/Nursing Research Ethics Board (ENREB)

Re: Protocol #E2015:091 (HS19042)
"Identifying First Nations Students with Invisible Disabilities"

Please be advised that your above-referenced protocol has received approval for renewal by the Education/Nursing Research Ethics Board. This approval is valid for one year and will expire on November 25, 2017.

Any significant changes of the protocol and/or informed consent form should be reported to the Human Ethics Coordinator in advance of implementation of such changes.

Appendix G: INAC's Special Education Criteria Descriptions Level II & III

On the following page, Appendix G displays the photocopied pages from INAC's Rising to the Challenge guidelines that clarifies the criteria for INAC's Level II of Level III high cost special needs' eligibility.

Level II Eligibility Criteria - \$8,780 per unit per School Year

General Eligibility Criteria

- The need for individualized instruction/support for 50% of the school day(150 minutes).
- Baseline of 80 percent daily attendance (if attendance is below 80%, justification for absenteeism and/or plan or support for attendance must be included).
- The need for information on interventions or support services to be provided directly to students, the family or care-givers.
- Submission of a Full Score IQ and recommendations when a psychological assessment is required.
- The need for follow up to recommendations for interventions provided in the assessment reports; for example, if a psychologist recommends a speech/language assessment, or an audiology assessment, then this must be followed through with to ensure continuation of Level II funding, and to ensure proper intervention is provided to meet the needs of the child.
- Submission of a Behaviour Plan if handicapping conditions involve unmanageable behaviour.
- Parent/guardian signature on official INAC level II application form.

Low Incidence Level II Categories:

- Severely Multi-Handicapped (SMHC)
- Severely Emotionally/Behaviourly Disordered (SEBD)
- Severely Autistic (SA)
- Severely Hearing Impaired (SHI)
- Severely Visually Impaired (SVI)
- Severely Psychotic (SP)

The following definitions of disability categories are provided to assist in identifying eligible students for whom applications may be submitted for Level II funding. Regional office staff will determine final eligibility.

For a more definitive description of the following categories, please refer to the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-R).

Severely Multi-Handicapped Criteria (SMHC)

Combination of **two or more severe handicaps** which result in:

- severe multiple learning and communication disabilities;
- developmental and/or problem behaviour and;
- severe intellectual disability, compounded by a severe physical handicap to the extent that the student cannot respond to the usual instructional techniques as provided in special education programs for the mentally or physically handicapped.

If not intellectually handicapped, the student will display two or more physical impairments. Some examples may include:

- Cerebral Palsy with physical impairments;
- Global, organic, or genetic physical exceptionalities; or
- Spina bifida and Hydrocephalus

Applications for the above conditions require either a medical, psychological, or educational assessment or a combination of these to support the request; and the student's Full Score Intelligence Quotient (IQ) must be included in the submission.

Severely Emotionally/Behaviourly Disordered Criteria (SEBD)

- Psychological trauma associated with past exposure to violence, neglect, or abuse.
- Pervasive and persistent maladaptive behaviour, e.g., behaviours are chronic, longstanding and occurring outside of school, in the home, as well as in the community.
- Very severe emotional/behavioural disorders characterized by inappropriate or disproportionate emotional and behavioural responses to various life situations.
- Behaviours do not appear to be caused by inappropriate school expectations; for example, academic and discipline expectations are achievable and are not causing the problem behaviour.
- Requires supports from ongoing formal interagency planning; for example, clinicians/counselors are actively involved. Complementary supports may include Elder counseling, role modeling, traditional teachings, or ceremonial practices.
- Behaviours are a danger to self and others.
- Requires psychological as well as an educational and/or functional assessment to support application.
- Requires function-based behaviour plan with proactive and reactive strategies as part of IEP.
- Other behaviour disorders relevant to this category include: Post-traumatic Stress Disorder, Oppositional Defiant Disorder, or Conduct Disorder. Three of the five presenting features must have been in occurrence for at least six months, as outlined in the Diagnostic and Statistical Manual of Mental Disorders (DSM-III or IV-R).

Severely Autistic Criteria (SA)

- Exhibits autism spectrum disorder (ASD) characteristics which are severe inhibiting factors in his/her learning and overall functioning which requires intensive individualized programming. Conditions that fall within ASD include *Aspergers* and *Rhetts*.
- Impairments such as extreme self-isolation and withdrawal from reality.
- Severe language delays; for example, student has limited or no communication /language ability, or presents with echolalic behaviour (repeats verbal and physical behaviour).
- Hypersensitivity and/or hyposensitivity in the sensory dimensions, e.g., extreme sensitivity to light, noise and environmental factors.
- Perseverates using ritualistic behaviours.
- Requires medical doctor's diagnosis, and/or psychological, occupational therapy, and/or speech/language assessment to support request.

Severely Hearing Impaired Criteria (SHI)

- Requires audiological assessment to support request.
- Severe sensory neural hearing loss.
- Hearing loss has significantly affected the development of speech and/or language.
- Requires major program modifications to effectively participate and benefit from instruction in the educational setting.

Note: If one ear is rated as normal on the test, then the child does not meet eligibility criteria. The child is considered to have good hearing potential and may benefit from wearing a hearing aid.

Severely Visually Impaired Criteria (SVI)

- Requires an ophthalmology assessment to support request.
- So severely impaired that the primary learning mode is not visual or requires printed materials larger than 24 font size.
- Disability is such that extensive modifications in the learning environment are required.

Note: Students whose visual impairment is correctable through an eyeglass prescription are not eligible for this category.

Severely Psychotic Criteria (SP)

- Severe thought disorders and associated inappropriate behaviours which are beyond the person's control, and which do not appear to be caused by inappropriate school expectations
- Highly inappropriate school behaviour which is chronic and excessive and may necessitate the child's removal from the regular program with placement in a highly intensive therapeutic program setting.
- Requires psychiatrist or medical doctor's diagnosis and educational assessment to support request.
- Student incorrectly evaluates the accuracy of his or her perceptions and thoughts and makes incorrect references about external reality, even in the face of contrary evidence.
- Direct evidence of psychotic behaviour indicating the presence of either delusions or hallucinations. Examples include markedly incoherent speech without apparent awareness by the person that the speech is not understandable; and agitated, inattentive, and disoriented behaviour as seen in alcohol withdrawal delirium.

Some psychotic disorders are: Brief Reactive Psychosis, Schizophrenia, Induced Psychotic Disorder, Delusional Disorders, some Organic Mental Disorders, and some Mood Disorders.

Profoundly Emotionally/Behaviourly Disordered Criteria (PEBD)

- Psychological disturbance/trauma associated with past exposure to neglect, abuse or violence.
- Reports and histories of family dynamics and significant occurrences that may account for present problem behaviors must be submitted.
- Pervasive and persistent maladaptive behaviour, e.g., behaviours are chronic, longstanding and occurring outside of school, in the home, as well as in the community.
- Exhibits profound emotional/behavioural disorders that interfere with own learning and the learning of others.
- Behaviours are dangerous to self and others and actions are impulsive, aggressive, and violent.
- Requires intensive and highly individualized programming (comprehensive Circle of Care plan involving the parents or care givers and other agencies).
- Requires intensive support services at home and in the community such as, Child and Family Services, Justice, Mental Health, etc..
- Requires a formal and detailed Individual Education Plan and function-based behaviour intervention plan, with comprehensive multi-disciplinary treatment intervention plans to address profound emotional/behavioural problems. Circle of Care or Multi-disciplinary plans must accompany the Level III funding application.
- A psychological assessment is required supporting documentation.

Deaf Criteria

- Deaf and whose hearing loss affects communications so profoundly that appropriate full time individual program support is required to effectively participate and benefit from instruction in the educational setting.
- Requires an American Sign Language (ASL) interpreter for all instructional areas of the day.

Note: Should a student acquire ASL skills, and thus not require an interpreter for all subject areas, she or he will be considered eligible for Level II funding.

Blind Criteria

- Requires braille materials.
- Requires orientation and mobility training.
- Communications are so profoundly affected that appropriate full time individual program support is required to effectively participate and benefit from instruction in the educational setting.

Appendix H: Teachers' Questionnaire on Disabilities

This appendix, on the following twelve pages, contains a copy of the teachers' questionnaire that was distributed to the classroom teachers to complete.

Teachers' Questionnaire on Disabilities

Please remember that in keeping with research ethics, respondents' confidentiality is assured.

Part I

Read each question and place an "x" the appropriate box.

1. How many years of teaching experience do you have?

1-5 years	5-10 years	10-15 years	15-20 years	Over 20 years
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2. To which group do you belong? (FN – First Nation)

FN male	FN female	Non FN male	Non FN female
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3. To which age group do you belong?

Under 25 years	25-35 years	35-45 years	45-55 years	55-65 years	Over 65 years
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4. What is your highest educational level achieved?

Under-graduate degree	Honors Under-graduate degree	Bachelor's degree	Master's degree	Post Master's studies	Post Baccalaureate Diploma.
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Part II

For these following questions, use the seven point Likert scale ranging from entirely disagree to entirely agree. Read each following statements and place an "x" the appropriate box.

5. The term “disability” means physical or mental condition that limits a person's movements, senses, or activities.

Entirely disagree	Mostly disagree	Somewhat disagree	Neither disagree or agree	Somewhat agree	Mostly agree	Entirely agree
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6. The term “disability” means a disadvantage or handicap, especially one imposed or recognized by the law.

Entirely disagree	Mostly disagree	Somewhat disagree	Neither disagree or agree	Somewhat agree	Mostly agree	Entirely agree
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7. The term “disability” means a restriction in the ability to perform a normal activity of daily living which someone of the same age is able to perform.

Entirely disagree	Mostly disagree	Somewhat disagree	Neither disagree or agree	Somewhat agree	Mostly agree	Entirely agree
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8. The term “disability” means any limitation, either internally or externally, that prevents an individual’s ability to perform.

Entirely disagree	Mostly disagree	Somewhat disagree	Neither disagree or agree	Somewhat agree	Mostly agree	Entirely agree
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9. A definition for the term “invisible disability” is any disability that is not immediately apparent to another person.

Entirely disagree	Mostly disagree	Somewhat disagree	Neither disagree or agree	Somewhat agree	Mostly agree	Entirely agree
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10. A definition for the term “invisible disability” is hidden neurological condition that presents significant challenges to learning, interacting with others, regulating mood and thinking patterns.

Entirely disagree	Mostly disagree	Somewhat disagree	Neither disagree or agree	Somewhat agree	Mostly agree	Entirely agree
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11. A definition for the term “invisible disability” is physical disorders not requiring visible supports such as walkers, wheelchairs, or other aids.

Entirely disagree	Mostly disagree	Somewhat disagree	Neither disagree or agree	Somewhat agree	Mostly agree	Entirely agree
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12. A definition for the term “invisible disability” is an absence in appearance difference from other individuals, but has cognitive issues.

Entirely disagree	Mostly disagree	Somewhat disagree	Neither disagree or agree	Somewhat agree	Mostly agree	Entirely agree
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13. I have worked with students whose disabilities were visible and officially identified and funded.

Entirely disagree	Mostly disagree	Somewhat disagree	Neither disagree or agree	Somewhat agree	Mostly agree	Entirely agree
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14. I have worked with students whose disabilities were visible but not officially identified and **NOT** funded.

Entirely disagree	Mostly disagree	Somewhat disagree	Neither disagree or agree	Somewhat agree	Mostly agree	Entirely agree
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15. I have worked with students whose disabilities were invisible and officially identified and funded.

Entirely disagree	Mostly disagree	Somewhat disagree	Neither disagree or agree	Somewhat agree	Mostly agree	Entirely agree

16. I have worked with students whose disabilities were invisible but **NOT** officially identified and **NOT** funded.

Entirely disagree	Mostly disagree	Somewhat disagree	Neither disagree or agree	Somewhat agree	Mostly agree	Entirely agree

17. The majority of visible disabilities fall into the physical disability category.

Entirely disagree	Mostly disagree	Somewhat disagree	Neither disagree or agree	Somewhat agree	Mostly agree	Entirely agree

18. The majority of invisible disabilities fall into the cognitive disability category.

Entirely disagree	Mostly disagree	Somewhat disagree	Neither disagree or agree	Somewhat agree	Mostly agree	Entirely agree

Part III

For the remaining sections of this survey, please use the following definitions:

Visible disability—is a physical or mental condition that limits a person's movements, senses, or activities; a disadvantage or handicap, especially one imposed or recognized by the law

Invisible disability—is not always obvious to the onlooker, but can sometimes or always limit daily activities, range from mild challenges to severe limitations and vary from person to person

For each of the following disabilities, indicate how much you think the disability is either invisible or visible. Use the seven point Likert scale ranging from entirely invisible to entirely visible. Place an “x” in the appropriate box.

19. Deafness

Entirely invisible	Mostly invisible	Somewhat invisible	Neither invisible or visible	Somewhat visible	Mostly visible	Entirely visible
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20. Blindness

Entirely invisible	Mostly invisible	Somewhat invisible	Neither invisible or visible	Somewhat visible	Mostly visible	Entirely visible
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21. Dyslexia

Entirely invisible	Mostly invisible	Somewhat invisible	Neither invisible or visible	Somewhat visible	Mostly visible	Entirely visible
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22. ADD/ADHD

Entirely invisible	Mostly invisible	Somewhat invisible	Neither invisible or visible	Somewhat visible	Mostly visible	Entirely visible
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23. Down Syndrome

Entirely invisible	Mostly invisible	Somewhat invisible	Neither invisible or visible	Somewhat visible	Mostly visible	Entirely visible
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24. Autism

Entirely invisible	Mostly invisible	Somewhat invisible	Neither invisible or visible	Somewhat visible	Mostly visible	Entirely visible

25. Oppositional Deviant

Entirely invisible	Mostly invisible	Somewhat invisible	Neither invisible or visible	Somewhat visible	Mostly visible	Entirely visible

26. Asthma

Entirely invisible	Mostly invisible	Somewhat invisible	Neither invisible or visible	Somewhat visible	Mostly visible	Entirely visible

27. Food allergies

Entirely invisible	Mostly invisible	Somewhat invisible	Neither invisible or visible	Somewhat visible	Mostly visible	Entirely visible

28. Diabetes

Entirely invisible	Mostly invisible	Somewhat invisible	Neither invisible or visible	Somewhat visible	Mostly visible	Entirely visible

29. Chronic Fatigue Syndrome

Entirely invisible	Mostly invisible	Somewhat invisible	Neither invisible or visible	Somewhat visible	Mostly visible	Entirely visible
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30. Brain Trauma

Entirely invisible	Mostly invisible	Somewhat invisible	Neither invisible or visible	Somewhat visible	Mostly visible	Entirely visible
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31. Epilepsy

Entirely invisible	Mostly invisible	Somewhat invisible	Neither invisible or visible	Somewhat visible	Mostly visible	Entirely visible
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31. Attachment Disorder

Entirely invisible	Mostly invisible	Somewhat invisible	Neither invisible or visible	Somewhat visible	Mostly visible	Entirely visible
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32. Crohn's Disease

Entirely invisible	Mostly invisible	Somewhat invisible	Neither invisible or visible	Somewhat visible	Mostly visible	Entirely visible
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Part IV

For each of the following disabilities, indicate how much you think the disability is either invisible or visible. Use the seven point Likert scale ranging from entirely disagree to entirely agree.

33. I believe that it is easier to identify students with visible disabilities than students with invisible disabilities.

Entirely disagree	Mostly disagree	Somewhat disagree	Neither disagree or agree	Somewhat agree	Mostly agree	Entirely agree
--------------------------	------------------------	--------------------------	----------------------------------	-----------------------	---------------------	-----------------------

34. I believe I can identify students in my class who have visible disabilities without assistance from others.

Entirely disagree	Mostly disagree	Somewhat disagree	Neither disagree or agree	Somewhat agree	Mostly agree	Entirely agree
--------------------------	------------------------	--------------------------	----------------------------------	-----------------------	---------------------	-----------------------

35. I believe I can identify students in my class who have invisible disabilities without assistance from others.

Entirely disagree	Mostly disagree	Somewhat disagree	Neither disagree or agree	Somewhat agree	Mostly agree	Entirely agree
--------------------------	------------------------	--------------------------	----------------------------------	-----------------------	---------------------	-----------------------

36. Students with invisible disabilities are more 'at risk' than students with visible disabilities.

Entirely disagree	Mostly disagree	Somewhat disagree	Neither disagree or agree	Somewhat agree	Mostly agree	Entirely agree
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37. Students with invisible disabilities have an easier time in school because they blend in with the general student population.

Entirely disagree	Mostly disagree	Somewhat disagree	Neither disagree or agree	Somewhat agree	Mostly agree	Entirely agree
--------------------------	------------------------	--------------------------	----------------------------------	-----------------------	---------------------	-----------------------

38. It is easier to accommodate students who have invisible disabilities than students with visible disabilities.

Entirely disagree	Mostly disagree	Somewhat disagree	Neither disagree or agree	Somewhat agree	Mostly agree	Entirely agree
--------------------------	------------------------	--------------------------	----------------------------------	-----------------------	---------------------	-----------------------

39. Students with invisible disabilities can use their disability to their advantage more easily than students with visible disabilities.

Entirely disagree	Mostly disagree	Somewhat disagree	Neither disagree or agree	Somewhat agree	Mostly agree	Entirely agree
--------------------------	------------------------	--------------------------	----------------------------------	-----------------------	---------------------	-----------------------

40. It takes extra time to prepare lessons for students with invisible disabilities.

Entirely disagree	Mostly disagree	Somewhat disagree	Neither disagree or agree	Somewhat agree	Mostly agree	Entirely agree
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41. Adapting and accommodating the environment for students with invisible disabilities as well as for students with visible disabilities adds more stress to teacher's workload.

Entirely disagree	Mostly disagree	Somewhat disagree	Neither disagree or agree	Somewhat agree	Mostly agree	Entirely agree
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42. There are not as many students with invisible disabilities as there are students with visible disabilities.

Entirely disagree	Mostly disagree	Somewhat disagree	Neither disagree or agree	Somewhat agree	Mostly agree	Entirely agree
--------------------------	------------------------	--------------------------	----------------------------------	-----------------------	---------------------	-----------------------

43. It is much easier to adapt and / or modify lesson plans for students with visible disabilities than for students with invisible disabilities.

Entirely disagree	Mostly disagree	Somewhat disagree	Neither disagree or agree	Somewhat agree	Mostly agree	Entirely agree
--------------------------	------------------------	--------------------------	----------------------------------	-----------------------	---------------------	-----------------------

44. Students with invisible disabilities need to be officially identified before any adaptations, accommodations or modifications to lesson plans and learning environment are made.

Entirely disagree	Mostly disagree	Somewhat disagree	Neither disagree or agree	Somewhat agree	Mostly agree	Entirely agree
--------------------------	------------------------	--------------------------	----------------------------------	-----------------------	---------------------	-----------------------

45. Students with invisible disabilities often use their disabilities as an excuse for not completing assignments.

Entirely disagree	Mostly disagree	Somewhat disagree	Neither disagree or agree	Somewhat agree	Mostly agree	Entirely agree
--------------------------	------------------------	--------------------------	----------------------------------	-----------------------	---------------------	-----------------------

46. Students with invisible disabilities can achieve academic success without any adaptations or accommodations if they just work more intensely at the assigned tasks.

Entirely disagree	Mostly disagree	Somewhat disagree	Neither disagree or agree	Somewhat agree	Mostly agree	Entirely agree
--------------------------	------------------------	--------------------------	----------------------------------	-----------------------	---------------------	-----------------------

Part V

For each of the following questions, indicate your level of training or personal experience on invisible disabilities. Use the 7 point Likert scale with 1 meaning none (no training or no personal experience) and 7 meaning extensive training or personal experience.

47. How much was covered you teacher's training on the topic of invisible disabilities regarding awareness of the difficulties students with invisible disabilities face in acquiring an education in your teacher's training?

None	Slight	Less than adequate	Adequate	More than adequate	Considerable	Extensive

48. How much was covered on the topic of invisible disabilities regarding adaptations and accommodations for students with invisible disabilities in your teacher's training?

None	Slight	Less than adequate	Adequate	More than adequate	Considerable	Extensive

49. How much previous personal experience have you had with individuals with visible disabilities within the school setting?

None	Slight	Less than adequate	Adequate	More than adequate	Considerable	Extensive

50. How much previous personal experiences have you had with individuals with invisible disabilities outside of the school setting?

None	Slight	Less than adequate	Adequate	More than adequate	Considerable	Extensive

Appendix I: Review of Resource Files

The next page displays the template that was to be used for the review of students' resource files in the original research study but was deleted out of respect for the resource teachers' concerns regarding confidentiality.

Review of Resource Files

	File A	File B	File C	File D	File E
(1) Reasons for initial referral					
(2) Descriptors used for the student's difficulties at or previously to time of referral					
(3) Descriptors used for the student's strengths at or previously to time of referral					
(4) Age and grade at time of student's referral					
(5) Any formally diagnosed conditions present at time of student's referral					
(6) Any history of poor attendance prior to student's referral					
(7) Any history of behavioral issues without mention of academic issues at time of student's referral					
(8) Any history of behavioral and academic issues at time of student's referral					
(9) Formal clinical assessment findings					
(10) Medical criteria for special needs funding (High Cost) from AANDC					

(11) Recommendations from the resource teachers' assessments					
(12) Recommendations from clinical assessments					
(13) Teachers' past accommodations and adaptations in the classroom for the student					
(14) Teacher's current accommodations and adaptations in the classroom for the student					
(15) Student's current academic performance					
(16) Student's current behavior performance					

Appendix J: Resource Teachers' Interview Questions

The resource teachers' interview questions chosen for this research study are listed on the following page.

Resource Teachers' Interview Questions

1. What do the terms visible disability and invisible disability mean to you?
 - a. How do they differ?
2. Did you receive any instructional training on to teacher students with disabilities? If yes:
 - a. Where did you receive this training?
 - b. How did you receive this training?
 - c. Were students with invisible disabilities included in that instruction?
If yes: How were they included in the instruction?
3. How and where did you acquire your knowledge on accommodation and adaptation for students with invisible disabilities?
4. Do you believe there are students with invisible disabilities on your case load for resource services?
If yes:
 - a. What percentage of your resource caseload would you say are students with invisible disabilities?
 - b. What types of invisible disabilities do you suspect they have?
 - c. Do you believe those student referrals are directly related to their invisible disabilities or to the presenting behaviors of the students with invisible disabilities?
5. Do you feel many students with invisible disabilities go unidentified by the teaching staff?
 - a. Why?
6. Are adaptations and accommodations made available in a timely manner for students with invisible disabilities?
If not:
 - a. What do you believe are the reasons for the lack of supports?
7. What should be done to assist teachers in identifying students with invisible disabilities?
8. Any other comments or thoughts on the topic of students with invisible disabilities?

Appendix K: Information Letter Classroom Teachers

This appendix contains the information letter, regarding this research project, which accompanied the teachers' questionnaire and is on the following two pages.

Information Letter Classroom Teachers



UNIVERSITY
OF MANITOBA

Faculty of Education

Research Project Title: Identifying First Nations Students with Invisible Disabilities

Principal Investigator: Gina Schall, Ph.D. Student, Faculty of Education, University of Manitoba.

Research Supervisor: D. Rick Freeze,

This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

Dear Classroom Teachers,

My name is Gina Schall and I am a Ph.D. student at the University of Manitoba in the Faculty of Education. I have worked for the Manitoba First Nations Education Resource Centre for the past 15 years within the special education unit. My thesis advisor is Dr. Rick Freeze in the Faculty of Education. I am writing this letter to inform you of my research study and to request your approval for your school's participation in this study. I am conducting research on developing a protocol for early identification of First Nations students with invisible disabilities. I believe that by early identification of students with invisible disabilities many barriers and issues that arise preventing the students' academic success can be avoided.

The purpose of this study is to establish a baseline of teachers' knowledge and understanding regarding First Nations' students with invisible disabilities including types of invisible disabilities, presenting indicators of invisible disabilities, their impact on students' academic achievements and what types of accommodation and adaptations work best to help students with invisible disabilities.

Please know that this study is not an evaluation of any specific First Nations schools/staffs, special inclusive education programs or education organizations. It is an opportunity for participants to share their knowledge and experiences, and contribute to providing overall recommendations for developing a protocol for early identification of students with invisible disabilities in First Nations schools in Manitoba in order to provide the most appropriate learning environment to all students.

All the teaching staff are considered to be eligible research participants regardless of the number years of teaching experience. Participation is voluntary and declining to participate will have no negative consequences on your staff, school, or community. I will be asking the participants to complete an anonymous teachers' survey.

Teachers' Survey: As the surveys are anonymous, the completion and return of them will be considered as consent by those participants. All data collected in the surveys will be treated as private and confidential. No names will be required anywhere on the survey. The surveys will be given out with unmarked envelopes into which the completed surveys will be placed and then sealed by each participant before being returned. Only I will tabulate, record and store the data.

All data will be kept in a locked desk drawer in my home office located at [REDACTED] Manitoba. Electronic data will be stored only on an encrypted memory stick which will also be kept with the all the other data in a secure and locked desk drawer in my home office. All data will be kept for a maximum of one year following final completion of the research project and the publication of the final report. At that time all paper data including consent forms, surveys, transcripts of interviews, file review analysis, researcher's notes, etc. will be shredded and burned. The electronic data including audio cassettes and memory stick will be destroyed by smashing them with a hammer. All the remnants will then be incinerated.

There will be no financial remuneration for participating in this study. Participation in this study is voluntary, and declining to participate will have no negative consequences. Participants are not obligated to answer any questions in this study that they do not want to, and are free at any time to withdraw simply by telling me that they wish to do so. Their data will then be removed from the study. All participants and schools in First Nations communities will receive this summary no later than the Winter of 2016 and will be sent by either email or mail, whichever they prefer. Results from this study will be shared through my dissertation along with presentations at each of the schools' community meetings if the schools' so wish and may also be disseminated through presentations at educational and scholarly conferences and through publication in academic journals. Chief and Council and the participating schools will also receive copies of the final results. Any community members who wish to receive a copy can contact me either by phone [REDACTED] or email and I will forward a copy to them.

I currently am employed, in the Special Education Unit with the Manitoba First Nations Education Resource Center. In no way will the services to your local school be affected in any way by your participation or refusal to participate in this project. This research is not part of my work at the MFNERC and is a separate project undertaken through the Department of Education at the University of Manitoba.

The University of Manitoba may look at my research records to see that the research is being done in a safe and proper way. This research has been approved by the Education Research Ethics Board at the University of Manitoba. If you have any concerns or complaints about this project you may contact the Human Ethics Secretariat at 474-7122, or by e-mail at Margaret.Bowman@umanitoba.ca and or my advisor Dr. Rick Freeze at [REDACTED]

If you agree to this research study please take time to complete the following survey and return it to me. Thank you and I look forward to working with you on this exciting and important project.
Sincerely,

Gina Schall

Appendix L: Consent Letters, Resource Teachers

The following pages contain the template used to inform the resource teachers about this research study and to acquire their informed, written consent prior to interviewing them.

Consent Letters, Resource Teachers

Department of Educational Administration, Foundations and Psychology



UNIVERSITY
OF MANITOBA

Faculty of Education

Research Project Title: Identifying First Nations Students with Invisible Disabilities

Principal Investigator: Gina Schall, Ph.D. Student, Faculty of Education, University of Manitoba.

Research Supervisor: D. Rick Freeze,

This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

Dear *Resource Teacher*, (*name of resource teacher to be inserted)

My name is Gina Schall and I am a Ph.D. student at the University of Manitoba in the Faculty of Education. I have worked for the Manitoba First Nations Education Resource Centre for the past 15 years within the special education unit. My thesis advisor is Dr. Rick Freeze in the Faculty of Education. I am writing this letter to inform you of my research study and to request your approval for your school's participation in this study. I am conducting research on developing a protocol for early identification of First Nations students with invisible disabilities. I believe that by early identification of students with invisible disabilities many barriers and issues that arise preventing the students' academic success can be avoided.

The purpose of this study is to establish a baseline of teachers' knowledge and understanding regarding First Nations' students with invisible disabilities including types of invisible disabilities, presenting indicators of invisible disabilities, their impact on students' academic achievements and what types of accommodation and adaptations work best to help students with invisible disabilities.

Please know that this study is not an evaluation of any specific First Nations schools/staffs, special inclusive education programs or education organizations. It is an opportunity for participants to share their knowledge and experiences, and contribute to providing overall recommendations for developing a protocol for early identification of students with invisible disabilities in First Nations schools in Manitoba in order to provide the most appropriate learning environment to all students.

All the teaching staff are considered to be eligible research participants regardless of the number years of teaching experience. Participation is voluntary and declining to participate will have no negative consequences on your staff, school, or community. I will ask the participants to complete an anonymous survey. The school's resource teachers who agree to participate will be interviewed and the interviews will be audiotaped with a digital recorder. The study also involves a review of randomly selected student resource files for the possibility of an invisible disabilities impacting student achievement. Informed written consent will be obtained from the parents / legal guardians before any review of the files is done. Names of individuals, schools or communities will NOT appear anywhere in the results. Confidentiality will be insured by not identifying individual students, teachers, parents, community members or individual schools or communities in the dissemination of the results of the study. Pseudonyms will be used for names of people, places and identifying information.

Teachers' Survey: As the surveys are anonymous, the completion and return of them will be considered as consent by those participants. All data collected in the surveys will be treated as private and confidential. No names will be required anywhere on the survey. The surveys will be given out with unmarked envelopes into which the completed surveys will be place and then sealed by each participant before being returned to either myself or the resource teacher from whom I will collect any envelopes that have been turned into him/her. Only I will tabulate, record and store the data.

Resource Teachers' Interviews: Before being interviewed, the resource teacher(s) will sign a consent forms agreeing to participate. Participation is voluntary and declining to participate will have no negative consequences. The consent form will also include agreeing to audio taping the initial interview and any future interviews if necessary for further clarification of data collected. The consent form will clearly indicate the right to voluntarily withdraw from the study at any time without fear of reprisal along with a guarantee of confidentiality and anonymity at all times. All data collected from the interview will be treated as private and confidential.

The interview will be no longer than one hour and will take place in a location selected by the resource teacher i.e. resource room, resource teacher's home, etc. I will be the only person to do the transcribing of the audio tape and will provide a copy of the written transcript of the interview for the resource teacher to review any revision necessary. I will contact the resource teacher after the transcription review and revision if further clarification is needed. All data will be encrypted by me.

Student resource file reviews: Signed written consent by the parents/ legal guardians will be obtained prior to the file review. All data collected in this study will be treated as private and confidential. If the parent / legal guardian does not sign the consent form, no data will be collected from their child's school resource file. The consent form will clearly indicate the right to voluntarily withdraw from the study at any time without fear of reprisal along with a guarantee of confidentiality and anonymity. The central theme of the research is also included in these forms along with any known or anticipated risks and benefits to the potential research participants. Selection of the student resource files will be done randomly i.e. every fourth file. No names will be used in the information recorded and all data will be coded by me. I will be the only one with the code key. Pseudonyms will be used for names of people, places and identifying information.

All data will be kept in a locked desk drawer in my home office located at [REDACTED] Manitoba. Electronic data will be stored only on an encrypted memory stick which will also be kept with the all the other data in a secure and locked desk drawer in my home office. All data will be kept for a maximum of one year following final completion of the research project and the publication of the final report. At that time all paper data including consent forms, surveys, transcripts of interviews, file review analysis, researcher's notes, etc. will be shredded and burned. The electronic data including audio cassettes and memory stick will be destroyed by smashing them with a hammer. All the remnants will then be incinerated.

There will be no financial remuneration for participating in this study. Participation in this study is voluntary, and declining to participate will have no negative consequences. Participants are not obligated to answer any questions in this study that they do not want to, and are free at any time to withdraw simply by telling me that they wish to do so. Their data will then be removed from the study.

All participants will have the opportunity to review, add to or revise the information they provide in their interviews and will also receive a summary of the findings at the completion of the study. All participants can withdraw at any time during the research by either phoning [REDACTED] or emailing me. I will then remove and destroy their data from the events in which they had been involved. All participants and schools in First Nations communities will receive this summary no later than Winter, 2016 and will be sent by either email, or mail, whichever they prefer. Results from this study will be shared through my dissertation along with presentations at each of the two schools' community meetings and may also be disseminated through presentations at educational and scholarly conferences and through publication in academic journals. Chief and Council and the participating schools will also receive copies of the final results. Any community members who wish to receive a copy can contract me either by phone [REDACTED] or email and I will forward a copy to them.

I currently am employed, in the Special Education Unit with the Manitoba First Nations Education Resource Center. In no way will the services to your local school be affected in any way by your participation or refusal to participate in this project. This research is not part of my work at the MFNERC and is a separate project undertaken through the Department of Education at the University of Manitoba.

The University of Manitoba may look at your research records to see that the research is being done in a safe and proper way. This research has been approved by the Education Research Ethics Board at the University of Manitoba. If you have any concerns or complaints about this project you may contact the Human Ethics Secretariat at 474-7122, or by e-mail at Margaret_Bowman@umanitoba.ca and or my advisor Dr. Rick Freeze at [REDACTED]

If you agree to approve this research study please sign this form and return it to me.
Thank you and I look forward to working with you on this exciting and important project.

Sincerely,

Gina Schall

Resource Teacher Interview Consent Form

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the researchers, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time, and /or refrain from answering any questions you prefer to omit, without prejudice or consequence. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation.

The University of Manitoba may look at your research records to see that the research is being done in a safe and proper way. This research has been approved by the [insert full name of appropriate REB]. If you have any concerns or complaints about this project you may contact any of the above-named persons or the Human Ethics Coordinator (HEC) at 474-7122. A copy of this consent form has been given to you to keep for your records and reference.

I, _____, resource teacher at _____
School agree to be interviewed by _____, Invisible Disabilities study
researcher, and to have my interview recorded the solely for the purpose of accuracy in data
collection. I also agreed to any further contacts by the researcher for clarification on any points
discussed in my interview.

I understand that:

- the purpose of this research study is to assist in developing an early identification protocol for First Nations students who have invisible disabilities so as to provide appropriate supports for achieving academic success.
- I may be called upon to hold any teacher surveys and signed parental consent forms that turned into me until the researcher collects them from me.
- I will be provided a copy of my interview transcript to review and revise where needed.
- all information will be kept confidential and that will be total anonymity for all participants. I also understand that there will be no risk to me and that I can withdraw my consent for participating at any time during this study by contacting the researcher through phone [REDACTED] or email and my data will be removed from the study and destroyed.
- There may be minimal risk to participants with the dissemination of the final report.

I am aware that the study's report will be presented at a community meeting when it is finished and I will be given choice of either a hardcopy or electronic copy of the completed study if I wish to have one. I am aware that this study will also be disseminated through the researcher's dissertation at the University of Manitoba.

Signature of Resource Teacher: _____ Date: _____

Signature of Researcher: _____ Date: _____

Appendix M: Consent Letters, Parents / Legal Guardians

This appendix displays the template letter that was to be used to explain all aspects of this research study and the parental informed consent form that needed to be signed and returned prior to reviewing any student resource file. But as this component of the study was deleted, the letters and permission forms were not distributed.

Consent Letters, Parents / Legal Guardians



**UNIVERSITY
OF MANITOBA** | **Faculty of Education**

Research Project Title: Identifying First Nations Students with Invisible Disabilities

Principal Investigator: Gina Schall, Ph.D. Student, Faculty of Education, University of Manitoba.



Research Supervisor: D. Rick Freeze,



This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

Dear _____,

My name is Gina Schall and I am a Ph.D. student at the University of Manitoba in the Faculty of Education. I have worked for the Manitoba First Nations Education Resource Centre for the past 15 years within the special education unit. My thesis advisor is Dr. Rick Freeze in the Faculty of Education. I am writing this letter to inform you of my research study and to request your approval for your school's participation in this study. I am conducting research on developing a protocol for early identification of First Nations students with invisible disabilities. I believe that by early identification of students with invisible disabilities many barriers and issues that arise preventing the students' academic success can be avoided.

The purpose of this study is to establish a baseline of teachers' knowledge and understanding regarding First Nations' students with invisible disabilities including types of invisible disabilities, presenting indicators of invisible disabilities, their impact on students' academic achievements and what types of accommodation and adaptations work best to help students with invisible disabilities.

Please know that this study is not an evaluation of any specific First Nations schools/staffs, special inclusive education programs or education organizations. It is an opportunity for participants to share their knowledge and experiences, and contribute to providing overall recommendations for developing a protocol for early identification of students with invisible disabilities in First Nations schools in Manitoba in order to provide the most appropriate learning environment to all students.

All the teaching staff are considered to be eligible research participants regardless of the number years of teaching experience. Participation is voluntary and declining to participate will have no negative consequences on your staff, school, or community. I will ask the participants to complete an anonymous survey. The school's resource teachers who agree to participate will be interviewed and the interviews will be audiotaped with a digital recorder. Confidentiality will be insured by not identifying individuals, schools or communities in the dissemination of the results of the study. Pseudonyms will be used for names of people, places and identifying information.

Teachers' Survey: As the surveys are anonymous, the completion and return of them will be considered as consent by those participants. All data collected in the surveys will be treated as private and confidential. No names will be required anywhere on the survey. The surveys will be given out with unmarked envelopes into which the completed surveys will be placed and then sealed by each participant before being returned. Only I will tabulate, record and store the data.

Resource Teachers' Interviews: Before being interviewed, the resource teacher(s) will sign a consent form agreeing to participate. Participation is voluntary and declining to participate will have no negative consequences. The consent form will also include agreeing to audio taping the initial interview and any future interviews if necessary for further clarification of data collected. The consent form will clearly indicate the right to voluntarily withdraw from the study at any time without fear of reprisal along with a guarantee of confidentiality and anonymity at all times. All data collected from the interview will be treated as private and confidential.

The interview will be no longer than one hour and will take place in a location selected by the resource teacher i.e. resource room, resource teacher's home, etc. I will be the only person to do the transcribing of the audio tape and will provide a copy of the written transcript of the interview for the resource teacher to review any revision necessary. I will contact the resource teacher after the transcription review and revision if further clarification is needed. All data will be encrypted by me.

All data will be kept in a locked desk drawer in my home office located at [REDACTED] Manitoba. Electronic data will be stored only on an encrypted memory stick which will also be kept with all the other data in a secure and locked desk drawer in my home office. All data will be kept for a maximum of one year following final completion of the research project and the publication of the final report. At that time all paper data including consent forms, surveys, transcripts of interviews, file review analysis, researcher's notes, etc. will be shredded and burned. The electronic data including audio cassettes and memory stick will be destroyed by smashing them with a hammer. All the remnants will then be incinerated.

There will be no financial remuneration for participating in this study. Participation in this study is voluntary, and declining to participate will have no negative consequences. Participants are not obligated to answer any questions in this study that they do not want to, and are free at any time to withdraw simply by telling me that they wish to do so. Their data will then be removed from the study.

All participants will have the opportunity to review, add to or revise the information they provide in their interviews and will also receive a summary of the findings at the completion of the study. All participants can withdraw at any time during the research by either phoning [REDACTED] or emailing me. I will then remove and destroy their data from the events in which they had been involved. All participants and schools in First Nations communities will receive this summary no later than the Winter of 2016 and will be sent by either email or mail, whichever they prefer. Results from this study will be shared through my dissertation along with presentations at each of the schools' community meetings if the schools so wish and may also be disseminated through presentations at educational and scholarly conferences and through publication in academic journals. Chief and Council and the

participating schools will also receive copies of the final results. Any community members who wish to receive a copy can contact me either by phone [REDACTED] or email and I will forward a copy to them.

I currently am employed, in the Special Education Unit with the Manitoba First Nations Education Resource Center. In no way will the services to your local school be affected in any way by your participation or refusal to participate in this project. This research is not part of my work at the MFNERC and is a separate project undertaken through the Department of Education at the University of Manitoba.

The University of Manitoba may look at my research records to see that the research is being done in a safe and proper way. This research has been approved by the Education Research Ethics Board at the University of Manitoba. If you have any concerns or complaints about this project you may contact the Human Ethics Secretariat at 474-7122, or by e-mail at Margaret_Bowman@umanitoba.ca and or my advisor Dr. Rick Freeze at [REDACTED]

If you agree to approve this research study please sign this form below and return it to me. Thank you and I look forward to working with you on this exciting and important project.

Sincerely,

Gina Schall