First Nations children diagnosed with Autism Spectrum Disorder in BC, Canada, appear to be under-detected. The children in this study use music for purposes such as communication, relaxation, security, self-soothing, happiness and when doing homework. The use of traditional Indigenous music, and music as a facilitator for inclusion, appear to be overlooked resources. This study was conducted within an Indigenist research paradigm, based on reciprocity and relationality. Culturally-sensitive, tribal-specific music interventions should be further investigated.
STEPPING OUT OF THE SHADOWS OF COLONIALISM TO THE BEAT OF THE DRUM

THE MEANING OF MUSIC FOR FIVE FIRST NATIONS CHILDREN WITH AUTISM IN BRITISH COLUMBIA, CANADA
Anne Lindblom

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**ABSTRACT**

This dissertation set out to examine the meaning of music for First Nations children with autism in BC, Canada. The research questions addressed were: How can the diagnosis of ASD be seen through a First Nations lens? How do the First Nations children with ASD use music? In which ways is music used in different domains? In which ways is music used to facilitate inclusion? How is traditional music used?

The dissertation is based on four original articles that span over the issues of under-detection of autism among First Nations children in BC, ethnographic fieldwork, and the paradigmatic shift to Indigenist research methodologies, the role of music in social inclusion and a First Nations lens on autism, the use of Indigenous music with First Nations children with autism, put in context with First Nations children’s rights. Material was collected during six week periods in two consecutive years, generating data from conversations, follow-up conversations, observations, video-filmed observations, and notes. Post-colonial BC, Canada is the context of the research, and issues of social inclusion and children’s rights are addressed. During the research process, a journey that began with an ethnographic approach led to an Indigenist paradigm.

It was found that colonial residue and effects of historical trauma can influence First Nations children being under-detected for autism. The First Nations children diagnosed with autism in this study use music in similar ways to typically developing children and non-Indigenous individuals with autism. These uses include for communication and relaxation, for security and happiness, to soothe oneself and when studying. However, music interventions in school settings are not culturally sensitive. Music as a tool for inclusion is overlooked and Indigenous music not utilized outside of optional Aboriginal classes. The most important lesson of the study was the significance of reciprocal experience, emphasized by the Indigenist paradigm. It can be suggested that carefully designed, culturally sensitive music interventions, in collaboration with traditional knowledge holders and Elders, would be beneficial for the development of First Nations children with autism. Consequently, culturally sensitive music interventions could have potential to ensure that the children’s rights are respected. For these interventions to be culturally adequate, specific Indigenous Knowledge must be the foundation.

**Keywords**: First Nations, Autism, Music, Indigenist research methodologies, Inclusion
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TIIVISTELMÄ


Väitöskirja perustuu neljään artikkeliin, jotka käsittelivät lasten oikeuksien kannalta alkuperäiskansojen lasten autismin alidiagnosointia, musiikin asemaa sosiaalisessa inklusiossa ja alkuperäiskansojen näkökulmaa autismiin ja perinnemusiikin käyttöä alkuperäiskansojen lapsilla. Aineisto kerättiin viikon jaksoina kahdeksan vuoden aikana peräkkäin vuonna ja se perustui keskusteluihin, seurantakeskusteluihin, videoointiin sekä muistiinpanoihin. Tutkimusprosessin kulussa etnografisesta lähestymistavasta siirryttiin indigenistiseen paradigmaan.


Avainsanat: alkuperäiskansat, autismi, musiikki, indigenistinen metodologia, inklusio
ACKNOWLEDGEMENTS

To my knowledge, I am the first person in my family to do a PhD. Perhaps this is due to my curiosity and persistence. I give credit for this to my mother Ann-Marie Sjögren (Larsson) and father Sven Sjögren, who have long passed, for moving from Vålberg to Vancouver (perhaps the title of my memoirs) when I was a baby. They let me explore boundaries and believe in my capabilities. Endless hours spent on the boat, on beaches, camping, watching wildlife, gave me an appetite for life and a craving for learning. For that, I thank them.

I want to thank my Indigenous family members in Canada; my stepmother Beverly Perry, paternal sisters Gina Perry, Linda Perry, and Candy Sjogren, my nieces and nephews, and other more distant relatives. Without you I never would have been able to do my PhD on this topic. I love and miss you always. Mike and Rose Bertacco, thank you for taking me in and giving me the royal treatment. Thanks John Bertacco and Cia Perry for your help too.

I want to give special thanks to all the Indigenous research partners involved in my research project. Your contribution is greatly appreciated and has the potential to benefit the lives of Indigenous individuals with autism and their families, not only in Canada, but around the globe. Thank you to the people of the Lake Babine Nation who have welcomed me in their activities and lives since I first visited the reserve in Burns Lake BC in 1998 whilst doing teacher training. I would also like to acknowledge the holders of Indigenous knowledge who are guiding me in my learning process. Thanks to Doctor Dawn Adams, who gave me the courage to believe in myself enough to make a paradigm shift. Thank you to my friends within Student Storytellers Indigenizing the Academy, SSITA, Doctor Jessica Venable, Christiane Rudmann, Frank Sage, and Jimi Del Duca for your inspiration and support. You gave me confidence to spread my wings.

My supervisor team has been essential in commencing and completing the dissertation process. Thank you Tero Timonen, Adjunct Professor, for assisting me in getting accepted for doctoral studies and having faith in my idea and capability throughout the whole process. Thank you, Professor Hannu Räty for providing guidance regarding the rules and regulations within Finnish academia and keeping me on track without setting boundaries for my ideas. The two of you also have been helpful with support letters that have assisted me in getting grants and stipends. Professor Grace Iarocci, you received me well when I first came to Vancouver to search for participants, for that I am grateful. Professor Carin Roos, it has been good to have a supervisor on speed-dial and in the same department in order to get quick, and honest, feedback.

Here, I would like to thank both of my pre-examiners for their contribution to my dissertation process. I am ever grateful to Doctor Lori Lambert, founder of the American Indigenous Research Association, who became my teacher in courses on Indigenous Research Methodologies, and finally, a pre-examiner of my thesis. Associate Professor Elena Kontu, your insightful comments helped me with the final touch to the thesis, and my thanks for acting as the opponent in the public examination of this dissertation. My sincere thanks to both of you.

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I met Reverend Dr. Howard Worsley, Joanne Jalkanen, and Katja Dindar at an Erasmus research methods course in Turkey in 2013. Howard, you set my head straight when
I was in deep distress. Joanne, you are a dear friend and I couldn’t have made it without your support and reality checks. Special thanks for proofreading of my final version of the summary. Katja, we are in touch almost daily via chat and weekly on Skype. My sanity has depended on our discussions. Soon, the three of us will have completed our PhD processes but I know we will find lots of topics to discuss in the future.

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I acknowledge that the knowledge generated from this research endeavor is relational and cannot be discovered or owned, as it belongs to the traditional lands and communities in BC where the research took place (Adams, Wilson, Heavy Head & Gordon, 2015). The most important lesson learned during this dissertation process has been starting to understand reciprocal relationality. I now know that the reason for my success in working with children with autism is nothing that I can learn in a university course or teach others, they must work to establish their own relationships. It was the relationship I had with the pupils and with the music itself. The reciprocal relationship, in which the pupils and I contributed and participated, was one of both learning and teaching, where we all were learners and teachers simultaneously. I hereby thank all my former, current and future pupils and students for teaching and assisting me on my personal and professional journey. In realizing this, other things and events in my life have fallen into place. The relationships developed between myself and my research partners in the research are strong which has strengthened my connection to the land, the various places in BC, that I have visited. Wilson (2008, p 137) says that research is ceremony and “The purpose of any ceremony is to build stronger relationships or bridge the distance between our cosmos and us”. My aspiration is that this dissertation can bridge the distance between Western academia and Indigenist research and researchers, even if it is just with a tiny baby step in that direction.

Another lesson is that I, as a researcher, have been as much in focus and under the microscope, as the meaning of music for the First Nations children with autism. In fact, I have learnt so much about myself in relation to everything around me, and nothing will ever be the same again. Through the research process, I myself have become more distinct. My ethics, my world view, my relationships, and my identity as a Swedish woman, mother, grandmother, wife, singer, teacher, farmer, biker, and researcher, all of which I am, are clearer and are more in balance and harmony. I thank all my relations.

This research was made possible by The University of Eastern Finland; Karlstad University, Sweden; Stiftelsen Kempe- Carlgrenska Fonden, Sweden; Stiftelsen Lars Hiertas Minnesfond, Sweden; Helge Ax:son Johnssons Stiftelse Sweden and Harald och Louise Ekmans forskningsstiftelse.

Torpstöd Bräten, Sweden. February 17th, 2017

Anne Lindblom
LIST OF THE ORIGINAL PUBLICATIONS:

The dissertation is based on the following original peer-reviewed publications:


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1 INTRODUCTION

1.1 BACKGROUND

First Nations, Autism Spectrum Disorder (ASD) and music, in the context of post-colonial British Columbia, Canada, are the focus of this dissertation. Indigenous populations and autism prevalence is an emerging field of interest in global research, but so far there is a dearth of empirical studies. This dissertation aspires to start filling the gap by providing a unique glimpse of the meaning of music for First Nations children with ASD, and how music, both traditional Indigenous and contemporary Western, holds many possibilities to promote development in areas in which the children with ASD experience difficulties. This dissertation is meant to be a contribution to the decolonization of Western research, and strives towards a more competence-based and culturally-appropriate approach when designing research projects and support interventions for First Nations children with ASD. Furthermore, as the title suggests, the beat of the drum is essential for all First Nations, and access to it can be a step towards decolonization, which is a topical theme in the daily lives of Indigenous peoples all over the globe. This also entails a discussion of the diagnosis of autism itself. The order of this text is designed to guide the reader into a complex context of which many non-Indigenous individuals, within and outside of academia, are unaware. In the introduction, the significance of the researcher’s background will be depicted, as without tribal connections, this research endeavor would not have been possible.

A research and literature overview outline the setting, followed by the design of the research, aim and research questions. The shift from ethnography to an Indigenist paradigm is presented along with the methods and procedures for data collection and analysis. The results are presented through summaries from the four original articles the dissertation is based on. Finally, the results are discussed and ideas on future research are presented. But first, a short personal introduction.

Indigenous peoples introduce themselves by telling about their family and life history (Lambert, 2014; Wilson, 2008). By doing so, it is possible for others to establish if they know who your relations are and start building a relationship with you. It is also a part of relational accountability which gives credibility as a researcher, so, this is how I choose to start my presentation. My name is Anne Lindblom, brought into this world in 1958, two months early, by my mother Ann-Marie (born Larsson) and father Sven Åke Ludvig Sjögren. They named me Ann-Charlotte, but growing up I called myself Anne, and later I acquired the name Lindblom in marriage. My mother’s family has lived in Värmland, Sweden, for generations to my knowledge. She had seven brothers and the family is well known in the community. My father was born in Holland where his mother had gone for work. The two of them moved back to Sweden when he was two years old. He never knew his father or Dutch family, but knew most of his Swedish relatives. Although he grew up in Vaxholm, close to Stockholm, most of the family lives in southern Sweden where they come from. My father joined the Marine Corps music program when he was ten years old, played the French horn, and went to sea. It was a ship that years later brought him to the lumber mill where my mother worked in the mid-1950’s and a ship that in 1959 brought the three of us to Canada, which came to be our new home. My mother and father gave
me two sisters. I am also the step-daughter of Beverly Perry of the Lake Babine Nation, who my father met years after my parents’ divorce and started a new family with. She is the daughter of respected Elders John Perry and Jessie Perry. My stepmother gave me a sister, and her and my father gave me another two. I am a mother of two. My daughter Rebecka and son Johan have given me five grandchildren (so far). My sisters all have children, my nieces and nephews, and their families are very dear to me as well. I have been blessed with a large family on two continents.

For as long as I can remember, music has been an important part of my life. At home, in Vancouver, only classical music was played. Swedish music was rare in our house. Perhaps some songs were played around Christmastime, but not otherwise. I started taking classical piano lessons at the age of five, and moved on to other instruments and choir as I grew older. There was not much cultural diversity in our neighborhood, and by the time I started school, I did not speak or understand Swedish anymore, and considered myself to be Canadian. The music I heard at home, at school, and when hanging out with friends was either classical music or rock and pop music. At the age of fourteen, my mother, my sisters and I moved back to Sweden in 1972, a few years after my parents’ divorce. With the exception of a few Swedish folksongs, the repertoire in Swedish school was similar to that of the Canadian school music curriculum. Interestingly, I never reflected on this, nor did I question the musical choices made. Thanks to my stepmother and my three paternal sisters, who are First Nations, my eyes were opened to Indigenous concerns. I had never heard of Residential Schools or cultural genocide. I had never reflected on the marginalization of Indigenous peoples in Canada, as this was well hidden from our history books in school. Nor did I reflect on the fact that the Swedish Sami people experienced similar treatment in my home country. During teacher training in Burns Lake, BC, I witnessed inequity, marginalization, and racism towards the First Nations pupils, which sparked my research interests.

Children and pupils who do the unexpected, or behave differently than others, have always interested me. As a temporary music teacher, I noticed that after music class the rambunctious boys usually wanted to stay in and play instruments rather than take a break. Music became our communication, and even if they just knew a couple of chords, we could jam together. Eventually, I became a music therapist, then a music and English teacher, and started working in a remedial group of four to six pupils with behavioral difficulties. There I had the opportunity to interact using music as medium. Music gave us a mutual foundation, mutual experiences, and joy. The pupils went on tour with their band, recorded music, but most importantly, found themselves and could relate to others through music. After a while, I noticed that I had particularly positive interactions and results with pupils diagnosed with Autism Spectrum Disorder, ASD. Most of the adaptations and interventions I tried worked. I have spent many years of reflecting, taking courses, reading literature, and talking to my former pupils, trying to figure out what I did right and how I could get others to do it too.

Upon entering the PhD process, I had dreamt of doing research on music therapy and First Nations children with school difficulties in BC, Canada, since 1992. After 19 years of hard work to get there, I assumed that the Canadian context would be similar to that of Sweden, and that it would be quite easy to find First Nations children with ASD in BC. After a visit to Vancouver to network and find research partners, it was disappointing to discover that there were few to be found. Of the six families that eventually were contacted, one did not want to participate. A literature review revealed
that autism appears to be under-detected among First Nations and other Indigenous populations across the globe (Lindblom, 2014). Furthermore, to my knowledge, there is no research on First Nations, autism, and music.

During my quest for a PhD, I have acquired more knowledge, refined my ideas, and moved on to teaching Special Education at Karlstad University, Sweden. Wilson (2008, p. 135) says “If research doesn’t change you as a person, then you haven’t done it right.” A gradual shift occurred during my research journey, moving from using ethnography to a critical-stance-inspired approach that was ultimately overtaken by an Indigenist paradigm. This proved to be a life-changing and somewhat challenging process. The personal, and professional, journey will continue after the defence of my dissertation and completion of the PhD.

Discourses are constantly evolving and it is important to stay updated on the field to use respectful terminology (American Psychological Association, 2012). In this text, the terms First Nations and Indigenous, which often are preferred by the persons involved, are used. Indian and Aboriginal are used when referring to official documents that still use them. These are names given by the colonists, and therefore, I aspire to use a more respectful terminology. Indigenous will also be used regarding things that are tribally specific, such as ceremonies, songs, and protocols, that are unique and proprietary. Wilson (2008, p. 15) points out the political implications connected with the word Indigenous. In the context of my research, this means that colonial residue, systemic racism, and other issues that are relevant to the lives of Indigenous people must surface and be explored. The term Indigenist will be used regarding the research paradigm and the philosophical aspects (see discussion in Adams, Wilson, Heavy Head & Gordon, 2015). In an attempt to balance power relations, the term research partners will be used instead of participant, unless referring to a Western research publication. Using the term conversation instead of interview is intended to reflect the development of the reciprocal relationship between myself and the research partners. Labels given to people with disabilities can also be offensive. Power is embedded in the words we use, and as professionals, it is important to “challenge stigmas associated with disabilities” (Darrow, 2015, p. 209). In this text, I will use the person first approach, a child diagnosed with autism. Autism Spectrum Disorder, ASD and autism will be used interchangeably in this dissertation.

1.2 FIRST NATIONS

In Canada, three Aboriginal peoples are acknowledged by the Canadian constitution. These peoples are 1) Indians (which still is the term used in many official documents for First Nations), 2) Metis, and 3) Inuit (AADNC, 2015). In this research project the research partners are all from First Nations. Although all of them come from BC, the geography of BC is diverse which will impact on their specific tribal knowledge and cultures. The coast of the Pacific Ocean defines the boundary to the west, there are plains areas, but the province is also very mountainous with the Rocky Mountains as a boundary to Alberta. There are 198 First Nations communities in BC, Canada, which is approximately one third of Canada’s First Nations (Aboriginal Affairs and Northern Development, 2010). The language and culture of First Nations are deeply and complexly linked (Kovach, 2009). This means that there are many variations of knowledge systems in BC. Worldviews and culture are discussed in the methodology section below.
The first Indian Residential Schools in Canada were in operation from 1867 (Truth and Reconciliation Commission of Canada, 2015). The ongoing gathering of statements from former students of Indian Residential Schools, often referred to as survivors, has brought many hidden stories into light, opening wounds that people have tried to heal in silence for years. This may go some way towards explaining the lack of trust in authority perceived as colonial. It is easy to think that cultural genocide is something of the far past, but the last Canadian residential school for Indigenous children closed in 1996 (Bradley, 2015). First Nations schools and education do not create sufficient educational experiences for First Nations pupils (Morcom, 2014) and underfunding is only one of the issues they face in post-colonial Canada. Today’s school system still lacks in providing First Nations children with knowledge and understanding of their language and culture, values and beliefs and knowledge systems, even if it is not as “aggressive as a residential school” (Morcom, 2014, p. 4). In the article, Morcom examines The First Nations Education Act and the policy of the Assembly of First Nations and concludes that their content differs on crucial points. Whereas the Federal Government’s proposal entails the study of culture and language, the Assembly of First Nations advocate language and culture immersion. The latter is more beneficial for students according to Morcom, and would require culturally-knowledgable, Indigenous teachers.

There are many rules and regulations regarding Aboriginal peoples. First Nations individuals can be registered Indians according to the Indian Act (Justice Laws Website, 2016). Usually, this is referred to as being a Status Indian. Having status entitles the person to provincial and federal programs and services, which vary depending on the province of residence. Over the years, the rules and regulations have changed, thus affecting who is eligible for status (Aboriginal and Northern Development, 2013). People who self-identify as First Nations, but are not eligible for registration, are commonly called non-Status Indians (Aboriginal and Northern Development, 2012). Johnson (2015, p. 237-238) refers to the Indian Act as “the racist, sexist, and paternalistic legislations known as Canada’s Indian Act”. First Nations individuals can live on reserve land or off reserve. In this study, there are research partners with and without status and those who live on and off reserve.

1.3 AUTISM SPECTRUM DISORDER, ASD

Autism Spectrum Disorder can be seen as a diagnosis based on a medical, deficit model of disability. This way of thinking does not fit within Indigenous worldviews, in which all people are valued for who they are. Kapp (2011) writes about the wellness philosophy within the Navajo culture, which is inclusive and accepting, thus more supportive for people with autism than the medical model of disability. Furthermore, the Navajo did not have a word for disability, and they have a “particular balance on supporting wide individuality within an orientation to the family clan and community” (Kapp, 2011, p. 585). By requiring an official label, whether it is a diagnosis or being recognized as Indigenous, Kapp argues further, that the Western model disables both these groups. At the core of the Navajo wellness philosophy lies spirituality, positive thinking, relationship, reciprocity and discipline, which contrasts with Western “materialism, competition, self-indulgence, and environmental degradation” according to Kapp (2011, p. 589). In another Indigenous context, traditional Māori values are inclusive, and incorporating these values into education and support services will
benefit Indigenous individuals with autism or other disabilities (Bevan-Brown, 2013). In addition to provision of culturally appropriate support for Māori, it is concluded that inclusion for all individuals, Indigenous or non-Indigenous, would be promoted by the incorporation of Māori values.

Autism and other disabilities can also be seen as socially constructed within a certain culture and can lead to marginalization (Darrow, 2015). Our understanding of autism continuously changes and is still under development, much due to research results, but also through the life narratives of individuals on the spectrum. These narratives are essential to our perceptions and definitions of ASD (and other labels), and accentuate the power of those who assess and set the diagnosis (Bradley, 2015). According to Lopez (2015), there is a risk that current research views autism as a static condition separate from social context. In my research, the social context is included, and the intent is to presume competence (Biklen & Burke, 2006).

As the five First Nations children in this study have been diagnosed with autism, this gives cause to recount the traits that are attributed to ASD within the medical, deficit model. Diagnostic criteria for ASD are deficits in social interaction and communication, and restricted, repetitive behaviors (American Psychiatric Association, APA, 2013). Originally, Kanner (1943, p248) spoke of “extremealoneness from the beginning of life”. Although our understandings of what lies behind the representations of autism have changed, the descriptions of the cases that Kanner recounts are still relevant to the diagnosis today. The prevalence of people diagnosed with autism has risen worldwide and has been reported to be approximately 1% (Autism Europe, 2016; Government of Canada, 2015). Changes in diagnostic criteria over the years make it difficult to compare studies from the past and current research studies (Matson & Kozlowski, 2011). Although autism is described as a diagnosis implying disabling symptoms in some or all aspects of a person’s life, some individuals diagnosed with ASD have excellent skills in visual abilities, music, math and art (Autism Speaks, 2016). Visual support is often used in interventions and support for persons diagnosed with ASD (Meadan; Ostrosky; Triplett; Michna & Fettig, 2011; Rao & Gagie, 2006). Since early identification of autism, the interest in and aptitude for music has been apparent (Kanner, 1943).

Approximately 25% of individuals diagnosed with ASD are non-verbal and they may also be diagnosed with other associated, or comorbid, conditions such as ADHD and intellectual disability (Autism Speaks, 2016). Problematic behaviors and reactions can be due to comorbid psychiatric disorders. In a study by Leyfer, Folstein, Baalman, Davis, Dihj, Morgan, Tager-Flusberg and Lainhart (2006), specific phobia, Obsessive Compulsive Disorder (OCD) and Attention Deficit Hyperactivity Disorder (ADHD) were high in prevalence among individuals diagnosed with ASD. The researchers emphasize the importance of assessing comorbid conditions and disorders in order to provide adequate treatments and support. Jang and Matson (2015) studied data on 207 individuals, ages 2-16, that all had received an ASD diagnosis from a licensed clinical psychologist with long experience. The results showed that individuals with severe autism symptoms had more comorbid symptoms. “Specifically, tantrums, repetitive behaviors, and avoidant behaviors were predicted by severity of ASD symptoms” (Jang & Matson, 2015, p. 410). In my study, there are children who only have the diagnosis of ASD, have comorbid diagnoses and/or are minimally verbal. Their autism diagnosis and autism representations, however, are the reason they are participating in the research.
1.4 SPECIAL NEEDS CATEGORIES AND BC AUTISM FUNDING

In British Columbia, the Ministry of Education offers special needs services (British Columbia Ministry of Education, 2013). There is a set of special needs categories that can be assigned to a pupil. The categories are: intellectual disabilities, learning disabilities, gifted, behavioral needs or mental illness, physically dependent, deafblind, physical disabilities or chronic health impairments, visual impairments, deaf or hard of hearing and Autism Spectrum Disorder. Within the categories, there are three levels of needs which determine the funding for the school to assist them in providing appropriate education for the pupils. Autism is a level 2 category, and for the pupil to be eligible for funding, a diagnosis must have been made by qualified professionals. “Students with diagnosed conditions should be identified in the educational category that best reflects the type and intensity of educational interventions documented in the IEP” (British Columbia Ministry of Education, 2013, p. 40). This means that if the student has comorbid diagnosis, the interventions determine which special needs category is assigned. All the children in this study have or have previously been assigned an autism special needs category in their school.

In addition to funding in schools, BC has autism funding that is available to families in order to be able to purchase interventions (British Columbia Ministry of Children and Family Development, 2016). A substantial amount of funding can be applied for, a higher figure for children under six and a lower amount for children from 6-18 years of age. In this study, the BC autism funding system has relevance for one of the families.

1.5 MUSIC

In this dissertation, music is seen as something essential to all humans and as a human right. All kinds of music, from humming, making noises, and banging on objects, to singing, creating music, playing instruments, and listening to music, are investigated in this study. Different settings for the music, such as school (music education, interventions and therapy), after school club and home, are included. Within many Indigenous cultures, such as First Nations and Sami, music and the drum are of integral significance. In the words of Lambert (2014, p. 2), “Our sense of community and place, the beat of our drums, and our hearts and minds connect us to one another”. Everything in creation is living, so also the drum and music, therefore they have agency. In a relational, reciprocal worldview, a relationship must be developed between the human and the drum and the music. Consequently, music has agency, as does Knowledge according to Adams, Wilson, Heavy Head and Gordon, 2015. Kroik (2007, p. 60) describes the Sami drum as “a tool that was the foundation of their survival” (my translation).

Making music is “the quintessential human cultural activity, and music is a ubiquitous element in all cultures large and small” (Brown, Merker & Wallin, 2000, p. 3). Molnar-Szakacs and Heaton (2012) refer to the ability to enjoy music as a human trait. For most teenagers, listening to music outside of school is an important activity which they spend much time doing (North, Hargreaves & O’Neill, 2000). North and Hargreaves (1999) discovered that adolescents find people who like the same kind of music as them more favorable. However, not all experiences with music are beneficial for the individual. In a review of empirical evidence, Hallam (2010) found that the experience of music must be rewarding and enjoyable to have positive impact on the individual’s development in intellectual, social, and personal areas.
2 RESEARCH AND LITERATURE OVERVIEW

2.1 FIRST NATIONS AND DISABILITY

Although there are many First Nations communities and individuals, not much has been published about their experiences of disabilities (Weaver & Yuen, 2015). First Nations cultures are traditionally inclusive (Kapp, 2011; Weaver & Yuen, 2015) and individuals are valued for what they bring to their families and communities. In most Western cultures, independence is valued, while interdependence is valued in many First Nations cultures (Weaver, 2015). This fundamental difference will inevitably impact the lives of First Nations individuals diagnosed with disabilities, as they most likely are reliant on the dominant culture’s support systems, even if they live on reserve land and have access to their own culture. Weaver (2015, p. 160) depicts disability through an American First Nations lens, and concludes that within social work, the discourse on decolonization and disability, unfortunately, is outside of “mainstream social work scholarship”. There are innovations and programs in tribal communities, but these are rarely known outside of the community (Weaver & Yuen, 2015), and emphasize the importance of recognizing the cultural context. Judging by the scarcity of scientific publications on First Nations and disability (including autism) in Canada, the situation appears to be the same in the Canadian context.

There is a global branch within the field of psychology that focuses on Indigenous psychology and seeking culturally appropriate methods of healing and conducting research (Lambert, 2014). Beals, Manson, Mitchell, Spicer & the AI-SUPERPFP team (2003) describe challenges that face researchers and service providers in the context of culturally diverse populations. Most research is done with large samples and methods that are not culturally adapted, which poses difficulties. The authors point out several incidents where the medical, deficit model conflicts with an Indigenous world view. For instance, having a vision, which in Indigenous spirituality would be common, but in a Western paradigm be a symptom of a psychotic disorder. Within research in psychology and First Nations, most of the publications I have found are about mental health and substance abuse, and attempts are made to incorporate traditional healing methods.

2.2 FIRST NATIONS AND AUTISM

It is difficult to find publications on First Nations children with ASD in BC, Canada, and autism appears to be under-detected within this specific group (Lindblom, 2014). Dapice (2006) says that American Indians are invisible in statistics and history books. Burstyn, Sithole and Zwaigenbaum (2010) examined births in Alberta, Canada, between 1998 and 2004 and followed up on assigned ASD codes through physician billing. They found that children of Aboriginal mothers had a lower rate of diagnosed ASD, and they were diagnosed later. Oulette-Kuntz et al. (2006) examined data from two provinces in Canada, Manitoba, and Prince Edward Island, and note that Aboriginal children are perhaps not detected or diagnosed due to their parents not seeking help or the lack of cultural sensitivity in diagnostic tools. The publication by Kapp
(2011) is the only one that specifically focuses on autism in a First Nations context, although it is about the Navajo in the United States of America (USA) and does not include empirical data.

2.3 INCLUSION AND THE RIGHTS OF INDIGENOUS CHILDREN

Indigenous peoples’ rights are enforced in the Declaration on the Rights of Indigenous Peoples (United Nations, 2008). Effects of colonialism are addressed as well as the respect for traditional practices and Indigenous knowledge and culture. Furthermore, Indigenous peoples and individuals have the right not to be subjected to forced assimilation or destruction of their culture. Issues of genocide and removal of children, which many Indigenous peoples have been subjected to, are also mentioned. Children’s rights are stipulated in the Convention on the Rights of the Child (United Nations, 1989). There it is stated clearly that the child should be protected from any kind of discrimination, and that the best interests of the child should be the priority at all times. Children have the right to express their views on matters regarding themselves. The rights of Indigenous children are doubly protected through these declarations.

Participation and interaction are key concepts of inclusion. Inclusion and the right to be included in school settings and in society are articulated in policy documents on national and international levels. The BC Ministry of Education (2013) declares that:

Inclusion describes the principle that all students are entitled to equitable access to learning, achievement and the pursuit of excellence in all aspects of their education. The practice of inclusion is not necessarily synonymous with integration and goes beyond placement to include meaningful participation and the promotion of interaction with others. (p. V)

This implies that it is not enough for a student to be placed in the class setting. The Salamanca Statement (UNESCO, 1994) stipulates that special needs education and inclusion are important issues for all countries. Child-centered pedagogies in school systems that are equipped to address diversity in the regular classroom are stated to be essential to battling discrimination and creating inclusive societies. The Incheon Declaration (UNESCO, 2015) strives towards equitable, inclusive education for all and builds upon the foundations of the Education for all movement. Social justice and inclusion are integral parts of the declaration. Cultural, linguistic and ethnic diversity is discussed as essential. Inclusive education is proclaimed to be crucial for the promotion of human rights and democracy. Individuals with diagnosed disabilities are particularly in focus regarding exclusion and marginalization. Indigenous children diagnosed with disabilities are considered as a marginalized and vulnerable group.

2.4 MUSIC AND MUSIC EDUCATION

Art and creative processes, in addition to other ways of knowing, have a role in Indigenous learning. Knowledge has agency and cannot be created, but is received by humans (Adams, Wilson, Heavy Head & Gordon, 2015). Wilson (in Adams, Wilson, Heavy Head & Gordon, 2015, p. 20) tells a Dakota story of how the flute came to be. A long, hollow stick had been drilled by a woodpecker so it had holes in it. A hu-
man happened to be present when the wind blew through it. The flute had not been invented but “Knowledge was translated from its source through the medium of wood, wind and woodpecker to the person who was watching and listening” (Adams, Wilson, Heavy Head & Gordon, 2015, p. 20). The relationality of knowledge makes participation necessary. In some cultures, the drum is believed to be “the heartbeat of the earth, the drum is the pulse of the Creator, the heartbeat of the Creator” (Elder Ed Onabigon, in Neil, 2000, p. 284). The Anishabe Elder goes on to tell how the teachings of the drum, and other teachings, teach about “the oneness of all creation with the Creator”.

Music education has the potential to counteract inequities. Bradley (2015, p. 195) points out that in North America, music education promotes Western music and consequently cultural whiteness, and cultural superiority is assumed in many school music programs. According to Bradley (2015, p. 200) the choice of repertoire can colonize or emancipate, and she suggests that White teachers think that they cannot use non-Western music with authenticity, which causes them to avoid including different types of music. Such challenges should be attended to. Hargreaves et al. (2007) point out that music teachers in the United Kingdom (UK) usually are trained in accordance with Western classical tradition. According to Saunders (2010, p. 72), “Music teachers may feel most comfortable teaching the music they know, in the way that they were taught and in the way that they were taught to teach it”. This will ultimately influence the content and nature of music education and music interventions. Kovach (2009, p. 28) says, “From an Indigenous perspective, the reproduction of colonial relationships persists inside institutional centres.” There is a need to raise awareness of the possibly reproductive and oppressive practices in school settings.

In Australia, Elders from the Indigenous community were involved in a project striving for reconciliation and reciprocity between cultures (Bartleet, Bennett, Marsh, Power & Sutherland, 2014). The project was about art-based service learning in Indigenous communities. Both Indigenous and non-Indigenous students were engaged in the project. Key concepts, that also are essential within Indigenous research methodologies, were defined including relationships and reciprocity.

Lubet (2011, p. 57) states, “Participation in music is both a human right and a disability right”, and describes music as a “vital human activity”. Furthermore, he describes music as a social activity that is learned and emphasizes music’s possibilities for participation and inclusion. Disability is an aspect of human diversity that must be addressed within the school context. Historically, children with disabilities were not educated, but in most countries inclusive practices are advocated. Segregation on the basis of disability in school context still occurs. Darrow (2015, p. 210) states that “Ableism in schools occurs when physical, attitudinal, social, or educational barriers are posed that prevent students with disabilities from successful inclusion.” For children diagnosed with ASD, social barriers can be a great challenge.

Heyworth (2013) conducted a study in an Australian school in which music was strategically used in a socially and economically disadvantaged area. The children were from diverse backgrounds, including Aboriginal and Torres Strait Islander. In the studied school, music was actively used to give the pupils a sense of belonging. Allowing the pupils to have positive musical experiences makes “music a powerful tool for social learning” (Heyworth, 2013, p. 235). Music contributed to the inclusive culture in the school.

In a study of three music teacher’s inclusive approaches to youth who either under-achieve or have low attendance, Burnard (2008, p. 59) found that “democratizing
music learning as a social practice” was a key factor in working with students with challenging behavior. Respect and building democratic relationships helped build a foundation for the students developing self-worth and identity. Revaluing marginalized groups and embracing cultural diversity were also seen as essential parts of the foundation of inclusive music education.

Darrow (2014) puts focus on challenges that pupils diagnosed with disabilities meet at school in the form of bullying and non-acceptance from peers. She stresses the need for these pupils to acquire skills and increase their social competence in order to meet these obstacles. Music education has the potential to offer possibilities to practice skills that will enhance social and emotional development.

Music therapy can be practiced as an expression of social justice. Curtis (2012) describes community music therapy with the focus of using the music groups and functions to move marginalized people to the center of the community but also changing attitudes within the community. She also explains that feminist music therapy focuses on power and privilege which includes other oppressions such as ableism and racism. Baines (2012) investigates the risk of advancing colonial goals and oppressive practices in music therapy. She suggests an anti-oppressive music therapy practice that addresses power imbalances due to, for instance, class, ethnicity, geographic location, and ability. This is considered to be an emancipatory approach. Furthermore, Baines (2012) stresses the fact that music therapy in Europe and the USA lies on the foundation of Western European music. “When music educators model inclusive practices that honor human diversity, students are more likely to act in service of a more just society in their adult lives.” (Darrow, 2015, p. 216).

### 2.5 MUSIC AND AUTISM

Historically, music has been used in work with pupils diagnosed with disabilities. “Music has been used as a way to facilitate learning and to reinforce students’ academic achievements” (Darrow, 2015, p. 206). Furthermore, Darrow notes that knowledge about a pupil’s diagnosed disability is needed and increases the opportunity for teachers to accommodate the pupils’ needs. A great deal of research has been done on music and individuals diagnosed with autism. For instance, Allen, Hill and Heaton (2009) found in their interview study with 12 high functioning individuals with ASD, that the participants, like typically developing individuals, use music for different purposes. Music was used to manage moods, but the participants had difficulty verbalizing their experiences and feelings. Furthermore, music made them feel less lonely and gave them a sense of belonging. Music was also used for social inclusion and personal development. In a pilot music program, Hillier, Greher, Poto and Dougherty (2011) found that self-reported anxiety was reduced, there was a significant increase of self-esteem, and the adolescents and young adults diagnosed with ASD were more positive towards peers.

Improvisational music therapy was shown to enhance motivational, emotional, and social development in a study involving ten children diagnosed with ASD in Korea (Kim, Wigram & Gold, 2009). The children expressed more happiness and took more initiative when they were leading and controlling the musical interaction. A study involving six adolescents diagnosed with ASD in Turkey used group music therapy sessions where the participants interacted in, for instance, rhythm games, body percussion, creative movement and dance (Eren, 2015). The participants initiated and sustained social interactions during the music therapy sessions.
In a review of 20 publications on music interventions and individuals diagnosed with ASD, Simpson and Keen (2011) conclude that the aim of the interventions has been to enhance the social, behavioral, and motivational skills of the participants. They also point out that the research has been done on small samples, and stress the need for further research to investigate if the participants maintain and can generalize these skills. James et al. (2015) conducted a review of publications on music therapy and individuals with ASD. Twelve studies were included in the review, and although some reported mixed outcomes, 58% of the outcomes were positive. Music therapy was used to address issues such as behavior, social interaction, dependence, understanding emotions and communication. The reviewers conclude “that music therapy is a promising practice for individuals with ASD” and that further research is needed (James et al., 2015, p. 39). Molnar-Szakacs and Heaton (2012) state that many individuals diagnosed with autism show strong preference for music early on in their lives.

*Music, as a form of nonverbal communication, constitutes a domain of preserved skills and interest and is a powerful and accessible affective stimulus that captures and emotionally rewards individuals with ASD.* (Molnar-Szakacs & Heaton, 2012, p. 322)

Accordingly, research on music and music interventions with individuals diagnosed with ASD reports results that can have impact on the nature and design of these interventions and, consequently, on the individual’s development.
3 AIM AND RESEARCH QUESTIONS

The major aim of this study is to investigate the meaning of music for First Nations children in British Columbia, Canada, diagnosed with Autism Spectrum Disorder, ASD. Furthermore, the study aspires to contribute to the existing body of knowledge about First Nations children diagnosed with ASD. The following research questions are addressed:

- How can the diagnosis of ASD be seen through a First Nations lens? (Articles 1, 2, 3 and 4)
- How do the First Nations children diagnosed with ASD use music? (Articles 3 and 4)
- In which ways is music used in different domains? (Articles 3 and 4)
- In which ways is music used to facilitate inclusion? (Article 3)
- How is traditional music used? (Articles 3 and 4)

The purpose of the literature and research review was to assess the current situation of First Nations children diagnosed with autism in Canada. The search revealed a dearth of research on autism and music in the context of First Nations, which resulted in the first original publication; Under-detection of autism among First Nations children in British Columbia, Canada (Lindblom, 2014). The second publication addresses challenges and opportunities in this research endeavor; Thoughts and Experiences from Ethnographic Fieldwork with First Nations (Lindblom, 2016c). The research questions are addressed and discussed in the third and fourth publications; ‘It gives them a place to be proud’ - Music and social inclusion. Two diverse cases of young First Nations people diagnosed with autism in British Columbia, Canada (Lindblom, 2016b) and Autism and music interventions through a First Nations lens (Lindblom, 2016a) submitted for publication. Summaries of the articles will be presented in the results section of this dissertation.

During the research process, a shift from a Western paradigm to Indigenous world-views and research methodologies took place, which made a fundamental change in the research approach and outcome. This paradigmatic shift can gradually be seen in the four articles, and is summed up in this dissertation, which reveals the understanding and implementation of an Indigenist paradigm I have at this point in my knowledge acquisition. Being a doctoral student entails learning the craftsmanship of research. Getting a PhD is the final step of the dissertation process but also the beginning of the onward journey towards deeper and more advanced comprehension and proficiency.
4 RESEARCH DESIGN

4.1 PARADIGM

When conducting research, philosophical assumptions help us explain our choice of methods. This is sometimes referred to as worldview or paradigm (Creswell, 2009). Crotty (1998) calls it philosophical stance or theoretical perspective. From the outset, an ethnographic approach was intended (Lindblom, 2016c), which corresponds with the social constructivist paradigm. Sometimes social constructivism is called interpretivism (Creswell, 2013; Denzin & Lincoln, 2011). The assumptions in this worldview are that “individuals seek understanding of the world in which they live and work” (Creswell, 2009, p. 8). In order to make sense of the participant’s meanings about the world, the context in which the participant lives, both historical and cultural, is important. Meanings are subjective, and the researcher is interested in multiple views (Creswell, 2013; Crotty, 1998).

One can see that although there are components of Western research and ethnography that can work well within an Indigenous research setting, there are certain aspects that are unique to Indigenous worldviews that contradict philosophical assumptions in Western research. Subsequently, in this dissertation process, the researcher’s background has set limitations and obstacles that have needed attention. During my research process, there has been a paradigm shift towards Indigenist worldviews and Indigenist Research Methodologies (IRM). Wilson (in Adams, Wilson, Heavy Head & Gordon, 2015, p. 20) has started using the term Indigenist instead of Indigenous to label the paradigm, and states, “This emphasizes that it’s a philosophical issue, not a claiming of ownership by one group of people. You can be a white Indigenist just like you can be a male feminist”. This is a relatively new branch of research in Western academia, and it is constantly being developed and refined by Indigenous scholars around the globe. I hereby emphasize that I position myself within this field and acknowledge that, as a non-Indigenous researcher, I am a learner not an expert. Nevertheless, I believe my research has potential to make a contribution to the decolonization of Western academia. As a doctoral student, I am also a learner, acquiring the necessary skills to conduct research. This dissertation, and the original publications it is based on, shows my progress during the PhD process, the relationship I now have with the knowledge that has come from my research and my understanding of that relationship.

Denzin and Lincoln (2011, p. 12) emphasize that decolonization of research is imperative and that “it no longer is possible for the human disciplines to research the native, the indigenous other, in a spirit of value free inquiry”. For decades, Indigenous researchers have defined the essential components of an Indigenous research design. Smith (2012) has influenced IRM and inspired many Indigenous researchers through her involvement in decolonizing research in the Māori context. Wilson (2008) explains an Indigenist research paradigm as a circle consisting of ontology, epistemology, axiology and methodology, and the parts are inseparable. “The whole of the paradigm is greater than the sum of its parts” (Wilson, 2008, p. 70). Ontology is about the nature of being and reality (Kovach, 2009). Crotty (1998) says ontology “is concerned with ‘what is’, with the nature of existence, with the structure of reality as such” (p. 10). Epistemology and ontology must fit together within the worldview. Within a relativ-
ist ontology, the assumption that there are multiple realities guides the researcher in the constructivist paradigm (Denzin & Lincoln, 2011). Within Indigenous ontologies there may also be multiple realities but “The difference is that, rather than the truth being something that is ‘out there’ or external, reality is in the relationship that one has with the truth” (Wilson, 2008, p. 73).

Epistemology is “a way of understanding and explaining how we know what we know” (Crotty, 1998, p. 3). According to Kovach (2009), “there is a fundamental epistemological difference between Western and Indigenous thought…” (p. 29). In some cultures, it is believed that teachings come from many places (Kovach, 2009), and some cultures are willing to share their knowledge (Battiste, 2008). Moreover, Indigenous knowledge systems are somewhat similar and are oral-based. Construction of tribal knowledge is connected to language. Being a Western researcher who does not speak the language can be a limitation. In this study, however, none of the children and only one of the other research partners are fluent in their First Nations language. In addition, access to knowledge can be acquired through dreams, ceremonies, prayer, and other cultural activities (Battiste, 2008; Kovach, 2009). Furthermore, talking with Elders and being attentive to the ancestors are also ways to gain Indigenist knowledge. Reflexivity is a valued type of knowing within Indigenous worldviews, and is an important part of the methodology (Kovach, 2009). Within Indigenist research methodologies “The act of sharing through personal narrative, teaching story, and general conversation is a method by which each generation is accountable to the next in transmitting knowledge” (Kovach, 2009, p. 14). Kovach (2009) also provides other forms of knowledge transmission, such as, sharing circles, story, protocol, feeling, spirit, experience, dream, ceremony, and prayer. Adams speaks of the importance of place; “The Land, or Place, participates in what happens as much as do the people” (in Adams, Wilson, Heavy Head & Gordon, 2015, p. 12). Although some of these forms are used within Western research paradigms, they are based on different sets of philosophical assumptions.

On the surface, it may look like ethnography and Indigenist research methodologies are a nice fit. However, the underlying philosophical assumptions do not correspond, which implies that, at some point, it will be necessary to make methodological decisions that either fit or collide with either one of the approaches. In my case, this ultimately meant that, after trying to fit the one into the other, I had to choose. My relationship to the all involved in the research, the knowledge given to me and to all in creation, demanded that I shed the Western constraints and embrace an Indigenist paradigm. Knowledge has agency and is relational (Adams, Wilson, Heavy Head & Gordon, 2015). This means that Indigenous knowledge “will do what it needs to do to protect itself or to make itself heard” (p. 15), and that working together in relation is the way to learn and be given knowledge. In this project, Indigenous knowledge was given to me by First Nations individuals in BC. However, not all the knowledge given and lessons learned are shared in the dissertation in accordance with Indigenous protocol. Within an Indigenist paradigm, knowledge cannot be owned by an individual and cannot be discovered “but is merely a set of relationships that may be given a visible form” (Wilson, 2008, p. 127).

Giving back to the community is essential (Kovach, 2009), and tribal knowledge is connected to place (Gray, 2013; Kovach, 2009). Many Indigenous knowledge systems are “holistic, relational and even spiritual” (Kincheloe & Steinberg, 2011, p151). Madden (2014, p. 59) refers to teachings taught to her “that one must always begin the process of learning by locating oneself within the ongoing relationships that shape one’s life” and that “relational positioning is a traditional protocol observed by many
First Nations.” Wilson (2009) calls this relational accountability. This means I am accountable to all my relations.

4.2 METHODOLOGY

Methodology is “the strategy, plan of action, process or design lying behind the choice and use of particular methods” (Crotty, 1998, p.3). The research approach or methodology used in my research began as an ethnographic study, but over time Indigenist research methodologies came to dominate my work. This has entailed a shift from a Western paradigm to a paradigm built on a British Columbian, pan-tribal worldview. Although ethnographic and Indigenist methods can be similar, Indigenous paradigms have aspects that are fundamentally different and therefore not compatible with a Western world view. Since first contact, Indigenous peoples have been researched and defined by outsiders. Ethnography has been, and probably still is, seen as a way for research from a Western perspective to reproduce the marginalization and stigmatization of Indigenous peoples. Smith refers to research “as an institution of knowledge that is embedded in a global system of imperialism and power” (Smith, 2012, p. ix).

4.3 METHODS

Interviews, observations, visual methods, and artifacts are examples of data collection methods (Denzin & Lincoln, 2011). The first research visit to Canada resulted mainly in interviews, referred to as conversations in this text to reflect the reciprocity of the relationships between myself and the research partners. During the second visit, follow-up conversations, conversations with five additional research partners in 2014, observations and video-filmed observations were conducted. These are all examples of methods commonly used in qualitative research such as ethnography. However, additional methods gradually came into the process. Other forms of knowledge transmission in this research project are people’s stories, and experiences of spirit, feeling, dream, ceremony, intuition, and prayer (see Kovach, 2009; Wilson, 2008). Dream and feeling were strong experiences for me during the whole research process (Lindblom, 2016c). The incorporation of these Indigenous methods of knowledge transmission altered the design of the project to one of Indigenist research methodologies. Chilisa (2012, p. 40-41) explains this in a table which illustrates the differences between four paradigms, of which the interpretative and Indigenous research paradigms are two. Although methods used in ethnography can be used in both paradigms, there are significant differences in the underlying philosophical assumptions. All the conversations were held in English. Only one of the research partners was fluent in his tribal language.

4.4 ETHICAL CONCERNS

Axiology is about the role of values in the research (Creswell, 2013; Wilson, 2008). The researchers’ values are incorporated in all aspects of the research, in all choices made (Lincoln, Lynham & Guba, 2011). Battiste (2008, p. 503) talks of “how to create ethical behavior in a knowledge system contaminated by colonialism and racism”. This means that the researcher has great ethical responsibilities when conducting
research in Indigenous contexts, not only in an academic sense, in terms of getting an ethical review approved, but also in the sense that ethical issues are embedded deep within the researcher as a person. The researcher’s ethical compass guides her as a researcher, and it is very important to follow that compass. It is imperative that Indigenous peoples and knowledge are not exploited. To ensure this, a supervisor or collaborator from the tribe should be involved in the ethical process during the whole project. In this research project, my ethical compass comes from a Western background, which may get in the way of ethical conduct which is more appropriate from a tribal point of view. During the PhD process, I have tuned in my compass with an Indigenist paradigm, but still must pay careful attention in order to recognize expressions of colonialism. As this project was not done in one First Nations context, it was necessary to rely on my own judgement and confer with traditional knowledge holders as much as possible.

Ethical concerns that must be addressed when conducting research in Indigenous contexts are: “(a) that the research methodology will be in line with Indigenous values; (b) that there is some form of community accountability; (c) that the research gives back to and benefits the community in some manner; and (d) that the researcher is an ally and will not do harm” (Kovach, 2009, p. 48). These ethical concerns should guide the researcher through the research process. Allowing the participants to review interpretations, and alter their statements, is a way of validating the results. Kovach (2009) used pre-existing publications by Cree Elders as a way to ensure tribal knowledge protection. I made mind maps from the conversation transcripts that I used when doing the follow up conversations, which is a way of having the research partners validate the interpretations. In some cases, tribal councils or boards may review a project’s research design. This, however, was not done in my case as the research partners come from different nations and the research was conducted in private or school settings. Ethical approval was required from the school districts of three children in order for me to observe in school. Unfortunately, there was not enough time to get this through in one case and a teacher strike also caused limitations, observations were only done in the home setting of this child.

In oral cultures, another type of accountability is knowing who has said what (Kovach, 2009; Wilson, 2008), in which case, it would be important for a research partner’s actual name to be directly quoted in a publication. This is the complete opposite to standard Western practice. Moreover, Indigenous knowledge must be protected, and the researcher must consider how much should be included in the written results (Kovach, 2009). As a non-Indigenous researcher, this can be challenging.

The material for this study was collected during two visits in two consecutive years. Prior to this, a formal ethical review application was submitted and approved by the ethical committee at the University of Eastern Finland. Although written consent from all but one child was given, there was a need to negotiate their participation during the research process as well. With the child who is minimally verbal, this was done non-verbally. The second time upon meeting him in 2013, he came and laid his head on my shoulder, which was interpreted as acceptance. His behavior was carefully monitored during observations to be aware if my presence disturbed him, in which case the observation would be paused or ended. With others, negotiations were mostly verbal. Steve2, for instance, was very clear about what he felt comfortable with. We

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2 The research partners are presented in 4.6.
were talking about an observation of his band practice in music class. They were going to have presentations for the class. He did not want me to come and listen to that.

Steve’s mother Brenda: Is it something that maybe you could send her a copy of after?
Steve: No, I don’t really feel comfortable doing, I don’t wanna.
Brenda: You don’t feel comfortable showing anyone.
Researcher: No, you don’t have to.
Brenda: Fair enough.
Researcher: Do you want to tell me what it’s about?
Steve: No.
Researcher: No. Okay, you don’t have to. (transcript from conversation with Steve and his mother Brenda)

Steve was fine with me coming to class and observing as long as he was not spoken to and no one knew that the observation concerned him.

Researcher: So if your principle says it’s okay ‘cause I’ve got clearance from the district to go. Then you’re okay with me coming to a band practice. If one happens before I leave back to Sweden?
Steve: Yeah. Yeah.
Researcher: And if, if I am coming, then I’ll, I’ll call your mom and tell her so that you know.
Steve: Yeah.
Researcher: Yeah. Okay. Alright. Thank you. (transcript from conversation with Steve and his mother Brenda)

These are examples of how participation and access was negotiated during the whole research process, but also illustrate the reciprocal nature of the relationship development. Paying attention and listening to the children was a part of my ethical behavior, showing respect. The last time I met Debbie, and told her this was the last time we were meeting before my departure to Sweden, she said she was going to miss me.

4.5 A PAN-TRIBAL FRAMEWORK

There is a desire to construct new forms of theory among non-Indigenous academics (Kovach, 2009), and I am no exception. From the body of Indigenous knowledge passed on to me in relationships with research partners, family members and other Indigenous individuals in BC, but also in the USA, Australia and Sweden, a theoretical framework has begun to take form. Caught in the middle of Western and Indigenous worldviews, I have been forced to do a great deal of inward reflection. During the process of this research, I have incorporated Indigenist research methodologies but acknowledge that I am only in the beginning of my learning process. To be an Indigenist requires deepened knowledge of Indigenous epistemologies. As my research partners come from different nations in BC, I have used a more pan-tribal approach. Due to the vulnerability of the children and the risk of them being identified, no tribal affiliations or actual names or living locations are used in the dissertation or publications generated from this research. In future research with Indigenous peoples in collaboration with communities there will hopefully be a more open process.
Worldwide, Indigenous researchers have developed research designs to fit Indigenous contexts. In Kovach’s (2009) framework, Plains Cree knowledge is the epistemology in the center of the research. Researcher and research preparation, decolonizing and ethics, gathering knowledge, making meaning, and giving back are the steps to be taken in her “Indigenous research (conceptual) framework” (Kovach, 2009, p. 45). Lambert (2014) has similar components in her “Spider Web Conceptual Framework” (p. 220) that she has constructed from themes she has found in stories from her research in Canada, Australia, and the United States. Indigenous worldviews are not homogenous, but hold common beliefs. Indigenous worldviews are holistic and non-fragmented (Kovach, 2009) and embody “the unity of spiritual and physical worlds” (Louis, 2007, p. 134). Relationships are central in an Indigenous research paradigm (Wilson, 2008). Everything in the world has life and spirit, and the relationships are reciprocal (Castellano, 2004). Inward reflection is essential in Indigenous knowing, and it is important to be “attuned to the ancestors” (Kovach, 2009, p. 50). Battiste (2008) stresses that Indigenous languages are essential for understanding Indigenous worldviews, which implies that “Researchers cannot rely on colonial languages to define Indigenous reality” (p. 504).

Research in Indigenous contexts should stem from needs, interests and priorities that come from the community (Lambert, 2014; Smith, 2012). My current research project is not generated from Indigenous interests, but from my own curiosity that became my doctoral studies. In fact, most of the gatekeepers and others that work in Aboriginal education to whom I spoke, had not heard of autism and First Nations together. However, from the onset, there was a motivation to meet community needs. Most research on or with Indigenous peoples is conducted from a deficit model, looking at things that are negative (Wilson, 2008). My focus has been to investigate the meaning of music which can be seen as focusing on the positive. In the background work to my PhD, I found that autism appears to be under-detected in First Nations children in BC (Lindblom, 2014). Seen from this perspective, autism would appear to be a non-issue in First Nations contexts, and one can question the use of autism and other diagnoses. However, if the reasons for the under-detection of autism are discrimination or the impact of historical oppression, my research can be important. Not that more labelling is desirable, but if a process of diagnosis is underway, it should be as accurate as possible. Since BC has autism funding that enables families to buy intervention services, a correct diagnosis could make a huge difference to the lives of the child and family (British Columbia Ministry of Children and Family Development, 2015). Another issue is ownership of the research results. Ideally, there should be tribal ownership (Lambert, 2014), but in my case the university owns the material. According to my ethical review at the University of Eastern Finland, all audio and video recordings must be destroyed after the dissertation is completed. In the transcripts, all names have been anonymized and tribal affiliation and location of living have been excluded. Future research endeavors should properly address ownership issues.

The components of the pan-tribal framework of my research all interplay and connect to each other in a constant flow (see Figure 1). My place, heart, passion, and voice: In the center of the framework is my dedication and devotion to the First Nations of BC and children in need of special support that comes from my heart. My place is Bråten in Sweden but also the coast, ocean, lakes, and land of British Columbia where I grew up in the city, in nature and on the boat. Connection to traditional lands is important. Due to my history and position as a teacher and researcher in
Swedish, my voice has the potential to raise awareness of the meaning of music for First Nations children with autism in BC, in Indigenous and non-Indigenous context, within and outside of academia.

Figure 1. A pan-tribal research framework adapted from the Spider Web Conceptual Framework (Lambert, 2014).

**Indigenous and Indigenist worldviews, epistemologies, and ontologies:** respecting tribal and Indigenous knowledge and value systems has gradually led to replacing a Western paradigm with an Indigenist research paradigm. The research partners come from different First Nations so this design has a pan-tribal approach. Indigenist ways of knowing have been incorporated along with embracing a reciprocal, relational worldview. **Axiologies; academic, tribal, and personal ethics:** Formal ethical approval for this project was given by the University of Eastern Finland. Tribal councils were not involved in ethical decisions as the research was conducted in home, school, or after-school settings. However, tribal ethics and protocols were respected in regard to knowledge transmission, for instance, when such issues arose. Consent was given by parents and guardians and children. My personal ethical compass had to be carefully tuned and refined. This is referred to as relational accountability (Wilson, 2008). By being in harmony, I can do the research in a good way. I strove to have spirit and emotion characterize my relationship with my research partners and all in the natural and spiritual world. Mind, body, emotions, and spirit cannot be separated.

**Indigenist methods and decolonization:** From the onset conversations, observations, filmed observations and fieldnotes were the methods of the design. During the research process, Indigenist methods such as dreams, spiritual experiences,
and feelings, of the research partners, and my own, were incorporated. Indigenous knowledge holders were constantly consulted and the group of Student Storytellers Indigenizing the Academy, SSITA, of which I am a member, was essential to the relational knowledge transfer and understanding. I have also participated in three conferences held by the American Indigenous Research Association, AIRA, on the Flathead Indian Reservation in Pablo, Montana, USA. My research has also been presented in seven other conferences, paper or poster presentations, in Australia, Turkey and Scotland, to mention a few countries. This has given me feedback from Indigenous and non-Indigenous individuals, on the autism spectrum, family members, professionals, and academics, which has deepened my relationship to my research and the knowledge that has shown itself during the process. Knowledge is relational and it is essential, especially for me as a Swedish, non-Indigenous researcher, to participate and build relationships to the people, and all in creation, including the knowledge itself. Lifting the issue of traditional music in interventions and support for the First Nations children with ASD, and traditional views on autism can have decolonizing effects.

Research partner needs and interests: Indigenous research should be centered in tribal needs. However, the research partners in my study come from different Nations. Therefore, it has been their rights, needs and interests in focus. Reflexivity: Inward reflection and reflection in discussion with research partners and Indigenous knowledge holders has been essential in the research process. Knowledge transferred to me in dreams has also been processed in inward reflection and with others. Respect, relationships and reciprocity. Listening: The reciprocal nature of relationships within Indigenous worldviews has influenced my relationship with the research partners in the study, with the land, the animals, the spirits and the knowledge. These relationships are grounded in respect. This means I am not the expert, in contradiction to the position of Western researchers, but in a reciprocal relationship where I am a learner and a researcher. In this reciprocity, my experiences and knowledge of interacting with individuals with autism has been an asset. Listening, not just with my ears, but with my whole being, has been central.

Giving back, empowerment: All research should contribute with new knowledge, but within Indigenous context it is of utter importance (Lambert, 2014; Kovach, 2009). In follow-up conversations, the research partners were given the opportunity to agree with or alter the interpretations of their conversations. The interpretations were drawn up in mind-maps that were presented to the research partners and used as a visual point of mutual focus. After the research is finished all involved will get a copy of the dissertation and articles and have the opportunity to discuss it with the researcher. Results are disseminated in publications, conferences and teachings within and outside of academia. By disseminating the results to the staff involved there is an opportunity to influence future interventions and support for the children. Involving Elders and traditional knowledge holders will be empowering to the whole community.

4.6 RESEARCH PARTNERS

In this dissertation, the term research partner is used in regard to the five First Nations children with autism who are a part of the research project, family members, gatekeepers, staff and others who are a part of the research project. This is a step in
balancing the power relationships in research. No tribal affiliations or living locations are mentioned for confidentiality reasons, and all names have been changed. All the children are or have been assigned an autism special needs classification in school and one of them has been diagnosed with comorbid disorders. However, his participation is because of his autism diagnosis and how it represents itself.

**Peter** (Table 1) was fourteen years old at the time of the first conversation. He has Indian status and was living on reserve with his mother and stepfather but had moved off reserve in 2014. Peter was diagnosed with autism at the age of five. He has an ASD Special Needs Classification in school. Peter does not speak much but he answered a few questions about music and musical activities. Conversations were held with his mother, Mary, and one of his teachers, Ruth, in 2013 but due to the teacher strike in 2014, and work overload a follow-up conversation with Ruth was not possible. However, a conversation, with Joseph, a District Aboriginal Education Coordinator, was able to take place. A filmed observation was conducted in Peter’s home.

Table 1. Material collected regarding Peter and music.

<table>
<thead>
<tr>
<th>Research partner</th>
<th>2013</th>
<th>2014</th>
</tr>
</thead>
<tbody>
<tr>
<td>Peter</td>
<td>Conversation 1min 57s. Film 1min 23 s not used in the study. Home setting</td>
<td>Follow-up conversation 2 min 16s. Film in home setting 11min 43s</td>
</tr>
<tr>
<td>Mary mother</td>
<td>Conversation 20 min 53s. Home setting</td>
<td>Follow-up conversation 20 min 38s. Home setting</td>
</tr>
<tr>
<td>Ruth teacher</td>
<td>Conversation 15 min 30s. School setting</td>
<td>-</td>
</tr>
<tr>
<td>Joseph District Aboriginal Education Coordinator</td>
<td>-</td>
<td>Conversation 40 min 2s. District office.</td>
</tr>
</tbody>
</table>

**Connor** (Table 2) was six years old when we first met. Connor has Indian status and lives on reserve with a family of several generations. This family took care of his mother, from when she was little until she passed away when Connor was a baby. His father is not involved. The issues of formal custody are still in progress. Connor was diagnosed with autism around the age of one. He has a Special Needs classification of ASD in school. Connor is minimally verbal, so he could not participate in a conversation. Conversations were held in 2013 with one of his caregivers, Elizabeth, who is the mother figure in the family, and a teacher’s aide, Anna. When I came back in 2014 follow-up conversations were conducted with them, and it was possible to talk with his grandfather figure, an uncle figure, and a Principal of Aboriginal Education. Connor’s grandmother figure had passed away and shortly after my visit the grandfather figure also passed. Observations, with filmed observation and interventions were conducted in Connor’s school setting.
Table 2. Material collected regarding Connor and music. This table appears in Lindblom (2016b p7).

<table>
<thead>
<tr>
<th>Research partner</th>
<th>2013</th>
<th>2014</th>
</tr>
</thead>
<tbody>
<tr>
<td>Connor</td>
<td>Film 2 min 42s in school, not used in the study.</td>
<td>Observations and interactions in school. School 6h 53min 44s. Field notes. 1h 16 min video filmed. Relevant sequences analyzed and coded in ELAN.</td>
</tr>
<tr>
<td>Elizabeth Mother figure</td>
<td>Conversation 22 min 33s. Recorded and transcribed. Home setting.</td>
<td>Follow-up conversation 24 min 21 s + 3min 4s. Recorded and transcribed. Home setting.</td>
</tr>
<tr>
<td>Anna educational assistant</td>
<td>Conversation approx. 20 min. Notes were taken as she did not want to be recorded. Notes transcribed. School setting.</td>
<td>Short follow-up conversation taking notes. School setting.</td>
</tr>
<tr>
<td>Earl grandfather figure and Todd uncle figure</td>
<td>-</td>
<td>Conversation 22 min 13 s. Recorded and transcribed. Home setting.</td>
</tr>
<tr>
<td>David District Aboriginal Education Coordinator</td>
<td>-</td>
<td>Conversation 25 min 34 s. Recorded and transcribed. School district office.</td>
</tr>
</tbody>
</table>

Tom (Table 3) was fifteen years old at the time of the first conversations. Tom is very shy. He did not want to meet me himself, so I had the conversation with both him and his adoptive mother, Patty, together. Additionally, I had a short conversation with his drama teacher, Evelyn. Tom has Indian status and lives off reserve with the family that has adopted him. Tom was diagnosed with autism at the age of seven. A year before that he had been diagnosed with Fetal Alcohol Syndrome, anger management problems, Oppositional Defiant Disorder and Attention Deficit Hyperactivity Disorder. None of the comorbid disorder diagnoses were taken away. Tom is high functioning and attends a regular class and has not been assigned a Special Needs classification since 2013. At different points in time he has had the classifications of physical disability, chronic health impairment and ASD. In 2014, I had follow-up conversations with Tom, and Patty and got to talk with an Education Coordinator that is acquainted with the family. A filmed intervention was done in my hotel room with Tom’s mother, Patty, present because Tom did not want me to come to their home. No fieldwork was done in the school as they have no music program.

Table 3. Material collected regarding Tom and music.

<table>
<thead>
<tr>
<th>Research partner</th>
<th>2013</th>
<th>2014</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tom</td>
<td>Conversation together with mother 14 min 25s. In Band office.</td>
<td>Follow-up conversation 13 min 18s. Film in private setting with mother present 32 min 47s.</td>
</tr>
<tr>
<td>Patty Mother (adoptive)</td>
<td>Conversation together with Tom 14 min 25s. In Band office.</td>
<td>Follow-up conversation 43 min 14s. Private setting.</td>
</tr>
<tr>
<td>Evelyn drama teacher</td>
<td>Conversation 6 min 17s. School setting.</td>
<td>-</td>
</tr>
<tr>
<td>Rita education coordinator</td>
<td>-</td>
<td>Conversation 27 min 35s. Private setting.</td>
</tr>
</tbody>
</table>
Debbie (Table 4) was fourteen years old at the time of the first conversations. She has Indian status and lives off reserve with her mother and sister since her father passed away. Debbie was diagnosed with autism at the age of four. Debbie attends a resource classroom for most of her lessons at school and has an ASD Special Needs classification. Debbie participated in a conversation with her mother, Grace, and her after school aide, Emily, present. Conversations were also held with Grace and Emily, as well as with the resource room teacher, Mona, the music therapist, Victoria, and an Aboriginal support worker, Sandra. Follow-up conversations were possible with Debbie and all of the other research partners in 2014, and observations were done in the school setting and a filmed observation done at the after-school club.

Table 4. Material collected regarding Debbie and music. This table appears in Lindblom (2016b p7).

<table>
<thead>
<tr>
<th>Research partner</th>
<th>2013</th>
<th>2014</th>
</tr>
</thead>
<tbody>
<tr>
<td>Debbie</td>
<td>Conversation 7 min 47 s. Recorded and transcribed. After-school club.</td>
<td>Follow-up conversation 6 min 58 s. Recorded and transcribed. After-school club. Observations 4h 3min school setting. Field notes. Video filmed observation 36 min 58s. After-school club. Relevant sequences analyzed and coded in ELAN.</td>
</tr>
<tr>
<td>Grace</td>
<td>Conversation 16 min 3 s. Recorded and transcribed. After-school club.</td>
<td>Follow-up conversation 32 min 41 s. Recorded and transcribed. After-school club.</td>
</tr>
<tr>
<td>Emily</td>
<td>Conversation 9 min 27 s. Recorded and transcribed. After-school club.</td>
<td>Follow-up conversation 13 min 39s. Recorded and transcribed. After-school club.</td>
</tr>
<tr>
<td>Victoria</td>
<td>Conversation 13 min 28 s. Recorded and transcribed. School context.</td>
<td>Follow-up conversation 17 min 44 s. Recorded and transcribed. School context.</td>
</tr>
<tr>
<td>Mona</td>
<td>Conversation 12 min 39 s. Recorded and transcribed. School setting.</td>
<td>Follow-up conversation 14 min 10s. Recorded and transcribed. School setting.</td>
</tr>
<tr>
<td>Sandra</td>
<td>Conversation 13 min 1s. Recorded and transcribed. School setting.</td>
<td>Follow-up conversation 8 min 52s. Recorded and transcribed. School setting.</td>
</tr>
</tbody>
</table>

Steve (Table 5) was twelve years old at the time of the first conversations. He lives off reserve with his parents and siblings. Steve does not have Indian status, but is identified as Aboriginal by his parents. His father recently got his status. Steve was diagnosed with autism when he was four years old and is high functioning. At school he has the Special Needs classifications of ASD, Pervasive Developmental Disorder and written output disorder. Steve is perceived to have social challenges, but things have improved. Steve has had problems at school, and has been in a resource room, but is now attending a mainstream class with support. Steve participated in a short conversation. Conversations were also held with Brenda, Steve’s mother, his music teacher, Harry, and an Aboriginal support worker, Doris. In 2014, follow-up conversations were conducted with Steve and the other research partners although Harry was no longer his music teacher. Steve did not want to be filmed but permitted me to observe a music lesson at school.
Table 5. Material collected regarding Steve and music.

<table>
<thead>
<tr>
<th>Research partner</th>
<th>2013</th>
<th>2014</th>
</tr>
</thead>
<tbody>
<tr>
<td>Steve</td>
<td>Conversation 5 min 46s. Home setting.</td>
<td>Follow-up conversation 13 min 14s. Home setting. Observation 45 min in school setting.</td>
</tr>
<tr>
<td>Brenda Mother</td>
<td>Conversation 25 min 27s + 3 min 55s. Home setting.</td>
<td>Follow-up conversation 22 min 43 s. Home setting.</td>
</tr>
<tr>
<td>Harry Music teacher</td>
<td>Conversation 13 min 6 s. School setting.</td>
<td>Follow-up conversation 22 min 36s. School context.</td>
</tr>
<tr>
<td>Doris Aboriginal support worker</td>
<td>Conversation 9 min 3s. School setting.</td>
<td>Follow-up conversation 10 min 6s. School setting.</td>
</tr>
</tbody>
</table>

4.7 PROCEDURE

4.7.1 Preparations 2011 and 2012

After I was accepted for doctoral studies in September 2011, I conducted a literature review on music and autism, and contacted possible gatekeepers who could help access the field. This was the starting point of the ceremony which is my research and the bringing together of relationships (Wilson, 2008). At this stage, the study was intended to be a comparison of the meaning of music for Swedish pupils diagnosed with Asperger syndrome, AS, and First Nations children in BC with the same diagnosis. Remedial groups and principals were contacted in Sweden. There was no shortage of pupils diagnosed with AS in Sweden. Key people in school districts in BC, such as school board members and principals, were sought for on the Internet and emailed. Researchers in the field of autism at the University of British Columbia (UBC) and Simon Fraser University (SFU) were also contacted. Although most of the people did not reply, these emails resulted in meetings with one person on a school board, two researchers at UBC and one at SFU. Members of my First Nations family put me in contact with a person in Aboriginal education a couple of hours away from the city, and a band council member a bit further north in the province. These people were also interested in meeting me. Within Indigenous research, the practice of using family, friends and relations to come in contact with participants is an important practice because it places the researcher “within a circle of relations” (Wilson, 2008, p. 129).

I made my first visit to BC in spring 2012 to network for the planned data collection. The findings from this first visit were not encouraging. The person on the school board revealed that although it was a large district, they had no First Nations pupils with ASD. The researchers at UBC were a bit skeptical on hearing the research focus, and said not many First Nations children with ASD would be found and that access would be very difficult to get. When told about my family ties with the Lake Babine Nation, they said that was a privilege. The researcher at SFU also said it would be difficult to find participants but that she would be happy to collaborate. She eventually became a part of my supervisor team. The person in Aboriginal education and the band council member had never heard of autism and did not know if there were any children diagnosed with ASD in their districts. The three-week stay was a starting point, but no actual research partners had been located.
Before the data collection commenced, the American Psychiatric Association, APA, announced that Asperger syndrome would not be in the new edition of the Diagnosis manual DSM-5 (2013). Therefore, the focus was changed to Autism Spectrum Disorder, ASD, in the two countries, and a third study was added to the research design, a screening study in a school district or First Nations band, to the research design. Initially, ethical clearance was received for three separate studies, of which the screening study was one. Before starting the research in Canada, a pilot study with one Swedish participant was conducted to test the questionnaire, interview and filmed observation. In 2013, while doing fieldwork, the screening study was mentioned and discussed with a few key Indigenous educators and researchers. Before long, it became apparent that this was an example of a Western research approach to Indigenous peoples. Thus, the supervisors were informed that the screening project would be removed from the design. This is an example of the decolonization process. Since First Nations children diagnosed with ASD are scarce in research publications, it finally was decided that this would be the main focus for this research project.

4.7.2 2013 - conversations

When I arrived in Canada in 2013 to start the research, only one First Nations child with autism had been found. Through networking with gatekeepers and First Nations family members, four more were found before the end of the six-week period of data collection. Another child with ASD was found, but the family did not want to participate in the study. As the research partners live in an area spanning over 1000 kilometers, the travelling and searching was time consuming. Very short filming with two research partners was done, which is not used in the dissertation due to other children in one of them and people moving boxes and furniture in the other. All conversations were recorded with exception for one. Notes were taken as the person did not want to be recorded. A questionnaire or grid over music activities was used as a focal point in the conversations (Appendix 1). General information questions were asked such as: at what age did the child get diagnosed with ASD? Does the child have status? Do they live on or off reserve?

When meeting the child for the first time, after the conversation, I gave them a CD I have recorded with my own music and a little metal tray with a Swedish motif of Midsummer or trolls. My relationships with my First Nations family members have taught me the importance of gift-giving (Lambert, 2014; Adams, Wilson, Heavy Head & Gordon, 2015). Giving gifts is part of a reciprocal relationship. Another gift I gave was my experience and knowledge on interacting with individuals diagnosed with autism, and I believe this was my biggest contribution in developing relationships with all the research partners. During the process of the research, a child in my close family was diagnosed with autism, and sharing mutual experiences with the families of the children in my research strengthened our bonds as well. Rituals such as “Sharing food, exchanging gifts, and communication with the nonliving in prayer, in song, in dance, or in speech are indigenous ways of communicating a philosophy, a belief system, a thought, or a collective worldview of a group” (Chilisa, 2012, p. 141). When meeting Peter and his mother, Mary, for the first time, they wanted to meet in a neutral place such as a restaurant. This gave me the opportunity to invite them to join me in a meal, and allowed us to start building our relationships. I also went with Mary to an open house at the reserve where she introduced me to people
we met. Respecting personal boundaries was an additional way to build trust and reciprocity in our relationships. Conversations were held in the homes of Peter, Connor and Steve and spending time there was a part of the relationship building. Debbie’s and Tom’s families preferred for our conversations to be held in other locations, and respecting this was important.

Connection to place is integral to Indigenist worldviews. I have always had a strong connection to the land and nature in BC, but during my research, this has deepened. Specifically, one incident stands out (Lindblom, 2014, 10). I felt uncomfortable and frightened about travelling alone to the northern interior of BC, and convinced one of my sisters and her three children to come with me. The nieces and nephew had never been to their reserve and were excited to go. My First Nations step-mother is Carrier from the Lake Babine Band, and is Caribou clan. Within the Carrier nation, individuals belong to their mother’s clan, so my sisters and their children are also Caribou. One day, when we drove around a bend, three caribou were standing in the middle of the road. I got very excited, and started talking about how there were three caribou on the road and four Caribou clan in the car. The children had never seen a live caribou and were thrilled. When we decided to proceed on our journey, the caribou would not move. Finally, they started walking slowly, and I followed them with my vehicle. Then, one of the caribou moved so it walked beside the car. We now had two caribou in the front and one on the side. The caribou were escorting the Caribou to their traditional lands. This reciprocal interaction was very spiritual and powerful for us all.

4.7.3 Analysis

All the conversations were transcribed. The notes from the conversation with Anna were written on the computer. The transcripts were printed out and color coded from the research questions. This was helpful when writing up the results in articles. Mindmaps, or conceptual maps as they sometimes are called are sometimes used in interviews to collect data (Scherp, 2012), or as a research method (Simonova, 2013). I used mind-maps in a different way and made one from each conversation on music and music interventions, and one mind-map with general information from each parent or caregiver regarding the diagnosis, if they live on or off reserve and such (Appendix 2). This gave a visual summary to be used in the analysis process. The mind-maps were also used as a visual support for validation of interpretations and dissemination of research results.

4.7.4 2014 Initial and follow-up conversations, observations, video-filmed observations and field notes

The mind-maps from 2013 provided visual support and a mutual focal point for the follow-up conversations. This can also be seen as way of giving back to the research partners in a reciprocal relationship. Conversations were held with two new family members and three new research partners in Aboriginal education with the intention of gaining more insight. Even though a strike in schools occurred during the field work, 40 meetings of some sort were made resulting in 20 hours 44 min and 26s of material. Peter’s teacher, Ruth, was not available for a follow-up conversation
because of the teacher strike. All conversations and follow-up conversations were recorded with exception of Anna’s as she still did not want to be recorded. She did, however, consent to being video-filmed when interacting with Connor. During the six weeks, I drove 8300 kilometers. The follow-up conversations gave new information, but were also a way of validating my interpretations and disseminating my results to the research partners (Hammersley & Atkinson, 2007). This can also be referred to as communicative validation (Flick, 2009).

4.7.5 Analysis

All the conversations and follow-up conversations were transcribed and printed out. Notes were written on the computer and printed out. Selected parts of the video-film material were coded in ELAN (available for download from the Max Planck Institute https://tla.mpi.nl/tools/tla-tools/elan/), which is a program for analyzing film that allows frame by frame viewing (Lausberg & Sloetjes, 2015). Some of the film material was transcribed, the dialogue and what occurred. Mind-maps were compared to the follow-up conversation transcripts and new information was added. The material from all the sources was then compared. In Western research this can be called triangulation. Triangulation involves comparing different sources of data collected around a certain topic or phenomenon but theories can also be triangulated (Flick, 2009; Hammersley & Atkinson, 2007). Indigenous research uses a more circular approach rather than linear (Wilson, 2008). The analysis process can be seen in Figure 2.

Figure 2. Analysis process.
In this case, mind-maps and conversation transcripts from 2013, and transcripts from 2014, coded and transcribed video material and field notes from observations, were the data that were compared in the analysis process. Responses from all the research partners in regard to one child were compared to what the child had responded. This was also compared with follow-up conversation materials, notes, observations and video-filmed observations. Towards the end of the PhD process, it became necessary to alter the research questions to some part, which gave cause to review the data again before concluding the process.

4.7.6 Validity and reliability

In Indigenous research, relational accountability (Wilson, 2008) ensures that the research is done in accordance with respect and ethics. Chilisa (2012, p. 171) states that in post-colonial research, all aspects of the research process are “derived from the researched’s frames or reference and indigenous knowledge”. Chilisa continues to explain that in the context of Indigenous research, validity lies in the researchers’ responsibilities to conduct the research in accommodation with Indigenous epistemologies. Indigenous knowledge holders and members of Student Storytellers Indigenizing the Academy were consulted regularly from 2014. I also took three distance courses on IRM and protection of human subjects at the Salish Kootnai College in Pablo, Montana, USA. These are ways in which validity was ensured in this research project.

Patton (2002) points out that for certain phenomena or outcomes, there are no valid or reliable measures, and uses this as an argument for the use of rigorous qualitative methods for validation. By comparing data from different participants, different phases of the research or different sources such as interview transcripts and observation notes, a validation check was provided. Hammersley and Atkinson (2007) describe this process as time consuming but point out that it adds depth to the descriptions. Respondent validity, or communicative validation (Flick, 2009), along with comparing data, or triangulation, was utilized in this study. The results of this research project are based on a small sample and cannot readily be generalized to the situations for all First Nations children with autism in BC, Canada.

Procedural reliability (Flick, 2009) involves the quality of the documentation. Reflexivity about procedures and methods can also increase reliability. Furthermore, documentation of the research process provides reliability. By investigating the data and procedures for dependability, reliability can be checked. One must be aware and be meticulous when representing and communicating the data (Patton, 2002). Some video material was discussed and analyzed in VIDA, a group of researchers using video recording as a method of data collection at Karlstad University, Sweden.
5  SUMMARIES OF THE ORIGINAL ARTICLES

5.1  ARTICLE 1


This article set out to examine previous research on First Nations in BC, Canada, and autism. A review of publications was carried out, which revealed that there was a scarcity of research on the topic. A search for publications on Indigenous peoples and autism in the global context was conducted to put First Nations children with ASD in context. The review revealed that autism, in fact, appears to be under-detected among First Nations children in BC, Canada, which also became the focus of the publication.

In order to receive a diagnosis, one must first undergo the assessment process. An explanation for lower prevalence of ASD within Indigenous populations in Canada and the USA could be that parents of Indigenous children might not be seeking help (Ouelette-Kuntz et al. 2006; Bernier, Mao and Yen, 2010; & Ticani, Travers and Boutot, 2009). Since some Indigenous peoples live in rural areas, there may be low access to facilities for diagnosis and treatment (Burstyn, Sithole & Zwaigenbaum, 2010). Tools currently used for assessment and diagnosis are not culturally sensitive (Bernier, Mao and Yen, 201; Ouelette-Kuntz et al. 2006). It was found that the under-detection of autism among First Nations in BC, Canada, could be due to “diagnostic substitution and symptom presentation, ethnic or cultural, area of residence or the impact of historical oppression and discrimination” (Lindblom, 2014, p 1248).

In Lindblom (2014) the final conclusion is drawn that First Nations children in BC, Canada, do not need another label. The point is, if they are being diagnosed, then the assessment should be as thorough as possible to ensure that they have the possibility to reach their full potential. Cultural sensitivity and collaboration with First Nations is needed in diagnosis processes, development of policies and research.

5.2  ARTICLE 2


This methodological publication explores the opportunities and challenges that emerged during the ethnographic fieldwork, and introduces Indigenous research methodologies. The importance of preparing a research process is outlined, along with the steps taken in the preparation of this research project. Ethical considerations are always important in research, and this article points out aspects of importance within research in Indigenous contexts. This methods case gives pointers to possible learning outcomes, practical lessons learned, and exercises and discussion questions.
Opportunities have included having relatives who are First Nations, my age and experience with children with autism, and not being tied to a particular research project or doctoral position. Challenges were finding participants, lack of internet access in some areas, safety issues and lack of funding. It can be concluded that ethnographic fieldwork with First Nations posed both opportunities and challenges, which were not anticipated in from the outset of the research endeavor.

5.3 ARTICLE 3


This article focuses on how music can facilitate social inclusion for First Nations children diagnosed with autism in BC. Connor and Debbie are presented and were chosen because they are very different and highlight an issue that, to my knowledge, has not previously been addressed in research publications. The following research questions were addressed:

- In which ways is music used as a motivator?
- In which ways is music used to facilitate inclusion?
- How is the meaning of music perceived by the children, parents and staff?
- What role does music play in other domains of the children’s lives?
- Is traditional Indigenous music used in music interventions?

It was found that at first, it may seem that Connor and Debbie have similar life conditions, as they both are First Nations children diagnosed with autism. When examining the cases closer, differences are apparent. Connor is a boy, lives on reserve with a family who is awaiting custody. He is minimally verbal and spends most of his school day in a small room with an assistant. Debbie is a girl, lives in a city off reserve with her mother and sister. She is verbal and social and attends a resource room class for most of her school day. Connor has difficulty interacting with peers but Debbie can interact with peers, largely due to her talent for singing pop songs and dancing. Outside school, Connor spends most of his time at home. Debbie has access to several workers due to autism funding and gets out on activities through that. Connor has easier access to traditional Indigenous music because he lives on reserve, but his sound sensitivity sets up obstacles. Debbie attends an optional Aboriginal class and has access to Indigenous culture there. Music plays an important role in both the children’s lives.

It was concluded that although music has large potential to facilitate social inclusion (Bartleet et al., 2014; Heyworth, 2013) this option is overlooked in the school setting. Culturally sensitive music interventions, both traditional and contemporary, could be an important link to social inclusion for Connor and Debbie. A citation from Debbie’s mother is the title of this article “gives them a place to be proud” (Lindblom, 2016b) which led me to perceive the Indigenous music as a room or space filled with opportunities.
5.4 ARTICLE 4


In this article three research questions are posed:

- How can the diagnosis of ASD be seen through a First Nations lens?
- How is music used by the First Nations children with autism and the other research partners?
- How is traditional music used?

All the collected material is used in this article. It was found that First Nations world views are inclusive, and labelling in a Western manner from a deficit model is not compatible with Indigenous worldviews. The children in the study use music for communication, relaxation, security, happiness, self-soothing, and while studying. For the five participants in the study, music is not often used as a motivator. Previous research (Allen, Hill & Heaton, 2009; Darrow, 2015; Kim, Wigram & Gold, 2009; Eren, 2015 and Simpson & Keen, 2011) has shown positive effects of music and music therapy on the social, motivational and emotional skills of individuals diagnosed with autism. As music is important for all the participants in this study, it is apparent that music as a resource is overlooked. The staff involved in this study, both Indigenous and non-Indigenous, do not know much about Indigenous music. First Nations were separated from their cultures due to colonialism and residential schools, which can be part the explanation for them not using traditional music with the pupils. The results point to the conclusion that music interventions for First Nations children with ASD should be culturally sensitive and be designed to match the individual’s tribal affiliation.
6 DISCUSSION

6.1 ADDRESSING THE RESEARCH QUESTIONS

This dissertation is article-based, which means that the results have been published in three articles and one article submitted for publication. Here, in the discussion, I will relate the research results to the research and literature presented in Chapter 2 of this thesis, and discuss the contribution my study makes to the current debate and the existing body of knowledge on First Nations, autism and music.

To my knowledge, this is the first scholarly study on First Nations and autism that is based on empirical data. As to the first research question pertaining to how the diagnosis of ASD can be seen through a First Nations lens, it was found that First Nations communities traditionally are inclusive, which is also reported by Kapp (2011) regarding Navajo in the USA (discussing the Navajo philosophy) and Bevan-Brown (2013) regarding Māori in a global context. This contrasts the Western deficit model as the First Nations view all individuals as a part of the community and value them for who they are. Seen within this context, the diagnosis of autism, or any formal categorization, would be unnecessary. However, First Nations children, even if they live on reserve, are dependent on community services and schooling systems on the most part, and access to diagnosis services can be sparse. This means that to be eligible for autism funding or for the school to get funding to provide special needs assistance for the child, a formal diagnosis is a prerequisite. As First Nations children diagnosed with autism in BC appear to be under-detected (Lindblom, 2014; Lindblom 2016a), they will most likely also be under-serviced. In one child’s school district with 1300-1400 First Nations pupils, there are less than five First Nations children diagnosed with autism, which is low in comparison to the estimation of an autism prevalence of 1% globally (Government of Canada, 2015.) This can also be seen in the light of over-representation of First Nations children in other special needs categories, apart from gifted (Lindblom 2016a). Effects of colonialism are apparent in the everyday lives of First Nations individuals, which is evident in the results and reflected in the title of my dissertation. My research results confirm previous research but also contribute, with new, empirical-based knowledge in the current discussion on autism and Indigenous peoples.

As to the second question, regarding how the First Nations children diagnosed with autism use music, the results show that the children use music for communication, relaxation, security, happiness, self-soothing, and while studying. This is similar to results found by Allen, Hill and Heaton (2009) in their study with high functioning adults with autism. It was also found that music is very important for the five First Nations children with autism in this study, as it is for most young typically developing individuals as well (North, Hargreaves & O’Neill, 2000). My findings show how access to music is an asset for the First Nations children diagnosed with autism in this study. This has the potential to influence special support in schools and autism services, which could have positive implications on possibilities for these, and other First Nations children diagnosed with autism, to reach their full potential.

In regard to the third research question on the use of music in different domains, it was found that music had been used for motivation in the home and after-school
setting, but not in school. A substantial amount of research has been done on the effects of music and music therapy on the motivation of individuals with autism (Eren, 2015; Kim, Wigram & Gold, 2009; Simpson & Keen, 2011). It is quite possible that research results do not reach practitioners, in which case the staff would not be aware of the potential positive effects of music as a motivator. In music therapy, goals involving social interaction were set for one child, who also went to camp where there was an abundance of music activities. Listening to music, playing instruments, singing and dancing was used by, and with, some of the children. Several of the children have difficulty describing the meaning of music or the type of music they like which corresponds with Allen, Hill & Heaton (2009). The present results suggest that there could be a lack in communication between the home, school and after-school settings. It can be very challenging to work with children diagnosed with ASD, and schools do not always receive the necessary resources to individually address every pupil’s needs. This could be one explanation for the lack of music used for motivation. Furthermore, two of the children had no access to music in their school. It may be difficult for First Nations children with ASD to assert their right to express their views (United Nations, 1989) regarding support and interventions in the school setting. This pinpoints the need for home-school communication and collaboration to ensure the children’s rights. To my knowledge, this is the first empirical study on First Nations, autism and music, so consequently, it can be the starting point for further research and knowledge production.

The fourth research question is about on ways music is used to facilitate inclusion. It was found that none of the schools utilized music for inclusion purposes. Previous research results show that music has great potential to facilitate inclusion (Allen, Hill & Heaton, 2009; Burnard, 2008; Darrow, 2015; Eren, 2015; Heyworth, 2013; Kim, Wigram & Gold, 2009; Simpson & Keen, 2011). One child was sometimes integrated with his peers in music class. One school used reversed integration, which meant a peer tutor came in for the music therapy sessions. Possible explanations for not using music to facilitate inclusion could be sound sensitivity or lack of initiative from the pupil, which led to music class being perceived as unsuitable. It was also suggested that less emphasis is put on inclusion if the child is in a special needs setting. If the pupils’ representations of ASD are only seen from a deficit model, then perhaps inclusion is not seen as an option or possibility for the First Nations children in this study. This could stem from stereotyped views on autism traits and individual capabilities. Inclusion is a fundamental right. This study highlights the lack of inclusion of the First Nations children diagnosed with autism.

The fifth, and last, research question concerns the use of Indigenous music in interventions. It was found that Indigenous music was not used in any music interventions for the five children in the school setting. Two children had heard Indigenous music in the home setting, and one participated in tribal functions. In the school setting, Indigenous music may have been used as background music but nothing more, and one child attended an optional Aboriginal class where they made a drum, which they played and sang to. These examples, however, were events that occurred within the lesson, not interventions tailored to culturally address the child’s symptoms of autism specifically. Several of the children in the study are sensitive to sound so they do not participate in assemblies where, potentially, there can be Indigenous music occasionally. It has probably not occurred to the family or staff members that one on one settings, like the music interventions with the researcher and Connor, could be beneficial. In a study on communicative spontaneity in autism, Rämä, Kontu and Pirt-
timaa (2014, p. 195) conclude that unexpected teacher behavior “compromises the prevailing structure and may support the pupil in communicating more spontaneously”. Perhaps the intervention with the Indigenous drum served as such an opportunity.

Two professionals state that they do not know anything about Indigenous music. This corresponds with Saunders (2010) who says that music teachers are likely to be most comfortable when teaching music the way they themselves were taught. The Western classical tradition is strong in music teacher education (Hargreaves et al. 2007). Bradley (2015) takes the topic further and states that in North America, Western music and cultural whiteness is promoted. Furthermore, she points out that White teachers may avoid including different types of music because they think they are not able to use it with authenticity. My findings contribute to the current debate on colonialism in Canada, and worldwide. Two of the children in the study respond strongly to Indigenous music (Lindblom, 2016a, 2016b), which is reflected in the title of this dissertation. This illustrates the potential of culturally-sensitive, tribally-specific music interventions, and consequently can inspire future research projects involving tribal communities, Elders and traditional knowledge holders, in collaboration with families and researchers.

Musical choices can colonize or emancipate. The effects of colonialism have been obvious during my fieldwork and it is apparent that even if a staff member is in fact Indigenous, he or she still may not have knowledge on Indigenous music. This is a far-reaching effect of residential schools, that were in operation up until 1996, and First Nations being bereaved of their cultures (Truth and Reconciliation Commission of Canada, 2015; Bradley, 2015). Successful projects could be an inspiration in addressing the lack of cultural sensitivity in music interventions for First Nations children diagnosed with autism in BC, Canada (Bartleet et.al., 2014; Heyworth, 2013).

In sum, based on the present findings it can be concluded that autism or autism representations may not be recognized in a First Nations context as the diagnosis is based on a Western deficit model. This is not always a good fit with First Nations world views. The First Nations children diagnosed with autism in this study use music in similar ways to typically developing children and non-Indigenous individuals with autism. These uses include for communication and relaxation, for security and happiness, to soothe oneself and when studying. Music is used in home, school, camp, and after school settings for various purposes, but music as a motivator is not used in the school setting. Two children have no access to music education in school. Music is not used for inclusion in school for any of the children, nor is traditional Indigenous music used in music or music interventions apart from optional Aboriginal classes.

6.2 **STRENGTHS AND LIMITATIONS OF THE STUDY**

This study addresses an issue that has not previously been specified in research publications, and can therefore contribute with new knowledge. It also made the First Nations children diagnosed with autism in the study visible and gave voice to people who have been silent so far. Data have been generated through multiple methods, conversations, follow-up conversations, observations, video-filmed observations and field notes. Indigenist methods such as intuition, feelings and dreams have been incorporated in the research. Comparison in the analysis of data strengthens the interpretations. In the follow-up conversations, the research partners could confirm or alter their previous utterances.
An obvious limitation is the small sample size and that one child was minimally verbal and could not speak for himself. Comorbid diagnoses can be seen as a complication. In this study, however, the parents and caregivers have given consent for their child to participate due to their autism diagnosis. Another limitation is that the research was not initially conducted in the context of Indigenist research methodologies or derived from tribal needs. The most important limitation, from an Indigenist Knowledge standpoint, is that the agency of music and Knowledge were not considered from the onset.

6.3 FUTURE RESEARCH

The results from the literature review in Lindblom (2014) show the need for further research on the diagnosis of autism and its relevance in Indigenous context. If I could do this research project from the beginning again, it would have been based on tribal needs. The prospects of conducting research in collaboration with an Indigenous community utilizing Indigenist research methodologies from the outset are hopefully in the future. One of the conclusions in this dissertation is that music interventions for First Nations children diagnosed with Autism Spectrum Disorder are not culturally sensitive. No traditional Indigenous music was used in any of the five cases in the study. Interviews and interventions indicated that the children were, in fact, interested in Indigenous music, and Connor, the minimally verbal child responded strongly during a music intervention. The song used resembles the traditional music from his tribe (Lindblom, 2016b). This sparked the interest to start a project together with an Indigenous community, engaging musicians, knowledge holders, and Elders to do one-on-one work with children in need of special support (perhaps diagnosed with ASD) using the specific tribal knowledge of the community the child comes from.

Children are our future. Dr. Lori Lambert (2014) named her book Research for Indigenous Survival, stressing the need for research that ensures the survival of Indigenous cultures. In such a project, language and culture revitalization could be combined with adequate culturally sensitive music, or other interventions. This could potentially lead to real possibilities for the Indigenous children diagnosed with ASD to take substantial steps out of the shadows of colonialism, and perhaps stay out.

6.4 CONCLUSIONS

Music is important for all humans and for young people, it is a big part of their lives (North, Hargreaves & O’Neill, 2000). I am tempted to say that young First Nations children diagnosed with autism are no exception. However, previous research actually shows that many children diagnosed with autism show exceptional interest and talent for music (Autism Speaks, 2016; Kanner, 1943; Molnar-Szakacs & Heaton, 2012). This gives us a wonderful possibility to utilize music to enhance the essential social, emotional and motivations skills of these pupils (Eren, 2015; Kim, Wigram & Gold, 2009; Simpson & Keen, 2011). Most importantly, within Indigenous cultures music is integral and the tribal-specific music of each child can connect them with the ancestors and all in creation. The healing qualities are infinite and cannot be fathomed within the constraints of this PhD.
This research project set out to investigate the meaning of music for First Nations children diagnosed with autism in BC, Canada. From a Western perspective, this research has produced new knowledge. However, within an Indigenist paradigm, the meaning of music has been known by all in creation since the beginning of time, and is nothing new or novel. Nevertheless, this dissertation is a contribution to the existing body of knowledge about First Nations children diagnosed with autism, how autism can be viewed through a First Nations lens and how music is used by, and for, the children in this study. Most importantly, the reciprocal relationality of an Indigenist paradigm has been explored through my mind, spirit, body and emotions, which has strengthened my relationship to Indigenist knowledge. Ultimately, this dissertation aspires to influence practice for First Nations children diagnosed with autism in BC. For the children and families in this study, being there, listening to their stories and building relationships, I believe my study has made a difference in their lives, as it has in mine.

David and Joseph (Lindblom, 2016a) speak of the inclusive nature of First Nations communities. The diagnosis of autism is based on a Western deficit model which does not fit within First Nations cultures. Due to colonialism, First Nations peoples were killed, forced off their traditional lands and bereaved of their cultures. Therefore, cultural revitalization and decolonization is imperative. This clash of worldviews has implications for the First Nations children with autism in my study. They are stuck in the dominant system through health, schooling and funding systems that demand categorization and separation. Connor and his family can be seen as living a traditional lifestyle with several generations living together, helping to care for Connor (see Lindblom, 2016b). Still, they live on reserve, which means they live in a segregated community within the dominant community, and therefore are still dependent on the dominant systems. Debbie and her family live a more contemporary, urban lifestyle, more separated from their culture. In Lindblom (2016b), it is shown how Debbie’s family lives an urban, more contemporary lifestyle and receives autism funding, but Connor, who lives a more traditional lifestyle on reserve, receives none. It is easy to see warning flags for systemic racism, and that conforming to the dominant system is required to receive benefits that they are eligible for according to the law. Both Connor and Debbie respond to their traditional music and the drum. I can only speculate on how the lives of the children in my study would have been if they had lived undisturbed on their traditional lands. However, it stands clear in the results, that incorporating traditional music in the interventions makes a difference. It will be beneficial if support and interventions for First Nations children diagnosed with autism become more culturally sensitive. This could perhaps be a step out of the shadows of colonialism.

The results show that music is important to the five First Nations children diagnosed with autism in this study. Debbie who lives and breathes music, Tom spends most of his free time listening to music. Connor communicates through music, something I like to call ‘communciation’. Peter enjoys films and their music and playing instruments. Steve thinks “music is good” even though no one has noticed. Music is not used for motivational or inclusion purposes in the school setting and Indigenous music is not used other than perhaps as background music at school. Debbie attends an optional Aboriginal class in which she got to make and play her own drum. She liked this as much as listening to her pop music. First Nations children have the right to their language, culture and knowledge systems (United Nations, 2008). Schools could do much more to enforce these rights for the children in this study.
The staff members involved in this study had not thought about using Indigenous music, and when we discuss it, they all say they have little or no knowledge about it. This can be due to them being educated in a system that teaches Western music which results in them reproducing the system and not feeling confident in using Indigenous music (see Bradley, 2015; Hargreaves et al., 2007; Saunders, 2010). Furthermore, all children have the right to express their views on issues that regard them and their lives (United Nations, 1989). It may be difficult for First Nations children diagnosed with ASD to assert this right to express their views regarding support and interventions in the school setting, especially if they are minimally verbal. This lays the responsibility on all adults, both in private and professional settings, to be aware of and attentive to the child’s attempts to communicate in order to ensure that their rights are being respected and enforced.

In the beginning of this dissertation, I wrote of presuming competence (Biklen & Burke, 2006). The results of this study do not show competence being presumed in the school context. However, Connor’s grandfather figure had a very strong opinion about the importance of their Indigenous language and presumed competence in Connor.

*Try talking to him so just in case… He might answer someone… It will be a lot of difference once he start talking… we’re not gonna talk to him in English all the time. He’s got to talk our language too.* (Earl, Connor’s grandfather figure)

This is in accordance with what Wilson (2008) describes is done in Indigenous learning, where provision of a foundation for growth is central, and there are no pre-set limitations for this growth.

Connor is diagnosed with autism and is minimally verbal. In some of my publications I have written about giving voice to individuals or peoples that cannot speak for themselves. The best thing, of course, is if they can do their own talking, on their own behalf. Research has a dark history of distorting the knowledge systems, traditions, protocols and experiences of Indigenous peoples. Connor cannot speak yet, but he has a voice, and he can sing. We need to learn to listen.
REFERENCES


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APPENDIX1: QUESTIONNAIRE OR GRID OVER MUSIC ACTIVITIES.

Questionnaire regarding musical activities in the study of the meaning of music for children diagnosed with Autism Spectrum Disorder, ASD.

**Name:**

<table>
<thead>
<tr>
<th>Musical activity</th>
<th>alone</th>
<th>group</th>
<th>planned</th>
<th>spontaneous</th>
<th>School</th>
<th>Home</th>
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</thead>
<tbody>
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<td>Play instrument</td>
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<td>Instrument lesson</td>
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<td>Sing</td>
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<td>Singing lesson</td>
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<td>Choir</td>
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<td>Listen to others play instruments or sing</td>
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<td>Music therapy</td>
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<td>Relaxing to music</td>
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<td>Watch music videos for example on YouTube</td>
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<td>Create music</td>
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<td>Play in an orchestra or band</td>
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<tr>
<td>Improvise</td>
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</tbody>
</table>
APPENDIX 2: EXAMPLE OF MIND-MAP.

2013

- Did a week of music at summer camp 2013. Drums, keyboards and xylophone.
- Sings mostly to radio. Sometimes bursts out
- Dances to CDs
- Goes to some Aboriginal functions at school. Uncle has dance troupe
- Music soothing for her. Uses it to relax. Sometimes tantrums.
- Listens to radio and watches youtube. Uses headphones.
- Watches music on TV in the morning
- Means of music 10
- Music on the bus
- Expanded musical taste
- Made a drum in Aboriginal class

2014

- Will go to camp in 2014 all summer and do musical
- Concerts too loud
- Grace mother of Debbie
- Music a big part of her structure
- Goes to start playing keyboard
- Wants to play guitar
- Did a week of music at summer camp 2013. Drums, keyboards and xylophone.
ARTICLES

ARTICLE I
Disability and Society, 29(8), 1248-1259. doi:10.1080/09687599.2014.923750

ARTICLE II
In SAGE Research Methods Cases. 2016. doi:10.4135/978144627305015595378

ARTICLE III
Psychology of music. DOI: 10.1177/0305735616659553

ARTICLE IV
Manuscript submitted for publication.


12. Teemu Valtonen. An Insight into Collaborative Learning with ICT: Teachers’ and Students’ Perspectives. 2011.


27. Hanna Mikkola. ”Tänään työ on kauneus on ruumis on laihuus.” Feministinen luonta syömishäiriöiden ja naisuutuuden kytköksistä suomalaisissa syömishäiriöromaanissa. 2012.
ANNE LINDBLOM

First Nations children diagnosed with Autism Spectrum Disorder in BC, Canada, appear to be under-detected. The children in this study use music for purposes such as communication, relaxation, security, self-soothing, happiness and when doing homework. The use of traditional Indigenous music, and music as a facilitator for inclusion, appear to be overlooked resources. This study was conducted within an Indigenist research paradigm, based on reciprocity and relationality. Culturally-sensitive, tribal-specific music interventions should be further investigated.