

**Musical Mobility:  
Understanding Everyday Musical Experiences Through Disability**

by  
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## **ABSTRACT**

### **MUSICAL MOBILITY:**

#### **UNDERSTANDING EVERYDAY MUSICAL EXPERIENCES THROUGH DISABILITY**

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This study examines how people with physical disabilities use music in their role as listeners to improve and impact their well-being and experiences of joy in their daily lives. Through an exploration of the music listening practices of people who self-identified as having physical disabilities in south-western Ontario, this project proposes the concept of musical mobility to provide an in-depth understanding of how participants make use of music in creative ways. This thesis illuminates the need to further explore how we conceptualize disability and demonstrates what we can gain from listening to peoples' experiences of joy and well-being.

**DEDICATION**

This work is for Joan Marson, whose work and life is the foundation of my own.

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## CHAPTER ONE – INTRODUCTION

### *Overview*

This anthropological study examines the experiences of music among persons with physical disabilities by exploring music through listening as a source of joy, a way to create and maintain bonds, and as a tool for coping with physical and emotional pain. An exploration of music listening as a form of leisure and social practice is important to enhancing our understanding of the feelings of well-being and the experiences of joy of people with physical disabilities. My research question thus asks: What is the relationship between the role of music listening among people with physical disabilities and their well-being? In anthropology, previous studies of people with disabilities rarely explored their uses and experiences of music (e.g. Ablon 1984; Murphy 1990).

Meanwhile, the existing anthropological studies of music and listening fail to address the perspective and experiences of people with disabilities. In medical anthropology specifically, disabilities have been examined by highlighting the limitations (see Shuttleworth and Kasnitz 2004:142), suffering, and othering experienced by people with disabilities, rather than exploring their experiences of leisure (Freedman, Stafford, Schwarz, Conrad and Cornman 2011:588). In interdisciplinary disability studies, some works have highlighted the experiences of music among people with disabilities (Bailey 2011; Clarkson and Robey 2000; Eidevall and Leufstadius 2013; Kittay 2008; Lubet 2011; McKay 2013; Watts and Ridley 2012), though there is a gap in the literature on this topic as most discussions of disability and music focus either on disability and musical performance, or position music listening in relation to disability as a passive experience. The interdisciplinary literature on the experiences of music among people with disabilities privileges the production of music and musical performances among professional musicians, rather than the experiences of non-professional listeners. The literature that does focus on music and people with physical disabilities is largely from the field of occupational therapy, which focuses on the use of music for treatment.

In contrast, my research takes a phenomenological approach to music and physical disability to reveal the ways in which people with physical disabilities use music listening and how this

relates to their mind-body connections, their self-social connections and ultimately, their experiences of well-being. By talking to people with physical disabilities about their musical experiences, this study became an exploration of the ways in which music is used as a tool for coping with emotional and physical pain, as well as being a means of taking control of one's mood and feelings, creating connections with others, and experiencing joy. These discussions exposed participants' joyful experiences despite potential barriers to settings, live music events for example, in which desirable musical engagements can occur. These musical engagements provide valuable opportunities for people with physical disabilities to express their being-in-the-worldness, which may be inaccessible through other avenues.

This study notably illuminates a sense of *mobility* experienced by people with physical disabilities as they interact with aural happenings in their daily lives and navigate their social and physical surroundings. In exploring the ways that music affects their everyday lives, participants emphasized the exploration of ideas, the thoughtful wandering, and the socializing that can be achieved through music listening. These actor-oriented patterns of involvement in music led me to conceptualize the idea of musical mobility, which refers to the ability for people with physical disabilities to move themselves emotionally and physically through music. This actor-centered perspective is missing from the literature on music and people with physical disabilities. Given this, throughout this work, I will refer to musical mobility to describe and explain how participants use music to move themselves both emotionally and physically. The terms movement and mobility here are used to describe physical movement, moving one's body within a place or from one location to another, for example, but it is also used to describe real emotional shifts and transportation to different states of mind, memories, and feelings. Musical mobility in particular refers to participants using music as a catalyst for these types of movements, whatever they need or want at the time. For example, participants used music to inspire movement physically, while exercising or commuting, and at other times, using certain songs or genres to help them shift from feeling sad to feeling happy, or from distraction to focus. In many cases, these movements happened together, moving physically, for example driving somewhere, and feeling moved emotionally, feeling free, excited, and hopeful. Using this notion of musical mobility, in my thesis I argue that participants with physical disabilities creatively and

intentionally take part in music listening as active agents. Their engagements in music reveal the ways in which music is used as a medium for bonding with others and to manage pain and distress. As such, their experiences of music contribute to their sense of well-being.

The idea of musical mobility proposed in this study was developed by combining feminist geographer Susan Smith's notion of the aural environment (2000), disability studies scholar Kuttai's description of music as "joyful embodied experience" (2010:109), and the concept of micro-mobility developed in a study of youth with vision and hearing impairments (Porcelli, Ungar, Liebenberg and Trepanier 2014). The focus on mobility importantly hinges on the idea that music listeners are not only passive, but have a constituting and artistic involvement in the music listening experience as curators of aural environments. An early understanding of music developed in Merriam's work, *The Anthropology of Music*, suggests that music forms part of human symbolic behaviour, though the meaning of music is highly fluid (1964:229, 232-233). To explain further, Merriam states that, "...meaning in music is not fixed by common consent of those who create or listen to it; rather, it is emotions and general meaning sets which are expressed" (1964:233). Then, what *is* music in the context of people's daily experiences, in particular, among people with physical disabilities? Part of this more traditional perspective of music as symbolic behaviour can be combined with an approach on sound and music from feminist geography to get at music and its meanings with a more nuanced understanding of the active role of the listener in shaping the meanings of music in particular aural settings. Feminist geographer, Susan Smith's work on the heard environment suggests that "...music occupies a particular space...between the myth of silence and the threat of noise" (2000:616). The spectrum of sound that Smith (2000) outlines puts music in a dynamic position between silence and noise, and in this formulation, music is more than a mere result of people's "symbolic behavior" but a product of people's creative engagements. On this spectrum, noise is the disorder (difference, discord) to music's order (sameness, harmony) and silence the absence of both (Smith 2000:616). As such, her perspective on music can also give some insight into the experiences of people with physical disabilities as listeners in creatively using music's power to shape their aural environments. In this research, therefore, I focus on the listener as a curator of their "heard environment" (Feld 1982:61; Smith 2000).



Furthermore, Kuttai, a Canadian scholar with a physical disability noted the power of music in ordering her life with a physical disability. This understanding of music is illustrated in her account of daily life as a mother with a spinal cord injury. Kuttai's description of music as a "joyful embodied experience," her use of music and song lyrics as a guide for her narrative and her assertion that "music brought order to my chaos" (2010:109, 111), all demonstrate the importance of music in her daily life and its contributions to her well-being. A further focus on music as a source of feeling well and as providing "a sense of legitimacy" (Kuttai 2010:115) to her experiences, helps to challenge commonly held assumptions and associations of disability with suffering and illness. This account hints at the potential uses of music by participants to order and make sense of their emotional and physical experiences in their daily lives and these will be explored further in this thesis.

In order to explore the relationship between physical disability, music, everyday life, and well-being, the idea of micro-mobility (Porcelli et al. 2014:864) is combined with Smith's notion of the heard environment and Kuttai's emphasis on the use of music in ordering experiences, as it notes that a social actor navigates social and physical settings by using their skills and competencies and manages day-to-day challenges (Porcelli et al. 2014:864). Porcelli and colleagues explored well-being and the abilities of youth with vision and hearing impairments to know their environment as agents. Though Porcelli and colleagues did not examine the experiences of music among their participants, I have adopted and modified this concept of micro-mobility to specifically analyze my participants' agentic involvement in their aural environments.

In sum, the idea of musical mobility is built upon these conceptualizations of music, the aural environment, and people with disabilities as agents. Smith examines music as a way to experience, impact, and organize one's social and built environment, and characterizes this position suggesting that, "music occupies a particular space...between the myth of silence and the threat of noise" (2000:616, 617). Kuttai emphasizes and illustrates Smith's account by describing the power she gained from music in bringing a sense of order to her "chaos" (2000: 111). Furthermore, the idea of micro-mobility with which people with disabilities actively navigate their environments (Porcelli et al. 2014:864), informs this study by highlighting the

ways in which people with physical disabilities creatively engage in and shape heard environments through music listening.

### *Outline of Chapters*

My research takes a phenomenological and anthropological approach to music and physical disability to reveal the ways in which people with physical disabilities experience their mind-body connections as well as their ties to others with or without disabilities (Chapter Two). The definition of disability changes depending on the model or approach to disability used, such as the medical model, the social model (e.g. Oliver 1990), the resistance model (e.g. Gabel and Peters 2004), and the cultural/sociocultural model (Shuttleworth and Kasnitz 2004; Snyder and Mitchell 2006). Rather than privileging one model over another, in this thesis I will use and reflect on multiple models of disabilities in order to make sense of my participants' discussions of disabilities through music.

Medical models of disability commonly examine disabilities by focusing on a personal deficit, rather than a larger social and structural issue (Linton, Mello and O'Neill 1995). The social models of disability feature the oppressive, disabling effects of society on the lives of people with disabilities and problematize the static categorization of disability as associated with lack, sickness, pain, and suffering (Barnartt 2010; Ginsburg and Rapp 2013; Gabel and Peters 2004; Oliver 1990; Rock 2000). The resistance model notes the significance of individual agency or struggle against disabling policies and the resulting economic distress (Gabel and Peter 2004:593-5). The critical realist model emphasizes that physical, biological realities that were ignored in the social model should be considered in addition to the social and cultural forces that shape disabling forces (Shakespeare 2006), given that individuals with disabilities still experience pain, impairment, and limitations even in a perfectly accommodating environment. As a result, in one context, a disability can be understood in terms of the patterns of social relations that shape the lives of people with disabilities, while in another context it can be grasped as a form of resistance enacted by social agents. Acknowledging the significance of the participants' use of terms and the North American standard in disability studies and communities, I will be using people-first language, in particular the phrasing "people with

physical disabilities,” in this thesis to refer to those who identify as experiencing disabling policies and practices, structural limitations, and physical pain.

The data for this study come from in-depth qualitative interviews, the method of a modified mapping exercise developed for this project, and observation conducted at concert venues (Chapter Three). The study involved fourteen meetings with ten adults who were interested in music and self-identified as having a physical disability and/or mobility impairment. Between July and September of 2016, participants were recruited by contacting Spinal Cord Injury Ontario (2 participants) and Student Accessibility Services at the University of Guelph (8 participants). Participants had a variety of disabilities, though they shared issues of chronic pain, injury, and accessibility. Some of the participants had common visible signs of disability, such as wheelchairs or canes. However, others did not use mobility aids at all. I had both male and female participants, ranging in age from 18 to 55. All were highly educated, including a Ph.D. candidate and a Master’s student with a previous Master’s degree. The initial in-depth interviews with participants involved interview questions on the topics of general music listening habits, music and place, music and accessibility, and music and well-being. In order to understand the characteristics of aural environments in which participants’ musical experiences occur, I also used a modified version of participatory mapping through music and drawing of a CD cover as a map of where participants listened to music. This created an opportunity to facilitate further discussion of participant’s perspectives on their music listening experiences. I also used observation as a supplementary method to make sense of aural environments where concerts and music festivals occur. The music festival was in late July 2016 and occurred outdoors over three days. I attended several concerts at different venues in Toronto: The Danforth Music Hall, The Virgin Mod Club, REBEL, and Massey Hall.

By talking to people with physical disabilities about musical experiences, this study reveals the ways in which music is used as a tool for coping with pain and emotional distress as well as being a mechanism for controlling one’s mood and feeling connections to others (Chapter Four). Talking to people with physical disabilities about music exposes their joyful experiences despite potential barriers and this provides a valuable opportunity for people with physical disabilities to express their being-in-the-worldness with disabilities. In this study, I found three

major patterns of musical engagements as listeners among participants. First, I found that participant accounts focused on music as a purposeful wandering. They make choices to distract, entertain, and enjoy themselves. Second, they used music as a way to explore and process new ideas and emotions. Finally, a major theme in music listening practice was its use as a way to connect to the artists, other listeners, and with family and friends, both connecting emotionally and physically through live music events, parties, and by enriching typical get-togethers.

In conclusion, I summarize my findings of this study and discuss its contributions to the anthropological literature on disabilities and studies on music and well-being among people with physical disabilities. This study makes a contribution to the rapidly expanding anthropological study of disabilities by exploring an understudied dimension of the lives of people with physical disabilities—music listening. While a number of previous anthropological studies examined stigma, liminality, disembodiment, and othering associated with people with physical disabilities, this study highlights the importance of a sense of mobility experienced by participants as they engage in aural happenings as creative agents. As such, this study shows that participants' musical experiences involve connecting with other people through music while coping with pain and day-to-day challenges of access.

Before delving further, it is necessary to address my current status as a scholar without a physical disability. It has long been a point of contention in the disability studies literature that authors and academics who do not currently have a disability encroach on topics that they do not know intimately and risk silencing voices of people with disabilities, or speaking for them rather than making room for them to be heard. This is an important point to make in the history of academic study and it is something that I grappled with as I developed an interest in disability studies. To this concern, there are several points to be made. Firstly, there are multiple scholars, with or without disabilities, who have made the case that disability is something to think with (Titchkosky 2004) and others who have argued that disability is a scholarly issue because it is something that affects everyone, albeit to varying degrees. Not only this but it is of interest to the general public, who are also affected by disabilities to different degrees, to consider this phenomenon, this part of life. Russell Shuttleworth's work on the sexual experiences and identities of men with cerebral palsy deals intimately with the issue of the anthropologist without

a disability engaged in multiple roles (Shuttleworth 2004). Though Shuttleworth has a 30-year connection to this community as an employee, researcher, advocate, and friend, I consider my work to fall into a similar tradition of anthropological works that undertake disability as a type of anthropology-at-home. I am a friend, a family-member, a colleague, and an advocate-in-training in my disability community at home. As a person currently without a disability, I have an interest in being more informed, making connections, and talking about something that is fundamentally a human experience. People I love live with physical, emotional, cognitive, and sensory disabilities and my research is inspired by them and for their benefit.

By exploring the lives of people with physical disabilities as curators of aural environments, this study reveals their experiences of bonding and joy through music. Given that music listening is common among diverse people with or without disabilities, this study's focus on "joyful embodied experiences" (Kuttai 2010:109) usefully shifts away from the centrality of suffering and isolation in academic and public discourses on people with physical disabilities. As such, this project serves to highlight the richness of the lives of people with physical disabilities despite daily challenges.

## CHAPTER TWO – LITERATURE REVIEW

### *Models of Disability*

The term disability is highly contested in terms of its meaning and usage. While some scholars include impairment in their definitions of disability as is the case with Freedman et al. who define it as "...the presence of any physical, cognitive, or sensory impairment" (2011:588), others take issue with this description. Shuttleworth and Kasnitz focus on negative perception to nuance their definition of both impairment and disability, suggesting that disability "...is then a negative social response to a perceived impairment" (2004:141). The definition has always depended on the model or approach to disability used, such as the medical model, the social model (e.g. Oliver 1990), the resistance model (Gabel and Peters 2004), and most commonly in anthropological works, the cultural/sociocultural model (Snyder and Mitchell 2006; Shuttleworth and Kasnitz 2004). A social model of disability was largely engaged to encourage a move away from the static categorization of disability as associated with lack, sickness, pain, and suffering (Barnartt 2010; Gabel and Peters 2004; Ginsburg and Rapp 2013; Oliver 1990; Rock 2000). This move has been undertaken as part of a reaction to common medical models of disability that focus on a personal deficit, rather than a larger social issue (Linton, Mello and O'Neill 1995).

The medical model of disability suggests that disability is something within the individual and the body, and most rehabilitation and therapy models hold this implicitly as these approaches seek to correct or cure the individual body (Oliver 1990). In Oliver's *The Politics of Disablement*, he offers a response called the social model of disability, which reframes disability as varying processes that occur in society that result in the disablement of certain individuals (1990). Oliver retraces these disabling processes politically and historically in a somewhat Marxist cultural evolutionary fashion, going back to industrialization and changes in society that rendered certain types of bodies and abilities "normal" and valued based on labour potential. The social model of disability marked an important turn in disability studies. Though it has been critiqued, the social model has usefully contributed to the vibrant debate on the conceptualization of disability. The interdisciplinary field of disability studies grew to see the development of the cultural model of disability, the resistance model, among other types of analytical styles such as the narrative and literary approaches (Davis 2002; Garland-Thomas 1997), as well as responses

to Oliver's social model in the form of the critical realist approach (Shakespeare 2006, seen also in Phillips 2011). Importantly, the cultural model of disability differs from the social model by emphasizing contextual and cultural understandings of disabilities (Shuttleworth and Kasnitz 2004; Snyder and Mitchell 2006).

Shakespeare's critical realist approach seeks to emphasize both the social and biological elements of disability. He suggests that we cannot gain a practical understanding of disability experiences with only the hard medical model or the strict social model, as each denies something about what it means to live with and to have a disability. Shakespeare explains that though the social model came about at a time when it was politically important to make a hard shift away from medicalization and individual tragedy perspectives, it was over-simplified for the purpose of making political gains and establishing organizations (2006). A result of this process is that physical, biological realities of living with disabilities were ignored—in particular, the fact that individuals experience pain, impairment, and limitations regardless of a perfectly accommodating environment. In other words, differences due to disabilities do exist and they are not always simply a product of cultural and social structures (Shakespeare 2006). Phillips (2011), in her work on spinal cord injury in the Ukraine, follows this realist, pragmatic tradition, which works well with the local understandings of disability in her research setting.

Resistance theory, as influenced by Shakespeare and Foucault, outlined by Gabel and Peters suggests that the extreme social model that reduces disabilities to structural barriers does not account for individual agency or struggle against disabling processes, such as discriminatory support policies and the resulting economic distress (2004:593-5). Gabel and Peters give examples of the ways in which resistance can be enacted, as is the case when they state, "Resistance is also evident in disability aesthetics within which art and experience are used to transgress, disrupt, and confront while also constructing a disability-centered notion of beauty and desire" (2004:593). This type of resistance is clear in McKay's (2013) work on musicians with polio and his account of the Canadian artists Neil Young and Joni Mitchell. Both artists had polio as children and experienced physical limitations in their lives as a result, but they also became key actors in defining Canadian folk music. Neil Young's fragile delivery and lyrical style show the influence of his experiences with polio, and these stylistic elements have been

imitated and desired in the genre. Similarly, Joni Mitchell's experience with polio resulted in limited hand and arm movement and she tuned her guitar such that she could make the chord formations and strumming patterns fit to her mobility. As a music student learning guitar, Joni Mitchell's songs pose a challenge to the typical style, what could be called the normative body movements in music instruction, but reproducing her sound is very coveted, and her creativity admired (McKay 2013).

Despite the different conceptualizations of disabilities in the above models, a unifying aspect of these models and of disability studies more generally is that many are influenced by and make use of Goffman's theory of stigma, the primal scene, and other influences from the social interactionist school. This is of course an important aspect of disability experiences; however, I suggest here, acknowledging Goffman's crucial contribution, that it is time to look at disability from a different perspective. Studies of disability in anthropology have also made use of Van Gennep and Turner's concepts of ritual and liminality to describe experiences of disabilities (Ablon 1984:170; Murphy 1990:74-75, 131). These works also, especially Ablon's (1984), draw on stigma to explain how people perceive the actions of others in response to their different bodies. Murphy's perspective on liminality suggests that the person with a disability is one who has not successfully transitioned from the subject of sick person to healthy person, as he phrases it, "they have broken the commandment to 'get well'" (Murphy 1990:100). As such, a person with a disability is considered to occupy an unacknowledged subject position and can be classified as disembodied, or a non-person (Murphy, Scheer, Murphy, and Mack 1988; Murphy 1990). However, a number of questions remain unanswered. Do people with disabilities experience themselves as non-persons? In what ways do they engage in activities that may contest the forces of disembodiment in their daily lives?

My study takes a phenomenological approach to explore disability experiences and the result has been that there are elements of three of the models, cultural, resistance, and critical realism, which have been helpful to understanding participants' lives as engaged music-listeners. In their review of disabilities studies, Ginsburg and Rapp highlight the turn to using phenomenological approaches in understanding disabilities (2013:54-55). A phenomenological approach is one that privileges lived experience and is an attempt to challenge assumptions of



what it is like to be in the world (Desjarlais and Throop 2011:88, 91). The insights of Kuttai (2010) and others who have written on music and disability (Kittay 2008) lead me to adopt a phenomenological exploration of musical experiences as a listener in order to complicate our understandings of the lived experiences of people with physical disabilities, which cannot be explained fully by the notions of stigma or liminality.

***Well-being and people with disabilities in anthropology and disability studies***

Research on disability and experiences of well-being and joy are largely missing from the anthropological literature (Freedman et al. 2011:588). In their overview of Ablon's contributions to anthropology and disabilities studies, Shuttleworth and Kasnitz discuss the relegation of disabilities studies in anthropology to topics of illness (2004:142). Specifically, some researchers have called for further investigation into the relationship between "productive, social, physical, or other leisure pursuits" and feelings of well-being for people with physical disabilities (Freedman et al. 2011:588). This research frames music as a type of activity that can contribute meaningfully to people's sense of well-being, which is particularly important for people with physical disabilities who are often positioned in the anthropological literature as not "able" to have these experiences.

While the anthropological literature on well-being has not theorized the relevance of disability to the conceptualization of well-being, Mathews and Izquierdo (2009) provide a useful overview on subjective experiences of well-being from an anthropological perspective. They explain in "Towards an anthropology of well-being," "Well-being is a matter of how well one's mind/body is felt to fit within one's physical and social world, and is never static but rather is in dynamic flux" (2009:255). In this work, the authors suggest that anthropology can contribute an important understanding to theories of well-being through an emphasis on what is relevant and reported by participants, rather than relying on statistics and surveys as is common in other fields that study and rank well-being (Mathews and Izquierdo 2009:258). They go on to divide well-being into four types: (1) physical, (2) interpersonal, (3) existential, and (4) national/global. These are defined as how a person experiences their body (1), their relationships (2), how they

might understand “the values and meanings of their lives” (3), and how the impact of institutions is felt (4), all within the individual’s context (Mathews and Izquierdo 2009:261).

While the work by Mathews and Izquierdo highlighted different types of well-being that may be experienced by individuals, Andrews and colleagues emphasize the inseparability of beings and the world, subjects and objects in people’s experiences of well-being, focusing on co-creation and co-constitution through relationships (Andrews, Chen, and Myers 2014:211). From this approach, well-being is thought to be “anchored in a common and familiar feeling-state” (Andrews et al. 2014:219) and arising from affective states that “manifest on a somatic register as vague but intense ‘atmospheres’ or ‘vibes’” (2014:214). These affects and feelings need to be positive and/or shared to contribute to well-being, resulting in individuals, things, all beings, and objects “acting together *as* the environment” and experiencing themselves “expansively as more than themselves, as part of a greater physical happening” (Andrews et al. 2014:217, emphasis in the original).

Well-being can also be simply defined “as reports of life satisfaction” (Freedman, Stafford, Schwarz, Conrad and Cornman 2011:588), though authors who write on this topic often rely on the subjective nature of well-being while also highlighting particular issues that people report as contributing to these types of feelings. Among these issues, they noted the significance of participating in preferred leisure activities and having a sense of belonging and recognition (Freedman et al. 2011; Sakellariou 2015). Regarding this sense of belonging, Sakellariou, in a study of the modification of a home in Wales in response to the owner’s disability, discusses the idea that increased accessibility in the home can contribute to feelings of well-being through the development of a sense of place (2015:458). This sense of place is created when the home is modified according to the owner’s preferences and in such a way that facilitates their well-being.

Well-being can also be examined by exploring the availability of preferred choices for people with disabilities. The capabilities model, developed by Amartya Sen and Martha Nussbaum, “conceptualises human well-being as the substantive freedom – or capability” and indicates that “individuals have to choose and lead lives they value and have reason to value” (Watts and Ridley 2012:362). Part of the capabilities approach is the distinction between

functioning and capabilities, and the difference between true freedom of choice and adaptive preference. An adaptive preference speaks to situations in which options are not made available so the existing situation is preferred, almost by default. An example, given by Watts and Ridley in discussing access to adaptive musical instruments, suggests that this approach, “acts as a warning against the legitimising of limited choices as individuals become grateful for life’s small mercies and restrict their personal desire to more modest and realistic proportions such as merely listening to music as they come to accommodate their musically creative aspirations with their experiences of dis/ability” (2012:358). My study will call this statement into question as listeners can be creative curators of their aural environments, not simply passive by default, but the authors’ position brings an important perspective to this discussion of well-being and agency.

The issue of agency is particularly important as the literature on well-being and physical disability emphasizes the significance of intervention, rather than the creativity of people with disabilities. Some studies emphasize technological interventions to increase well-being, such as medical interventions in the case of The Ashley Treatment (Battles and Manderson 2008). While medical interventions are hotly debated in some cases, they are also documented as providing great relief (Shakespeare 2006). Other types of adaptations for recreational activities such as adaptive sporting equipment and musical instruments (Honisch 2009; Lubet 2011; Watts and Ridley 2012) are seen as important ways to improve access to fun and greater quality of life. These are practical methods that can be part of a larger tool kit of resources available to people with physical disabilities.

However, there is a lack of attention to how people with disabilities are improving their quality of life without drastic intervention. Online community building (Obst and Stafurik 2010) may be an approach to increase well-being and reduce isolation among people who experience mobility and accessibility issues, for example. Forums and social media communities online are not restricted in the same way as coffee shops and bars. The Internet can provide a medium for community building in a much broader sense, and in cases of physical disability, it can be a useful tool in connecting with others.

In understanding activities that may increase well-being among people with disabilities, the concept of “micro-mobility” (Porcelli, Ungar, Liebenberg and Trepanier 2014) is useful, as it positions these people as navigators of social and physical environments. One study highlights the abilities of youth with vision and hearing impairments to know and experience their environment and appreciate, what the authors term, their “micro-mobility” (Porcelli et al. 2014). They describe micro-mobility “...as the skills and competencies young people use to navigate the social space (spatial dimension of mobility) and physical places (geographic dimensions of mobility) that provide them with the psychological, relational and contextual resources (such as opportunities to participate in their community, access to adapted educational programmes and recreation) they need to cope with everyday challenges” (Porcelli et al. 2014:864).

The above notion of micro-mobility sheds light upon people as navigators of different built environments, which may or may not be accessible. Accessibility is typically discussed in terms of the built environment, defined as physical and spatial, often in terms of accommodation and modification (Sakellariou 2015:458). Ben-Moshe and Powell, in their study on the signs and symbols of accessibility, suggest that accessible spaces are often separated and placed in isolated, small areas (2007:494). Rodman and Cooper make the claim that, “all built environments vary in their capacity to enable or inhibit people’s behaviours” (1995:590), and in this way even having designated accessible areas is not enough. Creating these spaces may still be (dis)abling in the placement of accessible spaces at a distance, reinforcing the value-laden difference of those who occupy such spaces. While accessibility is concerned with the varying qualities of spaces for actors to navigate, the focus on micro-mobility provides an actor-oriented perspective on the navigator’s interactions with the social and physical surroundings.

However, how does music listening complicate the notion of micro-mobility? Rather than seeing music as a form of human symbolic behaviour (Merriam 1964:229, 232-233), the importance of peoples’ engagements through music has been emphasized in more recent works. For example, Smith examines music as a way to experience, impact, and organize one’s social and built environment (2000:617). Kuttai describes music as an “embodied experience” (2010:109). In this project, I broadened the understanding of mobility to the heard environment (Feld 1982:61; Smith 2000), to explore how mobility can be experienced in an auditory capacity

rather than strictly in terms of physical mobility. This line of thought has led me to propose the concept of musical mobility in making sense of my participants' experiences (this issue will be discussed further in Chapter Four).

Opening up mobility to include the auditory aspects of the environment calls place into play as we consider how and where we experience certain sounds. Feld's work with the Kaluli demonstrates the ways that people living around Mount Bosavi in Papua New Guinea use their audition and sound to organize and navigate their environment (1982:3, 62). Furthermore, people here compose songs and music that are quite explicitly connected to the context and environment in which they live (Feld 1982:36). In this way, the experiences of music can reveal a sense of place and belonging among participants.

### ***Music listening and well-being among people with disabilities***

While leisure and entertainment among people with disabilities have attracted limited attention in anthropology, in the interdisciplinary disability studies, several works on disability and music examine pieces of music, music theory, and the lives of musicians (Lerner and Straus 2006; Lubet 2011; MacKay 2013), while others discussed their own experiences of music in their works (Honisch 2009; Kittay 2008; Kuttai 2010). Some of these studies emphasize composition and performance, often through adaptive instruments, as the main sites where musicians can challenge assumptions about disability and achieve a sense of well-being (Honisch 2011; Lubet 2011; Lerner and Straus 2006). Lubet (2011), a key expert in the field of music and disability, goes so far as to suggest that music participation is a human right. As Watts and Ridley's work suggests, this right is not only about "the freedom to choose the pleasurable experiences of, say, listening to music but with being able to choose to produce music as well" (2012:358). This follows in the tradition of emphasizing the roles of the active and the passive, the creative and the reactive, and de-emphasizing the interaction of these elements within and between roles. For example, for professional artists, such as Ian Drury, their non-dis/abled artistic identities were salient unless they chose to foreground their identities as people with disabilities. The non-professional musicians, who took part in the Drake Music Project, described in Watts and Ridley's (2012) collaborative work on musical performance and its

impact on identity-formation among participants with disabilities, had fewer opportunities to make that choice. In this study, the authors describe participants' roles as musicians explaining that "their choices were constrained by the frequent presumption that non-professional musicians with dis/abilities are engaging in therapy" (Watts and Ridley 2012:361). Experiences of ability and well-being are often discussed in studies of music therapy (Clarkson and Robey 2000), and listeners are positioned to receive professional intervention in these contexts.

Many studies on music and disability have focused on the empowerment of producing music, telling a story from a perspective of a person with a disability through music (Lerner and Straus 2006; McKay 2013; Watts and Ridley 2012) without acknowledging the creative power of the listener. Acknowledging this aspect of experience is another way to view well-being, empowerment, and emphasizing creative types of mobility. Watts and Ridley start to suggest this when they discuss the distinction made between "the concepts of the artistic (that is, of the creative processes of doing or making art) and the aesthetic (that is, a response to the artistic creativity of others) ...in apprehending the diversity of musical engagement, it makes clear that this central human functioning involves both the aesthetic and artistic dimensions of music" (2012:358). Importantly missing is the fact that responding through listening can be both an aesthetic and artistic experience, as will be shown by the accounts of my participants.

As the majority of studies on disability and music focus on professional artists and their creativity, an important group has been left out of discussions of music and disability: the audience. Kuttai (2010), a Canadian mother with a spinal cord injury, uses music lyrics in her book, *Maternity Rolls*, as a guide in her life story. In her work, she describes "a sense of legitimacy" that music has provided her through the expression of shared feelings, whether sadness or joy, between the artist and the listener (2010:110, 115). In this case, the meaning given to music by the listener is that of a shared expression, validating the individual's experiences and resulting in feelings of joy and well-being. Kuttai (2010) is both a musician and a music-listener but importantly highlights the feelings of joy associated with experiencing music as a listener, not only in performing or composing. She describes her experience, saying, "Music brought order to my chaos" (Kuttai 2010:111). Kittay (2008) also discusses the importance of music listening in the therapy of his daughter. Just as the music performance of those with

physical disabilities can be minimized as therapy, so can the music listening, but it should not always be mistaken as such. This calls for an in-depth account of everyday musical listening among people with disabilities.

***Together in mind and body: music listening and embodiment***

Moments of highly emotional, deeply aesthetic experience can blur the strict lines that are drawn between these elements, as Scheper-Hughes and Lock suggest, “It is sometimes during the experience of sickness, as in moments of deep trance or sexual transport, that mind and body, self and other become one. Analyses of these events offer a key to understanding the mindful body, as well as the self, social body, and body politic” (1987:29) Music listening can be such an emotionally charged aesthetic experience among people with physical disabilities. In their review of work on the body and cross-cultural understandings of the self, mind, and body, Scheper-Hughes and Lock suggest that attention to emotion, not only on “occasions when they are formal, public, ritualized, and ‘distanced’” (1987:28), can help us to understand and explain the ways in which the elements of our experiences are connected and interrelated. Here “elements of experience” refer to those forces and objects in our lives that are often framed as separate and isolated from each other, as in the self and others, the mind and the body, the cultural and the natural.

This concept of the mindful body is important in this study as it highlights the ways in which our bodies are the foundations of our connections and interactions with others. It both is the self and is a way to communicate to others about ourselves. It is interesting then that experiences such as pain or sickness have been understood, from the approach of Western science and medicine, “[as] either physical or mental, biological or psycho-social – never both nor something not-quite either” (Scheper-Hughes and Lock 1987:10). The phenomenon of existence, in all its variations, is embodied and is such that our bodies both mediate and create the terms of our being, which simultaneously and inherently involves the self, other people and the broader whole (political, cultural life). The example of pain can elaborate these levels, as pain is experienced by the individual in a physical way, and is perceived, reacted to, and (sometimes) understood by others, and it has a variety of definitions determined by the context

and institutions that surround the individual but which have already been understood and used to frame the physical experience at the personal level, and which have been created by groupings of ourselves and others.

This process is evident in Murphy's work *The Body Silent* (1990), in which he explicitly and painfully gives an account of his experience with developing a disability. He suggests that embodiment can be especially challenging for those who have culturally significant physical differences. Murphy notes that those who gain a disability status through injury or disease may become "dis-embodied," and in such cases seek, "re-embodiment" (Murphy 1990:100). This disembodied feeling can result from the moral and political valuations of the body in states of health and sickness. As Scheper-Hughes and Lock suggest,

Health is increasingly viewed in the United States as an achieved rather than an ascribed status, and each individual is expected to "work hard" at being strong, fit, and healthy. Conversely, ill health is no longer viewed as accidental, a mere quirk of nature, but rather is attributed to the individual's failure to live right, to eat well, and to exercise, etc. (1987:25).

Murphy outlines feelings of alienation from his body as his movement became increasingly limited and the elements of his self became disconnected. He describes this saying, "...of a more fundamental order, the quadriplegic's body can no longer speak a 'silent language' in the expression of emotions or concepts too elusive for ordinary speech, for the delicate feedback loops between thought and movement have been broken" (Murphy 1990:101). As he experiences others' perceptions of his body and his unclear, contradictory position in his community, he began to feel isolated and to actively isolate himself, as well as starting to experience a distance between himself and his body (Murphy 1990:87, 98). This experience belies the intimate connections that our bodies inherently create and mediate with others and with our surroundings, and further illuminates the damage that can occur to the self when it is not reflected in the world, understood by others, or recognized by the larger community (Lock 1993:141). Such alienation is felt at the level of the individual as a body without the self, or the self existing without connection to a body (Scheper-Hughes and Lock 1987:22).



While the notion of the mindful body enhances our understanding of pain, suffering, and disembodiment, this concept can also be useful in understanding experiences of joy through activities that promote integration. Emotional and aesthetic experience can serve to revitalize and emphasize the connections that always exist between the self, others, and society more broadly. The concept of *communitas* can be useful here as it refers to a social encounter “...in which formal structures are placed in abeyance and people confront one another as whole and caring individuals,” a moment when people in this temporary position together are equals (Murphy et al. 1988:238). During these events, all elements of the mindful body come together, the individual, the social, and the political co-occur and are indistinguishable from one another. In Scheper-Hughes and Lock’s review article, they explain an idea of John Blacking (1977) who “...refers to the “waves of fellow-feeling” that wash over and between bodies during rituals involving dance, music, movement, and altered states of consciousness” (1987:29). Understanding how this process works can provide a means to promoting greater sense of self and community for people with physical disabilities, and to explore ways of promoting this kind of well-being through music.

In summary, the literature on disabilities in anthropology tends to highlight stigma, liminality, and suffering experienced by people with disabilities, rather than their pursuits of leisure and entertainment that may provide embodied experiences, promote integration, and well-being. The existing studies on music and disability largely focus on the creative performance and production of music among professional artists, while minimizing the significance of music listening among non-professionals. Listening to music among people with disabilities is often associated with therapy, and they are cast as passive recipients of treatment. In order to address these limitations, this in-depth account of everyday musical experiences among people with disabilities examines their musical engagements as navigators, curators, and creators of their aural environments.

## CHAPTER THREE – METHODS

### *Research Design*

For the purposes of answering my research question, I chose to use semi-structured interviews, some observation at concerts and music festivals, as well as a modified mapping exercise. In this exercise, the participants and I created music playlists and a map based on some guiding questions, delving further into the main topics discussed in the interviews. During the initial interviews with participants, I asked them four demographic questions to gather information for my analysis on their age, gender, self-described physical disability, and occupation. I then asked between 20 and 25 questions on the topics of general music listening habits, music and place, music and accessibility, and music and well-being. After each interview, I asked participants if there was anything they wanted to discuss on the topics that I did not address. The interviews occurred in a variety of locations, which I left open to the participants to decide, although most wanted me to choose a location to meet up. I met the majority of people in a campus library, both in private study rooms and in common spaces, while I met other participants at their workplace, at a cottage, a coffee shop, and a shopping mall. I also employed participant observation in public places during music events such as concerts and at a music festival. The music festival was in late July 2016 and occurred outdoors over three days. I attended several concerts at different venues in Toronto: The Danforth Music Hall, The Virgin Mod Club, REBEL and Massey Hall. At each venue I made mental notes of my observations during the events and then wrote my notes upon arriving home. Finally, a modified version of participatory mapping, involving music and the drawing of a CD cover as a map of where participants listened to music, was created to facilitate a further discussion of participants' lives as related to their music listening.

I began with observation at concerts and musical events as a way to situate myself in live music participation. I also paid more attention to my own recorded music routines and those of my friends and family. In this way, I started to pay more attention to the way live and recorded music plays in daily life. This focus served as a preliminary exploration into music and evaluating music venues from a perspective of someone currently without a disability. One of the most important observations from this method was that visible physical disability, such as people

using mobility-aids, are largely absent and/or out-of-sight at most music events. This observation was supported by the reports of my participants with visible physical disabilities who had concerns about such venues. These reports will be discussed further in Chapter 4.

I used semi-structured interviews to explore and hear first-hand reports about the musical experiences of people with physical disabilities. This method provided phenomenological accounts of music listening which allowed me some insight into how music can be used and how people creatively mobilize it for a variety of needs and purposes. Finally, I chose to use a music mapping exercise, as described above, for a couple of reasons. First, I chose this method to facilitate second meetings with participants to talk more about the topic while having an activity added so we could talk about similar questions without feeling repetitive. Secondly, providing a visual and aural map of daily experience is something not commonly explored. I used this method to prompt participants to reflect on music in their lives and consider diverse aural environments for music listening.

### ***Research Site***

Though Ontario is too broad for the purposes of this project, all participants currently live in Southwestern Ontario and can therefore be considered part of this region. There is a high concentration of universities and colleges in this area, and as such has a large population of students, who may be temporary residents of this region. Speaking to the province as a whole though, the 2012 Canadian Study on Disability (CSD) has suggested that 15.4% of Ontarians over 15 years of age currently have a disability. This is over 1.5 million people in Ontario alone, but this, of course, covers a wide range of disabilities (Arim 2015:7). The CSD broadly categorized people with disabilities as, "...those whose everyday activities are limited because of a long-term condition or health-related problem" (CSD 2016). The figure was not broken down by specific categories of disability in each province; however, in Canada the CSD considers there to be 1% of Canadians age 15 to 24 who experience mobility disabilities (Bizier, Fawcett and Gilbert 2016:3). Considering that 60% of my participants fall within this age range, we can gather that they also are part of a rather small minority population in Canada, and likely smaller

in Ontario. According to a CANSIM database statistic from 2012, 485,680 Ontarians aged 15 to 64 reported having a mobility-type disability (Statistics Canada 2012).

As part of keeping my participant pool relatively open and to access the most potential participants, I chose Southwestern Ontario as my region of study. Southwestern Ontario can be defined as a grouping of smaller cities, including Guelph, Kitchener, and Waterloo, and counties such as Wellington County. Studies about disability are typically hard to pin down to one community because the population is so disparate. Choosing a broader region, like Southwestern Ontario, is useful because it expanded my reach but primarily my research focused on students at a university in the region. A survey conducted in 1985 on the prevalence of physical disability in the region suggested that, extrapolating from their sample, about 66,662 adults were living with physical disabilities at that time (Wood and Turner 1985:264). A more recent Statistics Canada survey on what they call “activity limitation” (defined as any restriction on day-to-day activities), when filtered for Public Health Units and District Health Councils (see note in reference section for more details) within Southwestern Ontario, suggests a much larger population. However, this is likely due in part to the more open definition. In this survey activity limitation was defined as “Population aged 12 and over who report being limited in selected activities (home, school, work, and other activities) because of a physical condition, mental condition, or health problem which has lasted or is expected to last 6 months or longer” (Statistics Canada 2003). I filtered for 15 years old and older, and selected several health regions in Southwestern Ontario to get a sense of the population. In the Wellington-Durham-Guelph Health Unit alone 62,646 people reported having activity limitations in 2003 (Statistics Canada 2003).

Disability policy in Ontario focuses primarily on employment and income as the Ontario Disability Support Program (ODSP), in place since 1998, offers two main support programs: Employment Supports and Income Supports (ODSP 2015). The Ontario Human Rights Commission (OHRC) also has anti-discrimination policies that specifically protect Ontarians with disabilities (OHRC 2016). The most relevant policy to my participants in terms of this study is the Accessibility for Ontarians with Disabilities Act (AODA). Compliance to AODA standards, which include specifications for design of public space, information, and communication, started to become mandatory in 2010 though the law was enacted in 2005

(AODA n.d.). The province is still, in practice, in a situation where accessibility is considered a courtesy rather than a requirement, and accommodation consistently falls on individuals, as evidenced by the reports from participants in my study. This is particularly important in Southwestern Ontario due to the large concentration of universities and colleges which are primarily public institutions, and which have yet to actualize the AODA standards (Mullins and Preyde 2012). Though it has been a slow process, this act, along with grassroots organizations such as StopGap, have made the region a friendlier place for those with disabilities; however, there is still a long way to go to make it fully functional and accessible.

Music venues in the area pose a particular challenge to people who use wheelchairs or mobility-aids, as well as those who have non-visible physical disabilities such as chronic pain and/or fatigue. As several participants explained, accessible seating is often far away from the stage, either set to the side or high up on a balcony, and is typically only allotted one companion seat which precludes people from being in a group or with all of their party. Furthermore, the set-up of having only seating or only standing room does not allow the movement that some people require. I was at a Sam Roberts concert at a club called REBEL where I saw this in action. The VIP section was on a balcony and had both seating and standing room, though there were only a handful of people up there. The packed club was very narrow and long and the crowd extended nearly to the back of the venue. People were standing shoulder to shoulder all the way to the front, such that I was in middle of the fray and could hardly see the stage. As I was walking to the bathroom I noticed a young man in a wheelchair way at the back of the crowd with one other person. I walked behind them to see if I could see the stage from their perspective, but even standing all I could see was the crowd, and though I could hear the band, the chatting of the less interested concert-goers was also louder than it was at my place in the middle of it all. This was an experience reported by several participants, the bad seating in spite of spaces that could accommodate them (VIP), restroom facilities that are officially accessible but up a flight of stairs, as well as many other accessibility concerns. Likely as a product of this, the majority of participants did not report attending many concerts, with the exception of one live music enthusiast who has creatively and determinately navigated the concert venues in his community.

However, even he described not being able to attend venues because they did not want to lose space to provide accessible seating.

Work on disability and music has been conducted in the UK, specifically George MacKay's work on polio and the punk and rock music scenes (McKay 2013). Though there have been other studies and readers on the topic such as Lubet's *Music, Disability and Society*, Lerner and Straus' *Sounding Off*, and a variety of articles, this research mostly uses pieces of music, music theory, and the lives of artists as the data, not so much using average people's experiences. Many works on music and disability use the individual experience of the author as the site of research, such as in Kittay (2008), Honisch (2009), and Kuttai (2010). Other works are highly theoretical and philosophical, such as that of Carlson (2013), whose work discusses music listeners with intellectual disabilities; however, it lacks a concrete research site. Research on the topic of invisible and intellectual disability has been conducted in universities in Southwestern Ontario (e.g. Mullins and Preyde 2012), and other Canadian universities (Titchkosky 2003). Though this region of Ontario has not been the focus of particular research in the areas of disability and music, it has many musical venues and yearly events, it is home to many students and disability organizations, and it has a larger temporary population during the school year due to the high concentration of educational institutions. The fact that the region has an influx of people from different parts of Ontario, Canada, and the world makes it a location where many cultures, peoples and abilities come together to create a new and somewhat temporary social landscape. In this way, it provides a concrete research site to study disability, which has often been researched in a more disparate way (with some notable exceptions, i.e. Ablon 1984; Phillips 2011; McKay 2013).

### ***Participant Recruitment and Characteristics***

The qualifying criteria for participation in my project was very broad, so as to attract the maximum number of participants. These criteria included being 18 and older, described in the information letter and call for participants as being an adult, having an interest in music, and self-identifying as having a physical disability and/or mobility impairment. In researching studies on physical disability, it became clear that many studies did not have a high number of participants,

with most ranging from one to fourteen people (Kittay 2008 (1 participant); Clarkson and Robey 2003 (1 participant); East and Orchard 2014:563 (4 participants); Eidevall and Leufstadius 2013:130 (6 participants); Mullins and Preyde 2012:150 (10 participants); Zitzelsberger 2005:389 (14 participants)). This prompted me to leave my participant pool fairly open as I had only a few months to conduct my fieldwork. I experienced some delays in my recruitment, in part due to the unexpectedly long time it took to make my documents accessible. Eight of ten participants were university students, and the remaining two were associated with Spinal Cord Injury Ontario in the region of Southwestern Ontario. I recruited primarily through Student Accessibility Services staff at the University of Guelph, who sent out my recruitment message in a monthly newsletter on two occasions, once in July 2016 and again in September 2016. This was to make sure I was accessing new students or those who were not around in the summer. Student Accessibility Services (SAS) is a department on the university campus which provides a range of services to students who have registered. Some of the services include note-taking, academic counselling, and peer helping. I reached out to several off-campus organizations affiliated with groups for people with physical disabilities, such as StopGap and Spinal Cord Injury Ontario (SCIO) though I was only contacted by two participants through this method. This was because I had a contact at SCIO who passed on the information to a colleague.

At the end of my fieldwork, I had interviewed ten participants, four of whom I was able to meet twice, for a total of fourteen meetings. All second meetings were based on an interest in the playlist and mapping activity. My call for participants was open to those who self-identified as having a physical disability and/or mobility impairment. This resulted in some unexpected participants, who identified themselves as having a physical disability when they have what might commonly be described as an emotional disability or a mood disorder. One individual described the physical effects of depression and anxiety as causing real physical barriers in daily life (to be discussed further in Chapter 4).

Participants ranged from those who have common visible signs of disability, such as wheelchairs or canes, to those who do not use mobility aids at all, and may at times have no visible indications of disability. Overall, I had five male and five female participants, ranging in age from 18 to 55. All were highly educated, including a PhD candidate and a Master's student

with a previous Master's degree. Participants had a variety of disabilities although some commonalities included chronic pain, injury, difficulty in diagnosis, looking to a future with further limitations, and dealing with inaccessibility. Though this question was not a part of my demographics section, I did find out about most people's home town: Hamilton, Ontario (x2); Mississauga, Ontario; Toronto, Ontario; Thornhill, Ontario (x2); Ottawa, Ontario; Kingston, Ontario, and 2 home towns unknown. When asked about their self-described physical disability, many participants identified using the definitions they have heard from the medical professionals in their lives. For example, a young woman with juvenile arthritis suggested that her doctor told her that this is classified as a physical disability, and mentioned that the form required to register with SAS also required this identification.

### ***Methods***

Observation – When conducting an initial exploration into my topic of study, I attended several music events to get in a frame of mind to analyze such settings and experiences, to set these apart from my usual mind-frame in concert settings of entertainment and socializing. At each venue I looked for accessible seating, visibility of disability, and I took note of the mobility of the crowd. The differences in venues were quite drastic, for example Massey Hall is a seating-only venue, although it is not uncommon for people to stand at their seats or move to the front of the stage, and accessible seating was visible and the age of the crowd was significantly older (compared to other events), as well for the most part people kept to their seats (limited mobility). By contrast, the outdoor music festival, taking place over three days in a large field, had no seating at all, not even in VIP, no accessible areas that I could see, and a very young and highly mobile crowd. People could be seen running from stage to stage to catch a show, and it was a requirement to have a lot of stamina and to move frequently. This helped to situate me and to discuss with participants some of their experiences with live music.

Interviews – In conducting semi-structured interviews, which comprised the bulk of my data collection, I divided my questions into four sections. I began with four demographic questions (age, gender, physical disability, and occupation) and asking the participants to provide a pseudonym. Following this we discussed some questions to introduce the topic and to start



people thinking about their music practices, such as what they listen to, when, and where. I followed this with questions specific to experiences with live and recorded music. The following section of questions focused on accessibility as related to music listening, such as “How do you experience music in relation to your physical mobility? Does this impact your everyday life?” I concluded the interview with questions about well-being and joyful experiences with music, which often elicited a broad range of responses, such as a focus on sadness and hardship as related to music listening. The major themes discussed were activities associated with music, musical influences, past-times, musical routines, and exceptional experiences. Interviews ranged between 45 minutes and 2 and half hours, and occasionally participants invited me to hang out, without audio-recording, afterwards. I met casually with five participants after our initial meeting, four of whom wanted to meet again for the music mapping exercise.

Music mapping - Four participants were eager to participate in this activity, some due to an interest in making playlists themselves, for others their love of music in general seemed to motivate them to take every opportunity to discuss music with a fellow enthusiast. The activity entailed participant’s being given a blank page with two squares drawn on (measured to be the same size as a CD cover). They were guided to draw or write in whatever way they wanted as a visual representation of where they listen to music and when, as well as any uncommon or special memories clearly associated with music. Overall, the exercise did not seem intuitive for most participants. They required a lot of prompting and did not find that drawing the places was the most effective way to talk about music. However, the exercise prompted participants to clarify to me their understanding of music-listening and activity, primarily as not reducible to a physical location (i.e. where) but rather requiring several other elements, but most importantly other people and activities such as studying or socializing. The findings from these interviews differed from the first meetings with participants as we tended to discuss more personal experiences and memories during the mapping exercise, with participants bringing up topics of health, religion, family, and nostalgia. The implications of this will be discussed further in Chapter 4.

After gathering my data through the described methods, I used a media player to slow down the audio recordings for transcription. I also typed up my handwritten notes from each interview

and added both these notes and the transcriptions as documents in NVIVO, coding software. For coding, I used both NVIVO and colour coding key themes and phenomena by hand with post-its on the physical handwritten notes.

### ***Challenges Encountered***

In my meetings with participants, which happened primarily at a campus library, either in private study rooms or in public study spaces, it was somewhat of a challenge to find an appropriate place to meet. Other places included a cottage, a rehabilitation centre, a coffee shop, and a shopping mall. Though meeting in private study rooms was ideal for having a quiet, uninterrupted environment, it was often too quiet, too formal, and most rooms did not have big enough doorways for wheelchair users. Finding an accessible location to meet was a challenge as many coffee shops and public study spaces are very crowded and inaccessible with few reserved accessible areas. Furthermore, the rare wheelchair accessible desks are often occupied by non-wheelchair users. In finding a place to meet, participants often left it to me to decide and the anxiety and hopelessness I felt in trying to locate and access such places gave me a glimpse into the added difficulty and energy of such an everyday endeavour.

Another roadblock, which I faced in my recruitment process, was creating recruitment materials and communication strategies that were accessible to a wide variety of participants. Though no one with a visual impairment responded to my call for participants, I took the time to make all of my information materials accessible in this way. This process took more time than I anticipated. To begin, I met with a staff member from the University of Guelph's Library Accessibility Services (LAS) to make all documents friendly to users who may be visually impaired. Though visual impairment may be more commonly known as a sensory disability, I thought by including "mobility impairment" in my call for participants it may encompass a broader definition of disability to include sensory impairments that affect mobility. It was a challenge to make the documents user-friendly. During my consultation with LAS, I was able to get tips on how to format my documents so as to make them as friendly as possible, given the technology freely available, for those with visual impairments. Going through this process was interesting as the consultant made it clear to me all of the things one can take for granted in

reading emails, documents, and articles online. For example, every time the document creator presses the “Enter” key to create a space in the document or email, a screen-reader will read “Space.” Furthermore, any text in text boxes or undescribed images will not be read but instead the screen reader will indicate that something is present but undescribed/no text and this will leave users wondering what they are missing. These are just a few ways that online content can be unfriendly and inaccessible to users with visual impairments. Using a trial version of Adobe Acrobat, and thanks to the consultation from the friendly staff at LAS, I was able to check the accessibility of my document, and gain a better understanding of the practical steps to making my information and communications more friendly to potential participants. I was told by the LAS staff that people who have visual impairments and who commonly use screen readers have adapted to this and typically speed through communications as they anticipate that the material(s) will not be formatted with them in mind.

Furthermore, as disability studies research suggests, I encountered some difficulty in accessing my research population. My preliminary research suggested that people with physical disabilities are generally an isolated part of the population, but I, perhaps overly optimistically, thought that this might not be the case for the people in my community. In trying to get in touch with and reach out to people with physical disabilities in the region, it did in fact seem to be the case that many individuals are isolated, not only from many aspects of everyday life, but more often isolated from people who may share their experiences of disability. I say this because snowball sampling only worked in one occasion, and it happened to be through a rather formal institutional connection. I asked most participants at the end of our meetings whether they knew of or would be willing to share information about this project with people they thought might qualify and be interested. Only two people mentioned that they might know someone else, and neither ended up being able to meet with me. Seven of ten participants were recruited from SAS newsletters. As I mentioned previously, SAS provides many services to students and it would seem that students trust this department and take seriously the information distributed from this source compared to others. I also sent out a short email and information letters to two departments (Psychology and Sociology and Anthropology) but no participants were recruited from this strategy.

In creating a playlist, following the mapping activity, participants were asked to give me a musical guided tour of their lives. Knowing that music is very important to these individuals was necessary for this activity, as some participants did not have enough experience with music for this exercise to be relevant. One participant, who frequently makes playlists of her own, chose eleven songs that she felt captured important parts of her life. She even described one song as her personal theme song, which related directly to her experiences with disability and as a graduate student. The song, “Go The Distance” sung by Roger Bart from the Disney movie Hercules, is a hopeful and rousing anthem describing self-doubt, optimism for the future, and being strong and steadfast in overcoming obstacles to achieving one’s goals. The place in question during this discussion was a place in a certain time in Meadow’s life. She has been in graduate school for several years and is currently doing very well physically relative to how she has been in the past. This playlist and mapping activity really helped to delve further into participants’ understandings of how music plays in their lives and their specific experiences of music listening.

### ***Ethical Considerations***

An important consideration in this research, especially in selecting methods, was accessibility and the different abilities of participants. Consultation with Student Accessibility Services (SAS) at the University of Guelph was undertaken to review appropriate language to include in communications and in interview questions. Recruitment was also done with the help of SAS. I completed two modules on the AODA (Accessibility for Ontarians with Disabilities Act) compliance and standards for communications so that any recruitment materials, consent forms, and information that went out to participants would comply with this act.

Though disability is only one part of a person’s identity, this is an identifier that often results in the individual being described as categorically “vulnerable.” This is not to discount the real disadvantages and vulnerabilities that are experienced by people with physical disabilities, but only to suggest that a sharp division between the vulnerable and the non-vulnerable populations may not capture the various degrees of vulnerability experienced by people over time, as everyone is dependent and vulnerable in different ways and at different times in life. My research aims to highlight the well-being that can be experienced by people with physical disabilities as

well as to understand how the social and physical environments can be changed to further encourage these positive experiences. In so doing, I attempted to discuss issues of well-being with participants while minimizing the risk of individuals feeling embarrassed, upset, or distressed as a result of the topic and/or the questions. Emphasizing feelings of well-being and joy did not always help to guide the discussion away from more negative experiences, but it did provide an opportunity for participants to discuss how they use music to facilitate moving from a negative feeling or experience to more positive feelings and experiences.

Furthermore, I did not have ethical clearance to delve into the aspects of emotional disabilities and mood disorders, although this seemed to be a really important aspect of well-being and physical disability. I did not anticipate this and did not feel I had the training or expertise, or of course the ethical clearance, to discuss these potentially distressing matters with participants. As a result, although this was a highly valuable part of understanding the lived experience of those who have physically disabilities, I did not explore them further in this study.

Each meeting began with a discussion of the research project and the consent document as well as the specific interest or reason for individuals' participation. I asked for oral consent from each participant after they read the consent form and were given an opportunity to ask questions. There was a particularly dense section of the consent form (describing the storage and use of their information and data) which I summarized verbally before asking if participants gave consent. I chose to do this after noticing that people would often brush off or rush through reading the form and often do not ask questions. Though my research is considered fairly low-risk, I could not really achieve informed consent if participants were not aware of how their information was to be used and kept. Participants then gave separate consent for audio-recording. Interviews ranged from 45 minutes to 2 and half hours. At the end of each interview, I asked participants if they did or did not want to receive follow-up communications from me regarding whether they would be willing to meet again.

## CHAPTER FOUR – MUSICAL MOBILITY

### *Overview*

Participants' accounts of everyday music experiences reveal a sense of well-being maintained through their mobility—their day-to-day navigation of social and physical surroundings. There are several key roles that music plays for the participants in my study, (1) music used as purposeful wandering, (2) music used in exploring ideas, (3) music used as a connective force. Music can be used to shift the focus onto entertaining and amusing things and move away from unwanted thoughts or feelings, to explore complex ideas and emotions, and to create and strengthen social ties. All three of these roles of music highlight participants' expressions of the complex interaction and co-constitution of their disabilities, bodies, and music. These three aspects of participant experiences reveal the ways in which music becomes a medium for creating different types of mobility for people with physical disabilities that shape their experiences of well-being.

### *Mind, Body, Music*

Participants' accounts of music listening blur a strict division between mind and body, and mental and physical disabilities. Most of the participants highlighted that their well-being was largely reliant on their mental state as related to their physical state. For example, Meadow suggested that her mood greatly affects how she feels physically. Of course this may sound obvious. However, experientially it is meaningful to participants when they discuss music listening as this can be used as a control over their moods and their bodies. This was clearest when Ferris met with me to discuss his depression and anxiety which he described as taking a very physical form – he identified himself to me as having a physical disability, while depression and anxiety are usually categorized as mood disorders. The effects are quite similar to other participants' accounts who had what are more commonly considered to be physical disabilities. For example, Marie-Agnes, told me she has anxiety and depression which is part of her physical syndrome, and she experiences similar lack of motivation, drive, and difficulty sleeping, which negatively affect her physical state greatly. As she explains,

I started getting really exhausted, um I suffered from depression and anxiety as well as ADHD because your body is more fatigued. And so you can't cope with different things because those things take on a very physical aspect. Um and so first what was dealt with was the mental illness. And then once you know they kind of hope that 'oh that's what is causing body aches' um but then it started getting more severe to the point where my hips were hurting to the point where I could no longer walk up a hill.

Later she elaborated the added difficulties that experiences of depression and invisible disability can bring:

Also the lack of empathy that people have for chronic illness because it's so invisible, which I totally understand, because we're a society that expects tangibility—because we are not so much religious anymore and the fact that we don't see a more spiritual side to our beings but we need to see the gash on somebody's body. Like even depression now you are not depressed unless you cut yourself because those are things that are very visible.

Alias, who has the same syndrome as Marie-Agnes, also experiences depression and listens to music that reflects this mood. In this case his physical disposition reflected his mood, showing signs of depression and fatigue.

Additionally, George and Adam, both men over 50 years old, were clear about experiencing sadness and low moods after their injuries. George describes himself as tetraplegic resulting from one injury and Adam experiences extreme chronic pain from several injuries. Music played a key role in both of their lives before and after their injuries.

Back to when I first had my injury all the songs that were out on the radio at that time I now have that association with that time frame. Sometimes it stirs up the ghosts and you know it's not necessarily a bad thing but I kind of use it as a measuring to say this is how far I've come and I've kind of beat the odds so it's really nice to be able to reflect when I get to hear those songs.

This account highlights the ways in which music is experienced as a medium that incorporates physical and emotional responses as well as responds itself so that we can experience these elements of our existence all at once. In particular, many of my participants with physical disabilities discussed music as affecting their mood which in turn affected their physical feeling, or discussed a certain mood impacting their choice of music which served to

achieve or maintain a desired physical feeling. Participants would often start describing music's effects this way and then shift to explaining a situation more holistically including, company, time, location, setting, and genre of music to illustrate their feeling. For example, Erin described a cycling class (which she loves but her doctor discourages her from doing due to her disability) in which the music is very fast paced with heavy beats, it crescendos as they reach the peak difficulty of the session and then calms. She suggests that having this type of music in this setting is meant to "mirror how you are supposed to move...it helps to push you" (Erin, 07/30/2016). The described impact has to do with a physical and mental motivation, as well as the contextual elements of the classroom and the sounds of the exercise bikes matching the speed of the music. It is not a linear interaction where the music is played, the mind receives motivation and stimulus, and tells the body to move accordingly. Other participants also conveyed their experiences to me, indicating that the impact of music is not felt in a linear way.

This embodied experience of music as a listener is important to understanding the impact of physical disability as well. People's physical disabilities do not only have physical effects but rather they can be more accurately understood as having impacts on many aspects of a person's experiences and identities. In this sense, defining people according to categories of disabilities and abilities cannot account for their lived experiences.

Nonetheless, the importance of diagnosis and formal recognition of a physical disability, that can often be invisible, cannot be undermined. Both Marie-Agnes and Erin described their experiences with diagnosis as bittersweet, and both have invisible physical disabilities. It was important for them to be able to have formal recognition so they could access educational and logistical supports and to have medical validation of their experience. It was incredibly difficult for them to be diagnosed, they continue to have to fill out piles of paperwork to affirm their new (so-called) status as a person with a physical disability, and most of all, they are now certain that there is no cure, only possible treatment. They will have many challenges as they age. Erin elaborates on this experience, saying:

I think when I was diagnosed I'd had my condition since I was 15 but I only got diagnosed when I was 18 – it's really difficult to diagnose...juvenile arthritis in general...I was in a very confusing, confused state because I had just started grade 12—



I had a really bad year with my arthritis and we didn't know what it was, so it was like a very confusing time for me. And then um at one point or another, I went for an MRI and it came back. And I was sent to a rheumatologist, which is an arthritis doctor, and like they came back and they said this is like the conclusion we've come to, this what you have and it's like a clarifying moment but it's also like so much. You've got so many emotions—like yay I'm diagnosed—but I have to go through a process of what to do next.

Similarly, Marie-Agnes, whose diagnosis process involved many specialists and appointments explained her thoughts on the topic:

I think that one of the most important things you can do as somebody suffering from chronic illness is getting a diagnosis, because once you have that diagnosis you can get things. I now have accessible parking from the MTO. I have an official diagnosis to show my teachers if I can't write a test or um I don't think it should come to that and I've suffered through waiting for a diagnosis. I had to get diagnosed with ADHD in order to get an IEP in high school, which I think is ridiculous. I think I was fine but you have to start taking medication and doing all that you can before you get extra time on a test...so everything leads up to this one diagnosis and its labelling and it's just a really difficult thing. And then once you're labelled—that's when you start looking at everything that is going to happen and it starts giving you a life outcome. And that can be very very overwhelming.

This account illustrates how participants' understandings of their bodies rely in part on how their experiences with illness and disability are defined and recognized by the institutions in which they participate in their daily lives. As Marie-Agnes tells above, in order to receive recognition and the support that one requires, as well as to start to understand the implications for the future, an individual's body has to be understood in social and political terms. Both of these women experienced pain and lived with their bodies, largely without treatment, prior to diagnosis, but felt relief upon having these feelings formally acknowledged. As indicated by the concept of the mindful body proposed by Scheper-Hughes and Lock (1987), the individual, the social, and the political aspects of the body are in play in defining embodiment. Furthermore, a formal diagnosis shifts an individual's prior understanding of the body. As Murphy explains, "To complicate matters, the disabled also enter the social arena with a skewed perspective. Not only are their bodies altered, but their ways of thinking about themselves and about the persons and objects of the external world have become profoundly transformed"

(1990:87). Participants' accounts of music listening explored below illuminates their new views of themselves and the world in which they live.

What follows is an account of some of the ways that participants use music as a way to navigate their daily lives and to make sense of their being-in-the-world with disabilities. My analysis will clarify how music is used in such ways as a purposeful escape, a processing tool, and as a shared experience. As such, music listening contributes to their sense of well-being in important ways. Music is a type of medium that brings many elements of experience together in an instant, a single moment, and this characteristic of music allows participants to gain insights into their own lives and feelings.

### *Music used as purposeful wandering*

Many participants reported using music to help them get up in the morning and to help them fall asleep at night. They use music as entertainment, to pass the time, and to distract from pain or distress during commutes whether they are driving a car, walking, or taking a bus. For example, Marie-Agnes described the experience of driving and blasting music when she is feeling upset:

When I'm in the car if I'm like driving anywhere my music will be blasting. If I'm upset, I'll literally just go in my car and drive and blast my music really loud but like really fun music and just breath and just like feel it like so overwhelming because you can't focus on anything else when music is just like loud like that...

Most participants also discussed listening to music in social settings such as studying with friends, hanging out and talking, playing video games, playing music in a band practice, doing karaoke, among other activities. In many of these scenarios, music is backgrounded so much that it is hardly noticed. In others, music becomes the focus to the exclusion of obligations like school work, as Meadow put it, "music can be a great tool for procrastination." Melanie suggested that music to her was mostly a distraction, something in the background, something fun. Marie-Agnes describes how music can distract from her symptoms, or simply to pass the time, saying:

For example, if I have to walk I'll put on music to distract. I find it distracts me and then certain songs I won't be able to listen to because they just bring me back to my pain or they don't take me enough out of reality...I'll be like no I have to skip the song I can't listen to this and then if I'm in pain I'll often put on something that will calm me down. I don't know how much effect it has on my physical pain but it passes the time.

Meadow suggested that it can be such a distraction that she couldn't listen to music when walking or at dinner, as for example when she listens to the Jurassic Park soundtrack she expects to see dinosaurs. She said this jokingly but she meant to convey how greatly she can become immersed in the music.

In these cases, music is used by participants as a way to distract and entertain for a variety of reasons. It can also serve to indicate the experience of escape and freedom from obligations and regulations as it does in Adam's experience. He has a very distinct memory of listening to Ain't No Mountain High Enough by Diana Ross and the Supremes whenever he left the army base to attend specialized physiotherapy following his injury. Here is how Adam described the experience he associates with this song:

So I'd drive but that got me an extra day off. So I'd get four days off for to go and get this physio... and it just happened to be the first day that I got that pass that was the tape that was in the car and that song then became synonymous with freedom—freedom from pain, freedom from the base, freedom from the army. And for years I played that song every time I drove off that base. It sort of builds to that crescendo so there's a timing to the song, as I drove off the base out of the main gates, yeah there is a certain time it took me to get to the highway and once I hit the highway that was just when the song [crescendo-ed]. I used to actually replay it and replay it until I was about 10 or 15 minutes away from the base. For a minute I was away and nobody was looking at me either. It was just me and my car and this song.

This anecdote effectively illustrates how music is used to punctuate a moment and to conjure a feeling. The first instance of leaving the base and getting physiotherapy became so closely associated with this song for Adam that he was able to manipulate his mood to feelings of joy and escape by playing this song in a certain context. It became part of a ritual of well-being following his injury.

Participants positioned music in the foreground and background of their experiences according to its purpose in each context. I would suggest here that music being put to use as an escape is music that is the focus of the moment or scenario. When participants discussed music being a distraction, this was a case in which music was meant to be backgrounded but started to draw their focus away from other things such as work or their immediate environment. For example, when Erin suggested that certain music is too distracting to listen to while studying, she is demonstrating that some music draws her attention away from her task and she needs to change to music that will easily remain in the background of her experience.

Studying and working were commonly brought up as activities where music can be helpful, but also distracting. These activities illustrate an overlap in the uses of music outlined by participants in my research, as it serves as both a means of distraction and escape, but it can also be used to help us focus on something in particular. In the following section, I will discuss the ways in which people can mobilize music to serve as a processing tool.

### *Music used to explore ideas*

Music can help you figure stuff out – Melanie (09/2016)

In Melanie's quote above she is referring to her use of music to help her think when studying and to help her process emotions such as when she feels sad. Many participants specified that they can only listen to certain music when studying such as non-vocal or instrumental music, or genres like classical or electronic, whereas music that helps to process complicated emotions (sadness, anger, disappointment etc.) can vary greatly, and often has to do with expressions of shared experience. I will begin this section by discussing music as a tool to think with, whether in work or school contexts, and move to its use as an aid to understanding and processing emotions and life events.

As early as high school, Marie-Agnes was given an approved playlist to listen to while writing tests and exams in high school which was shown to help her think and focus. Though her physical syndrome is mainly categorized as a physical disability, it has a variety of effects on her mood and her learning style. She explained that her syndrome has caused her to have anxiety and

depression as well as ADHD. Adam uses music to help him think through “complex ideas and processes,” when working on his dissertation. He even said music helps him to think in multiple dimensions, meaning that music helps him to think through several layers or aspects of a problem and listens mostly to classical or trance music in these contexts. George and Jennifer also mentioned listening to music in the context of their work, for example listening to the radio while doing office work. Meadow also specified that she likes to have music on to help her study or while she is writing, although it has to be non-vocal otherwise she will feel the temptation to sing, causing her to lose focus.

In the studying context, music is very much in the background of people’s experiences. An interesting part of participants’ accounts is that they were very specific about the type of music that can help with thinking and studying, the type of music that does not become too great a distraction. For most people, music with lyrics was more distracting than that without. Participants are careful about what music they chose in these situations. These accounts illustrate that music’s impact can be adjusted and mitigated based on the will and interest of the individual. Though music certainly has great affective power, it largely depends on being contextualized and supported to be mobilized for the most impact. A clear case would be the live music scenario, which is quite different from the minimal impact music has in the studying or working context.

Marie-Agnes described music “as a way to relive moments and work through your feelings.” She has the added experience of synesthesia, for example her experience of music can sometimes be of places, colours and lights, in other words she can have very visual experiences of music. In describing this experience, she explained to me that repetitive music with synthesized beats may appear dull, or certain artists conjure scenes in black and white. Additionally, she sometimes makes playlists based on these feelings/perceptions received from the music for example collecting/categorizing songs that appear neon, dark, light, blue/purple, or that appear as a mountain range. This is quite a unique experience of music, and it adds a visual element to memories associated with songs and sounds as well as adding a component to the ability to process and reflect on one’s emotions.

Many others told me that they use music as a processing tool. Alias and Meadow also described using music as a way to process their diagnoses, feelings, and to cope with the worst moments, for example break-ups and hospitalizations. Meadow, during our music mapping meeting, suggested that her theme song is Go the Distance sung by Roger Bart in the animated movie Hercules. She identifies with the lyrics and the inspiring music as relevant to making sense of her physical disability as well as her journey through graduate school.

A number of participants found that musicians' expressions could offer them understanding, empathy, and ideas on how to cope with their own lives and experiences. Steve describes his feeling when an artist can effectively communicate a common human experience:

I find if they are good you can kind of take something away from who the person is that made the music and it's like pretty obvious depending on what you are listening to—if it's a depressing song or what the lyrics are—but you can tell that it's this certain emotions coming across and also get a bit of their character and things. And maybe that's just part of listening...it's art so I can take whatever I think from it. But I also feel like that's what they are trying to do with the art. You know there are all these love songs and things like that so they are trying to get something across. And some message you can learn from like Wish You Were Here by Pink Floyd—it's just like the most anybody can empathize with that song...everybody misses somebody in the world.

In this account, music is experienced as a means of identifying oneself or more simply as a channel for understanding and accepting our feelings and experiences. Similarly, Meadow, Melanie, and Erin all discussed listening to music to help them understand, process, and respond to their physical disabilities. During moments where they are troubled by pain, thoughts of their futures, and barriers and challenges that they face, listening to music is a way to shift the mood to one of calm and happiness or it can help to affirm and release sad feelings.

In the following section, I will discuss participants' emphasis on the social aspects of music listening. Their accounts reveal their experiences of mobilizing the power of music as a shared human experience.

### *Music used to make connections*

“Music is people” – Adam (09/20/2016)

The quote above from Adam was given during our meeting to visually and aurally map his life according to music. When he began to draw the places where he commonly listens to music (office at home, office at school, car, and bars), it became obvious to him that he does not think of music in terms of particular locations so much as he associates music with certain people in his life. For example, spiritual music (*ragas*) that he was exposed to by his grandparents and parents, a Prince dance song he listened to with an ex-girlfriend, or a group of co-workers who used to listen to Supertramp and Billy Joel all together. In this case, the mapping exercise served to emphasize the multi-dimensional nature of musical experience such that this participant felt drawing a specific location was inadequate to capture his life according to music. Importantly missing from the visual representations were the people, the music itself, and the time period. Adam felt that a timeline and written descriptors would better illustrate his music experiences.

In this section, I will present a variety of circumstances described by participants that will illustrate the three types of cases where music is used to create and strengthen connections. The first is listening to music in public, such as at a concert or a party where music is the focus. The second is a scenario in which music is the background to a social event, a dinner party, get-together, or playing video games with friends (online or in-person). Finally, even listening to music in private can be experienced as a shared moment with the artist(s) and/or other fans, while also focusing on oneself and the music. These instances of music listening highlight my participants’ emphasis on the inherently connective and communicative force of this medium. As one participant described it, music can be experienced as a “positive, unifying energy” (Jennifer, 08/14/2016).

Those who have been to or frequently attend live music events found that “live music has more energy” (Ferris, 08/04/2016) and that it is hard to “capture the live energy” (Steve 08/24/2016) with recorded music. This energy that participants are referring to is a product of the music’s magic. By magic I mean this “indescribable” (Meadow, 07/26/2016), almost intangible creative, communicative force produced by the artist, presented to the audience, which is then

acted upon, and in turn reacted to by the audience. The time and space where these elements converge is real life magic; a place is created where we can feel close to each other and share in a moment through music. As Ferris, a student of physics, suggests, through music's sound (reverberations), the environment, the audience, and the artist all feel/are on the same frequency and therefore feel a connection. Clichés abound on this topic. People commonly discuss their connections with others by saying they “vibrate on the same frequency,” or they are “riding the wave,” or “on the same wavelength.” Participants in my study seem to indicate that there is some truth in these clichés that speak to a real experience of feeling connected through something we cannot see. As Marie-Agnes suggests, “music is like that; you let it wash over you” (09/30/2016). This also accounts for the lack of control noted by other participants. For example, Melanie described her experience as follows:

I usually listen to music on my phone or my record player...and I like that because like I'm in control of the music that whole thing. I think that a lot of the reason that I don't do live music because there is that accessibility aspect...so ya it was definitely weird especially with the ACC (venue). You would think they would be accessible but they have that one-person rule which is annoying, but also just the way it is situated. It is on the same level but the people in front of you stand up and you can't see...It's on the general admission level.

Though all participants identified themselves as music-listeners, even enthusiasts, many indicated that they do not frequently attend live music performances. Some prefer listening to music live but find they do not have the time, money, or ease of access to attend shows or venues where their preferred music is playing. Others suggested that they prefer recorded music and find the lack of control and discomfort of live music off-putting, whether it is due to inaccessible seating and washrooms, the noise and crowd, or the artist(s) sounding different than the recordings.

Music can also be in the listener's control, and can be used to make others feel comfortable and at ease in a variety of social settings, creating connections and providing contexts for social bonding, other than those available in a live music setting. For example, Melanie works with students on campus and plays music in her room to invite her fellow students and wards to feel



comfortable socializing and coming to her with any concerns. About her open door playlist, she explains:

In my room I usually have music because I'm a residence assistant so I play music to try to invite people in. I think I try to listen to much more of a mix, a fair distribution between pop and country and I try to keep it pretty clean.

Similarly, Jennifer plays music that she thinks her guests will like, trying to cater to their music taste when she is hosting a dinner party or get-together. She tailors the music she plays to her company, for example playing pop and dance music when with friends, putting on vintage oldies for her mom, and listening to country with her boyfriend. This is quite a different encounter than that of the live concert where the interactions and connections are with strangers. In these circumstances, connections are reinforced between friends, family, and acquaintances by communicating a shared interest, taste, or even knowledge about someone else's preferences and experiences.

In other cases, music can be a reminder of an important part of creating a bond. Marie-Agnes has a very intimate experience of music, more specifically one particular song called "Draw You Near." While living with a friend who had epilepsy, Marie-Agnes found her roommate in the midst of a seizure and while caring for her she put on this song to help calm the situation. To this day the only thing her friend remembers from that night is the song that played. They both remember this song and think of each other when it plays; this musical experience bonds them.

Music also serves as a catalyst for connections in the virtual world through video games and their soundtracks. Alias describes the joint efforts of friends and co-gamers online to work through different levels and challenges. The soundtrack changes in different areas and times in the game to match the tone of the challenge. He describes feelings of accomplishment and teamwork whenever he listens to these songs, whether during these online expeditions or whether listening while studying or hanging out.

These examples illustrate that music can serve to strengthen feelings of connection and social ties as well as providing a clear reminder of these instances of bonding. Sometimes the

connections are more straightforward, in the cases of someone introducing music, as with Steve's father, who shared his expansive CD collection with him, or simply associating a song with a special moment and loved one, as in the case with George and his daughter.

Music can also be something very private and has the power to be mobilized to form a connection to oneself or to a musician or band. Erin indicated that some of her favourite moments of listening to music happened on her own in her bedroom. In these instances, she purposefully diminishes the location, her bedroom, by closing her eyes and turning off the lights, and chooses to focus on the music. She suggests that during these times, music can be like a "wave of calmness; [it] takes you away from whatever is happening in that moment" (Erin, 07/30/2016). Even in these private moments, the shared experience is still a factor. Erin said that she looked for music to "mirror the emotion"—she is feeling in these moments. She also characterizes music as a shared expression. What the artist expressed in song may be what she feels and this creates a connection. Alias also indicated that he looked for and chose music that "reflects whatever emotions" he is feeling at that time, in particular during moments of depression.

Ferris described his personal music listening in a similar way, saying that music is someone else's expression that can help you to express how you feel and to get it out. He explained how metal music is angry and aggressive and how he has mobilized it in his life to release these feelings of his own, saying:

I find metal is great at doing that. If you actually look at a lot of people who dress like metal heads they're actually very calm and collected because I feel like they get rid of a lot of their anger...Growing up, when I was going through my parent's divorce, I listened to a lot of metal and...it seemed like maybe that's why I didn't turn out like my sisters, who are quite angry at the world...I guess yeah – It's someone else's expression that you relate to that allows you to release whatever it is you are feeling inside. And if you look at like a balloon it needs a certain type of belt to release the stress inside, so someone else's expression that relates to you allows you to do that. It's the right balance sort of thing.

Erin emphasized a similar process in talking about her preferred artists and why she listens to music, explaining,

Yeah I mean I think that's why music is made—people expressing their emotions and if they can write it and do it then why not and then I can listen to it and maybe I'm feeling the same way that they are. Or maybe I'm experiencing something similar to them and I can't write my own music and I can't sing my own music but they've done it for me. So I just follow along with it...I think like that's why music is so important—it's what first made me into it. It does something or other life changing or just in that moment it has some type of effect on you.

These accounts indicate that participants seek out music that expresses a shared human emotion, that of sadness, loneliness, anger, in order to help them express these feelings themselves and to feel less sad, less lonely and less angry because others, in this case the artists, understand these feelings.

### *Discussion*

In my study, participants emphasized exploration, thoughtful wandering, and socializing that can be achieved through music listening, and this has led to my discussion of musical mobility: an ability, for people with and without physical disabilities, to move themselves and others with music. This importantly hinges on the idea that music listeners are not only passive, but have a constituting and artistic involvement in the music to which they listen. I found that participants' accounts primarily focused on music as a purposeful wandering, the choice they exerted to be distracted, music as a way to explore new ideas and emotions and to process these, as well as music as a connective force, to the artists, to other listeners, and to family and friends. I collected literature from a variety of disciplines such as anthropology, disability studies, and music studies, but there is very little if any work on the listener at home. My participants' accounts illustrate that they adjust music's impact according to their will and interest for their benefit. They purposefully make use of music's great affective power. My findings indicate that music is strategically employed by participants, as the impact of music largely depends on being contextualized and supported to be mobilized in certain ways. The anthropological literature on disabilities and the literature on disabilities and music both lack this understanding of music listening among people with physical disabilities from a phenomenological perspective.

Participants use music as a medium for coping with pain and distress as well as for promoting connections with artists, friends and family. Despite their day-to-day challenges of

access, my participants shape their mobility through music, which contributes to their physical and interpersonal well-being—subjective experiences of their bodies and relationships (Mathews and Izquierdo 2009:261). However, participants' accounts revealed the mindful body (Scheper-Hughes and Lock 1987), or the connectedness between their mind and body when they discussed their experiences and the impact of music. As I highlighted in this chapter, participants' responses blurred the lines we draw between mental and physical disability, mind and body. Furthermore, participants discussed the merging of their mindful bodies and their surroundings through music listening. What is presented here is ethnographic evidence in support of the work conducted by Andrews, Chen and Myers (2014)—it is an experience of music in which "...the togetherness of well-being comes to the fore; the idea of well-being as things, beyond the individual and personal, acting collectively *as* the environment." (218). They conclude that in these moments of musical experience the listener and/or performer may feel as if they are "...part of a greater physical happening" (Andrews et al. 2014:218), which is connected to feeling well (well-being).

My study took a phenomenological approach to explore disability experiences and the result has been that there are elements of three of the models of disability (cultural, resistance and critical realism) that have been helpful to understanding participants' lives as music-listeners. An important element in the cultural or sociocultural model (e.g., Snyder and Mitchell 2006; Shuttleworth and Kasnitz 2004) is the emphasis on contextual understandings of disability. In public institutional settings, such as Spinal Cord Injury Ontario and a Canadian university, my participants are highly knowledgeable and educated people who have thought about and reflected on their physical disability and who have even taught and mentored others on the topic. This makes for quite a specialized understanding and experience of disability that needs to be taken into account. As well, the resistance model (Gabel and Peters 2004) is important in exploring the ways that everyday choices for leisure activities, such as music listening, can have great political implications for individuals' self-perception, and for helping to shape and orient their perspective on their experiences and emotions. Finally, many participants emphasized the practical realities of life that keep them too busy to focus on the disabling structures and practices in society. Participants often used creativity and determination to make changes or accommodations to

navigate different situations and settings, and suggested that they just accept certain facts to be able to function and go through everyday life. This is reminiscent of Shakespeare's critical realist approach (2006), which seeks to account for both the social and physical realities that are part of disability. Importantly, these elements all work together in participants' experiences. For example, it is not enough to say that participants just accept difficulties and move on, especially in this context where many participants have the education and training to reflect on disability theory as well as in the position as music enthusiasts being able to use music to actively express, understand and challenge certain feelings and experiences.

## CHAPTER FIVE – CONCLUSION

This thesis examined how music can be used in such ways as a purposeful escape, as a processing tool and as a shared experience among people with physical disabilities. My participants' accounts reveal that music is experienced as a type of medium that brings many elements of experience together in a single moment, giving them insights into their own lives and feelings in unique ways. In this study, I have emphasized the use of music as a way to experience, impact, and organize one's social and built environment (Smith 2000:617) and as "joyful embodied experiences" (Kuttai 2010: 109), in order to examine the relationship between music listening and well-being among people with physical disabilities. In exploring the ways that music affects their everyday lives, participants in this study often used words such as energy to illustrate their experiences of music as a connective force that binds 1) their mind and body, 2) the listener/self, the artist, and co-listeners, and 3) the listener and their situations and surroundings.

Participants gave accounts of their experiences of music where there is a simultaneous interaction of the individual listener, the artist and other fans and friends (social), the listening setting (environment), and the sonic happening (music). In some cases, the music becomes backgrounded to the environment where the individual/listener interacts with others and the surroundings demanding the individual's attention. In other cases, however, the music can become quite foregrounded as in the case described by one participant, Erin. She closes her eyes in the privacy of her bedroom and allows the music to become the focus, letting the setting become background and largely out of notice, only serving to provide the privacy for this experience. In these moments, participants found it difficult to describe the relationship between their feelings, their surroundings, and the music as they are all interconnected in a way that cannot occur or be experienced in a linear, cause-and-effect type equation. The participants discussed the impact of their individual mood, energy, or feeling on their experiences of music in specific situational and environmental contexts as well as the impact of music on one's mood, energy, or feeling. Therefore, the argument to be made here is that experiences of music through disability can crystalize the potential of music available to people with physical disabilities as

well as the strategic use of music among them to challenge the assumptions held about their existence as passive and isolated.

To capture participants' engagements in music described above, I proposed the notion of musical mobility by elaborating on the notion of micro-mobility, which highlights the ways in which people with disabilities "...utilize skills and competencies to navigate their social and physical settings while meeting day-to-day challenges" (Porcelli et al. 2014:864). Musical mobility refers to participants' emotional and physical movement through the use of music. It describes the creative ways in which participants make use of music to expand their mobility by using music to move themselves, their aural environment, and others around them emotionally and physically. This concept of musical mobility is built on the idea developed in my study that music listening has implications for individuals' self-perceptions and the ability to shape and orient their perspective, their experiences and emotions, therefore having an impact on their actions, environments and others. Musical mobility also refers to participants' use of music to feel connected to others, both through sharing common human experiences and feeling understood by others. An example would be listening to a song with which you identify and not feeling isolated. In addition, participants' mobility through music listening can also provide an opportunity for physically being close to friends and family via live music events, dancing, or enriching typical gatherings and creating bonds.

### ***Contributions and Further Research***

The study of disabilities in anthropology has explored disabilities in the context of illness (Shuttleworth and Kasnitz 2004:142) and failed to examine joy and well-being among people with disabilities (Freedman et al. 2011:588). This phenomenological study makes an important contribution to the literature by exploring the creative production of well-being among people with disabilities. By using Van Gennep and Turner's concepts of ritual and liminality (Ablon 1984:170; Murphy 1990:74-75, 131) and Goffman's work on stigma (Ablon 1984), previous anthropological works on disabilities explained how people perceive the actions of others in response to their different bodies. Murphy noted that the person with a disability has not successfully transitioned from the subject of sick person to healthy person and occupies an

unacknowledged subject position and becomes disembodied, or a non-person (Murphy et al. 1988; Murphy 1990). However, my findings emphasized making use of music as part of participants' creative and aesthetic ways of being in the world, including expressing, understanding, and challenging feelings and experiences. Participants can have their emotions, situations, and physical experiences recognized through music and this can help with feeling re-embodied, taking control over their lives after injuries or diagnoses. Participants' accounts thus stressed their moving toward re-embodiment through music, understanding their new abilities with regards to their bodies, and re-possessing well-being. Despite the sense of disembodiment that people with physical disabilities may experience, as Murphy phrases it, importantly this study suggests that musical mobility can provide a path to feeling re-embodied.

This study makes a contribution to the study of music and disability by highlighting the role of people with disabilities as music listeners from an actor's perspective. In the study of music and disability, previous works have devalued and downplayed the role of the music listener and emphasized the production of music, aesthetic and creative style that speaks to the experiences of disability. Many studies on music and disability examined the ways in which artists with disabilities produced music as a form of empowerment, telling a story from a perspective of disability through music (Lerner and Straus 2006; McKay 2013; Watts and Ridley 2012). A number of works on disability and music examined pieces of music, music theory, and the lives of musicians (Lerner and Straus 2006; Lubet 2011; MacKay 2013), while others discussed their own experiences of music in their works as performers and artists (Honisch 2009; Kittay 2008; Kuttai 2010). These works often dismissed music performance and listening among non-artists as having a passive and limited role, such as for use in therapy and rehabilitation, and provided limited understanding of the ways in which people with physical disabilities use music in their daily lives.

Some studies examined leisure for people with disabilities, but they often stressed the significance of interventions by focusing on various types of adaptations for recreational activities such as adaptive sporting equipment and musical instruments (Honisch 2009; Lubet 2011; Watts and Ridley 2012). However, a focus on music listening gives the opportunity to see how people with disabilities can exert creative and aesthetic force on music that is not



necessarily produced by or for others with similar circumstances of living with a disability. This highlights the importance of the elements of human experience that are relatable and shared among many individuals and groups, producing the potential to challenge barriers and strict divides.

The importance of music listening as a shared experience brings me to the public significance of this study. The joyful experiences of music examined in this study are useful in enriching the public discourse on people with disabilities that tends to focus on suffering and isolation. My findings are useful in reframing public understandings of disability through emphasizing participants' experiences of connections with others, who live with or without disabilities, through music as well as understanding disability in a more inclusive way.

There is a common fear of physical and cognitive disabilities as well as mental health and mood disorders in Canadian society, largely because of the challenges that our built environment and social expectations present to these types of experiences. This fear causes us to relegate those who identify with these experiences to the margins of society so *we* need not be faced with *their* embodiment of our fears. Changing policy and the built environment is the most effective way to change people's thinking away from fearing disability and mental health issues by ensuring that there are supports and environment settings that minimize the negative effects these experiences have on peoples' daily lives. This will necessarily create a more accepting place for everyone. Disability is both a product of a society built for the privileged as well as a physical reality in people's lives that we must address. During the course of this research, I have formed the opinion that despite the strict dividing lines that we might draw, whether bureaucratically or unconsciously in our daily lives, disability is a human experience. This is not to say that everyone experiences it equally, of course. Those who are currently living or in the past have lived with physical, cognitive, developmental, and/or emotional disabilities are those who know these experiences intimately. They know of the stigma, the challenges, the joys, and the insights that these experiences can bring. Family and friends, even professional service providers, of these individuals may also know something more of the experiences of disability (Shuttleworth 2004). The reality is that disability is something that may happen as we age and as we encounter different events, experiences, and/or environments in our lifetimes. Disability is not inherent in

an individual or a group, it can happen to anyone at any time and we all have loved ones who experience disability in some way. This statement does not need to bring up feelings of fear or be perceived as tragic. It is of great public importance that we shift our understandings of disability from a conception of “us/them” and move toward thinking of disability as our shared experience. We can use this understanding to work towards a friendly place where all citizens can flourish. Disability affects all Canadians; it is a shared human experience.

The ideas of musical mobility and listening as a creative activity can be mobilized when leisure programs and services for people with physical disabilities are designed and implemented. Given that people with physical disabilities in this study process feelings through music and mobilize music during group activities to encourage the creation of social bonds, the findings of this study could be utilized in a range of services provided by therapy and rehabilitation centers, disability communities and activists, and simply to enrich everyday life. For example, an emphasis on the role of a listener as an active agent could be incorporated into approaches to therapy and rehabilitation programs, by potentially implementing music listening and performance programs with a different lens and goal and repositioning listeners as creative agents. Further research is needed to investigate how the understanding of music listening highlighted in this study can be effectively used to improve the existing programs.

My intention with limiting my research to focus on physical disability was both a practical and a theoretical choice. Firstly, physical disability is not as commonly discussed in research about music. Theoretically, focusing on physical disability challenges the very deeply held assumption of the mind-body duality that exists, though is increasingly challenged in our society. Most every participant discussed their mental health and well-being at one point during our conversations, whether this was in regards to coping with pain, injury, injustice, discomfort, frustration, lack, or barriers. This study of music listening practices of people with physical disabilities inherently brings to the fore our assumptions about how the mind and the body work together, how they are separated, and how they are conceived. The result of choosing to work with participants with physical disabilities in my study was that many participants who were interested could not participate. Although my call for participants emphasized self-identification with physical disability, once potential participants contacted me for more information, around

seven told me they did not qualify as they had cognitive, developmental, learning, and/or emotional disabilities (self-described). Most of these seven people were very interested in music and were looking for a formal way to talk about it and their musical experiences. It is clear that further research should go into looking at the role music plays in people's lives, especially for those with a variety of disabilities, whether they be cognitive, emotional, developmental, and/or physical.

My research took an experiential and exploratory approach to finding out how music is experienced by people with physical disabilities in south-western Ontario, in particular as related to feelings of well-being and experiences of joy. As this study illustrates, music listening among people with physical disabilities highlights the experiences of bonding with other people. My study also brings into perspective the realities of inaccessibility and the many other challenges that can result from physical pain, injury, and mobility limitations. With this in mind, my project indicates the need to further explore how we might move toward both thinking of ourselves in terms of disability as well as thinking of how we might work with people who are currently experiencing physical disability to improve their lives, facilitate their feelings of well-being, and embodiment.

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