

How Lived Autistic Experience Can Inform Considerations of Potential Harm in Music Therapy  
with Autistic People: A Philosophical Inquiry

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## ABSTRACT

### How Lived Autistic Experience Can Inform Considerations of Potential Harm in Music Therapy with Autistic People: A Philosophical Inquiry

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Examinations of music therapy practice through a neurodiversity lens are generating and expanding discussions about considerations of harm in music therapy beyond contraindications. This philosophical inquiry contributes to both these efforts by centering the experiences of autistic individuals as an essential source of knowledge regarding potential harm in music therapy with autistic people. First-voice and allied literature are brought into dialogue with music therapy theory through the framework of the Music Therapy and Harm Model (Murakami, 2021). According to this model, it is the client who identifies the potential harms in music therapy, therefore music therapists working with autistic individuals must look to the experiences of autistic people to inform their understanding of harm. The literature revealed that the potential for harm resulted from dominant narratives of pathology, ableism, and the requirements of normalization. Allowing autistic individuals to identify harms in their music therapy experiences requires therapists to be open to various forms of communication, to presume competence, and to resist normalization by examining the foundational assumptions of their practice. Limitations of the philosophical inquiry, implications for research, practice, education, social justice, and recommendations for future research are discussed.

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## Chapter 1: Introduction

Music therapy is often recommended for autistic individuals, yet the diversity of autistic experiences is not readily represented in existing music therapy literature (Davies, 2022; Pickard et al., 2020). In medical literature, Autism Spectrum Disorder describes a range of deficits related to social interaction and repetitive behaviours (American Psychiatric Association, 2013). Many autistic self-advocates and activists challenge the pathologizing nature of such biomedical and deficit models of autism and instead embrace an inclusive neurodiversity paradigm (Autism Self Advocacy Network, 2021). The growing recognition of concepts from the neurodiversity paradigm requires an examination of music therapy through that lens (Davies, 2022; Devlin, 2018; Pickard et al., 2020). This philosophical inquiry facilitates a dialogue between the experiences of autistic individuals through first-voice and allied<sup>1</sup> literature and music therapy research about the potential for harm in music therapy.

Considerations of harm, beyond longstanding discussions of contraindications, are increasingly present in music therapy theory and practice (Isenberg, 2012; Murakami, 2021; Silverman et al., 2020). This is the result of North American music therapy organizations' efforts to become regulated in their respective states and provinces. Legislative bodies require regulated professions to demonstrate how harm to the public is possible beyond criminal boundary violations and medical contraindications (Murakami, 2021; Manitoba Health, n.d.). The American Music Therapy Association (2019) Code of Ethics similarly indicates the music therapist must be aware of potential harms, these resources, however, offer no concrete definitions of harm. Encouragingly, the recent update to the Canadian Association of Music Therapists (2022) Code of Ethics includes steps for minimizing harms in responsible music therapy practice.

Music has affective power which is often presented exclusively in a positive light (Edwards, 2011; Gardstrom, 2008); negative effects are also possible (Cloonan & Johnson, 2002; Cusick, 2008; Isenberg, 2012). Music is a physical phenomenon and can cause sensory discomfort and physical damage (Maguire, 2012; Metzner et al., 2018; Pelliccia et al., 2019; Weilhammer et al., 2021). Recently, music therapists have developed theoretical models to

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<sup>1</sup> Keeping in mind the complexities of allyship (Norris, 2020; Onaiwu, 2020; Pillow, 2019), here, "allied" is used as an imperfect category to describe scholars who embrace neurodiversity and center the voices of autistic people in their research designs.

describe the potential for harm in music and music therapy (Murakami, 2021; Silverman et al., 2020). This present study will contribute to the emerging conversation around the subject of harm in music therapy by making the case for why and how the experiences of autistic individuals can and should be an essential part of this conversation.

### **Personal Connection**

When planning this study, I started with a specific interest related to the potential harm of music as an isolated stimulus. However, I began to understand that music, as an experience, cannot be separated from meaning. Music is a powerful tool with the potential to benefit or harm clients in obvious and hidden ways. Much of my clinical work to date had been with autistic youth; this influenced my decision to further focus my research on autism and music therapy. Additionally, my own neurodivergent identity and commitment to neurodiversity-affirming practice supported my decision to centre autistic scholarship; I knew I could not gain insight into potential harms without engaging autistic activism and research. However, writing this philosophical inquiry required a process of extricating myself from the dominant narratives of ableism and normativity because these narratives are influential in the structures of society, research, and therapy (Bottema-Beutel et al, 2021; Rolvsjord, 2014; Wolbring, 2008).

### **Purpose**

The purpose of this study was to explore the phenomenon of harm as reported in the literature by autistic individuals and to understand how harm might manifest in music therapy contexts. I examined the following primary research question: Why is lived autistic knowledge essential to understanding harm in music therapy with autistic people? These subsidiary questions were generated to articulate the argument: How do autistic people describe, in the literature, experiences of harm in autism intervention and support contexts? How is harm described in music therapy theory? What are the contextual factors that influence experiences of harm in music therapy? How might music therapists proactively address issues related to harm when working with autistic people?

### **Considerations of Language**

In this philosophical inquiry, I favour identity-first language and avoid biomedical language regarding levels of functioning when writing about autistic individuals and their experiences. This assumption is made to align this study with the preferential language indicated

by many autistic scholars, artists, and self-advocates (Andrews et al., 2014; Bottema-Beutel, Kapp, et al., 2021; Brown, 2011). While there is a multitude of perspectives on preferred language within autistic communities, I have chosen to use identity-first language in an effort to remain centered on the narratives of autistic people.

### **Definitions of Key Terms**

**Autism.** Autism is a developmental disability characterized by differences in thinking, communication, sensory processing, movement and support needs. These differences lie on a spectrum of support; some individuals requiring more global supports while others need focused or minimal supports (ASAN, n.d.).

**Client.** In this thesis, the term client is used to describe the individuals receiving music therapy services. There are many other possible terms, *service user*, *participant*, *patient* and, though the term *client* is not without critique (Bruscia, 2014), I have determined it remains the best descriptor in this context. Here client encompasses both the self-referred and third-party referred service user. This choice of terminology also distinguishes therapeutic service users from research participants.

**Harm.** For the purpose of this research, *harm* is defined as a negative experience resulting in physical or psychological distress with immediate or long-term health effects. Harm may occur in personal, relational, political, cultural and societal contexts. Harm may be self-directed (Silverman et al., 2020); however, for the purpose of this inquiry harm is specifically considered in the relationship between the therapist and client (Murakami, 2021).

**Music therapy.** “*Music therapy* is a discipline in which Certified Music Therapists (MTAs) use music purposefully within therapeutic relationships to support development, health, and well-being. Music therapists use music safely and ethically to address human needs within cognitive, communicative, emotional, musical, physical, social, and spiritual domains.” (CAMT, n.d.).

**Neurodiversity paradigm.** This definition is paraphrased from Walker (2021). In this paradigm, *neurodiversity* is a “natural and valuable form of human diversity” (p. 43) resisting attempts to construct any one style of neurocognitive functioning as normal, healthy, or correct. Neurodiversity is influenced by “dynamics of social power inequalities, and also the dynamics by which diversity, when embraced, acts as a source of creative potential” (p. 43).

## **Summary of Thesis Chapters**

The potential of harm in music therapy when working with autistic individuals will be explored in this study. Chapter 1 outlined the researcher's connection to the topic as well as the need for research based on the perspectives of autistic individuals. Chapter 2 lays out the methodological foundations of philosophical inquiry as well as the delimitations for data collection and analysis. Chapter 3 presents the evidence for potential harms described in the experiences of autistic people and the potential harms described in music therapy literature. In Chapter 4, autistic experiences of potential harm, as reported in the literature, and current considerations of harm in music therapy theory are pulled into dialogue. The Music Therapy and Harm Model (Murakami, 2021) provides the framework for this dialogue. In Chapter 5, the final argument will be synthesized and discussed along with the study limitations and implications for future music therapy practice, research, education and social justice.

## Chapter 2: Methodology

### Design

This study aimed to center the experiences, perspectives, and scholarship of autistic individuals as an essential source of knowledge for music therapists considering the potential for harm when working with autistic people. Philosophical inquiry is a natural fit for research regarding epistemology, that is, questions around knowledge and knowing. The practice of philosophical inquiry may take various forms, but is generally a process of clarifying terms, evaluating assumptions, and presenting a formal argument (Aigen, 2005). It is a methodology that employs reflection and critique to challenge latent assumptions arising in the data, the contextual philosophies, and the researcher's perspective (Stige & Strand, 2016). In this present study, philosophical inquiry generates a dialogue about harm between theories in autism and music therapy.

### *Epistemology*

The term *epistemology* relates to both the study of knowledge or knowing, and the researcher's theoretical approach to a topic. Because this philosophical inquiry seeks to dialogue with lived autistic experiences, a poststructuralist approach was deemed the best fit. Poststructuralism seeks to challenge hegemony in language and knowledge production by engaging with non-dominant perspectives (Hesse-Biber, 2017). This theoretical approach also aligns with the neurodiversity paradigm, in that it seeks to engage with lived experiences and resist deterministic understandings of personhood (Davies, 2022; Walker, 2021). As such, I approached this study with an emerging poststructuralist orientation rooted in a desire to center non-dominant narratives (Pillow, 2019; St. Pierre & Pillow, 2000) and, in doing so, to disrupt my own tendency toward deterministic thinking through a process of circling the text (St. Pierre, 1997a, 1997b, 2018).

### Materials

In this philosophical inquiry, scholarly and commercially published literature (articles, books, and journals) served as the source of data. Articles were printed and kept in binders, allowing for the physical organization of literature into different topic areas. Additionally, notes and reflections were made in the margins or on sticky notes kept with each article or book. Long-form research reflections were written in Word documents stored on the researcher's computer. The mind mapping software, MindMeister™, was used to create digital mind maps of themes.

## Data Collection

The literature for this inquiry was intentionally sampled through an iterative process of collection and analysis. Specifically, the body of literature that generated the data prioritized autistic experiences through first-voice and allied literature. First-voice literature included peer-reviewed articles and anthologies of essays from autistic individuals published by self-advocacy organizations. Allied literature included peer-reviewed articles and books that centered autistic experiences through community-academic partnerships, qualitative interviews or dialogues, and survey research with autistic respondents. At the time of data collection, there was limited literature about music therapy and autism from autistic perspectives. As such, music therapy research articles pertaining to autism and music, autism and music therapy, or music therapy and harm were evaluated for inclusion based on their alignment with a neurodiversity paradigm.

To begin, general searches included the following databases: *Sofia*, *Google Scholar*, *PsycArticles*, and *ERIConProQuest*. The following music therapy journals were consulted: *Canadian Journal of Music Therapy*, *Journal of Music Therapy*, *Voices: A World Forum for Music Therapy*, *Nordic Journal of Music Therapy*, and *British Journal of Music Therapy*. The following disability studies journals were consulted: *Disability Studies Quarterly*, *Canadian Journal of Disability Studies*, *Disability & Society*, *Journal of Disability Policy Studies*. Additional journals were consulted including: *Autism in Adulthood* and *The Arts in Psychotherapy*.

Two search streams were followed to inform this inquiry. One focused on harm in autism intervention and used the following search terms in combinations: *autism*, *autism spectrum disorder*, *autism spectrum condition*, *harm*, *neurodiversity*, *sensory*. The other search stream focused on harm in music therapy using the following terms in combinations: *music therapy*, *harm*, *music-induced harm*, *music*, *autism*. Selections were limited to books and peer-reviewed articles published between 2000 and 2022. Articles were sorted into the following general categories: a) authors identifying as autistic or research teams that included autistic members; b) autism or music therapy research within a neurodiversity paradigm; c) survey or interview research with autistic participants; and d) research within a pathologizing paradigm. Priority was given to books or articles in the first three categories and the bibliographies of these articles were searched to generate more data from first-voice and allied literatures.

## **Data Analysis**

Initially, articles were read to identify the possible explanations for the importance of understanding harm in music therapy from the perspective of autistic individuals (Aigen, 2015). As themes emerged, the Music Therapy and Harm Model (MTHM) (Murakami, 2021), described in chapter 3, was used as an organizing framework. Mind maps were created to visually represent the connection between first-voice literature, music therapy theory, and the six aspects of the MTHM. The argument was operationalized (Aigen, 2015) through the logical questions that emerged from the mapping. As stated previously, the data collection and analysis were iterative processes, therefore the data literature was frequently consulted for further insights and to re-evaluate previously created maps. “Circling the text,” or writing and re-writing the final argument, generated insights that further clarified the themes (St. Pierre, 1997a; 1997b; 2018). Both these processes supported the refinement of the research question to focus more specifically on the narratives of autistic individuals.

## **Summary**

The methodology chapter outlines the procedure for the research that follows. In this philosophical inquiry, first-voice and allied literatures were the primary sources of data. Literature selection was informed by the neurodiversity paradigm and poststructuralism necessitating the centering of non-dominant narratives. The literature reviewed in Chapter 3 will outline possible explanations for why the experiences of autistic individuals must inform considerations of harm in music therapy with autistic individuals. In Chapter 4, a dialogue between autistic experiences, as represented by the data literature, and music therapy theories considering harm will be facilitated by the framework of the MTHM.

### Chapter 3: Literature Review

The lack of autistic perspectives in autism-related research and program design is generating an unstable basis for therapeutic intervention and support (Devlin, 2018; Kapp, 2019; Kupferstein, 2018, 2019; Milton, 2012; Milton et al., 2014; Nicolaidis et al., 2013, 2015; Raymaker, 2019; Raymaker et al., 2020; Williams, 2018). Research driven by medical and psychological science frames autism in terms of pathology and deficit which leads to problematic understandings of autistic experience rooted in ableism and normalization. As such, fear and otherness become the rhetoric of mainstream autism research agendas and interventions (Heilker & Yergeau, 2011; Kapp, 2019; Yergeau, 2013). Despite the biomedical milieu of traditional autism research, there is a growing body of research generated by autistic scholars about autism. From this rich source, it is evident that harm is experienced by autistic individuals in therapeutic intervention and healthcare spaces (Kapp et al., 2019; Milton & Sims, 2016; Nicolaidis et al., 2013, 2015; Nicolaidis & Raymaker, 2013; Yergeau, 2013).

Harm is a concept constructed within a given societal and historical context (Haslam et al., 2020). It is an experience that may have physical, psychological, or cultural consequences occurring on a continuum of time and intensity (Murakami, 2021; Silverman et al., 2020). Music therapist scholars are becoming increasingly aware of the possibility of harm in music therapy practice, beyond negative outcomes and contraindications (Edwards, 2011; Gardstrom, 2008; Isenberg, 2012; McFerran, 2021; Murakami, 2021; Norris, 2020; Rolvsjord, 2006; Shaw, 2022; Silverman et al., 2020). These theorists indicate that the best source of information regarding experiences of harm in music therapy are the clients themselves (Isenberg, 2012; LaCom & Reed, 2014; Murakami, 2021; Silverman et al., 2020).

This literature review responds to the lack of autistic voices in research about autism and the previously mentioned assertion that clients are the best source of information regarding experiences of harm by engaging with first-voice autism research. The chapter begins with an overview of common paradigms that frame current understandings of autism and autistic experience. Then the experiences of autistic individuals are centered to identify potential areas of harm in existing intervention and support models. Finally, emerging theories of harm in music therapy are introduced including an overview of the Music Therapy and Harm Model (Murakami, 2021) which structures the analysis in Chapter 4.

## **Paradigms Defining Autism**

To begin, three common sets of assumptions that influence perspectives on autism are reviewed (Davies, 2022; Kapp, 2019; Straus, 2013; Walker, 2021). Similar to how dominant philosophies, such as humanism, influence narratives about society and politics, paradigms influence research priorities, actions and therapeutic interventions. Three paradigms framing autism are explicated here: a pathologizing paradigm, a neurodiversity paradigm, and a cultural paradigm.

### ***Pathologizing Paradigm***

A pathologizing paradigm of autism undergirds biomedical autism research and knowledge production, creating a hostile basis for therapeutic intervention development. Models in this paradigm, such as biomedical or social deficit models, locate the perceived problems of autism within the individual and prioritize cure over accommodation (Heilker & Yergeau, 2011; Kapp, 2019; Straus, 2013, 2014; Yergeau, 2010). However, even these models of autism are unstable because the diagnostic parameters are subject to fluctuating political and societal values (Hens et al., 2019; Milton, 2012; Straus, 2013). These models consider autism as a deficiency, abnormality, or deviance from standardized norms and frequently call into question autistic personhood (Kapp, 2019; Kapp et al., 2019; Mitchell et al., 2021; Yergeau, 2013).

Rooted in pathology, the influential weak theory of mind hypothesis implies that autistic individuals have more trouble than non-autistic individuals imagining that other people have thoughts and minds. Importantly, Gernsbacher and Yergeau (2019) published a systematic review explicating the failures of theory of mind research. They challenged the validity, replicability, specificity and universality of these studies. Their findings suggested that the only consistent predictor of performance on theory of mind tests was comprehension of complex language. The authors conclude, “the claim that autistic people lack a theory of mind is empirically questionable and societally harmful” (Gernsbacher & Yergeau, 2019, p. 2). Other research by Gernsbacher and colleagues (2005, 2006, 2016, 2017) have similarly challenged many empirical claims about autism through scientifically accepted measures of research rigor. They question the gold standards of quantitative research as applied to autistic subjects, especially when matching autistic experimental groups with non-autistic comparison groups (Gernsbacher et al., 2017). The lack of clarity in quantitative autism research methodologies casts doubt on the precision of the results of these studies. The influential ideas produced by

seminal autism research are present in textbooks, intervention training, and popular culture; however, studies unable to reproduce the seminal results are given much less attention (Gernsbacher & Yergeau, 2019, p. 8).

Pathologizing paradigms grow out of the “ableist strategy of fixing people” (Rolvjord, 2014, para. 14). Ableism is a dominant narrative, or set of beliefs and assumptions, that values abilities and behaviours that align with prevailing societal expectations and devalues those that do not (Shaw, 2022; Wolbring, 2008). It influences language and discourse around autism in research, therapeutic intervention, and policy agendas (Bottema-Beutel et al., 2021c; Yergeau, 2013). Ableism problematically links human value to the ability to contribute to economic production – value that is determined by the ableist, neoliberal, capitalist standards that prevail in Western society and medicine (Broderick & Roscigno, 2021; McGuire, 2015, 2017; Williams, 2018; Yergeau, 2013). As a result, autism is framed as an economic burden that requires intervention to prepare autistic people for productive contribution to society (Broderick & Roscigno, 2021).

In pathologizing paradigms, an autistic individual’s value is measured by their capacity to behave, contribute, or function in externally determined, normative ways. McGuire (2017) examined how the language of spectrum in the DSM-5 reinforces such neoliberal capitalist ideals of productivity and independence. The author argued that while the rhetoric of the spectrum offers opportunities for resisting normalizing agendas, the support-level scale for ASD is also an example of how the DSM-5 continues to reinforce dichotomies of normal and abnormal in the guise of spectrum which creates vulnerabilities for those with high support needs.

Despite the positive intentions of spectrum rhetoric, there appears to be no winning for autistic individuals, regardless of their position on it. Functioning labels are frequently used to discredit the experiences of autistic activists, scholars, and individuals. Autistic rhetorician, Melanie Yergeau (2013), therefore, questions the very notion of spectrum and its attempt to define who is autistic enough to be considered autistic in current cultural and economic contexts. On one hand, those formerly labelled as *high-functioning* are considered too “normal” to speak to possibly common experiences in autism; on the other hand, those formerly labelled as *low-functioning* are considered unable to contribute to the discourse entirely (Yergeau, 2010, 2013; Zisk, 2021). Support resources are frequently limited to those who are clinically diagnosed; those who are self-diagnosed need not apply.

Taken together, the foundational ideology of ableism and the fluctuating ontological and epistemological status of autism create fertile ground for problematic power differentials in therapeutic relationships. As its starting premise, a pathologizing paradigm questions the autistic individual's capacity for self-determination, self-knowledge, and competence due simply to the fact that support resources may be required. The default presumption that autistic individuals are non-intelligent and/or incompetent regarding their self-determination undermines the ethical obligation to engage clients in consent/assent for therapeutic services (Bascom, 2012; Yergeau, 2013). Competence is frequently questioned for autistic individuals who do not communicate with verbal language or who may require additional time or technology to communicate (Biklen & Burke, 2006). Broderick and Roscigno (2021) analyzed the cultural and economic history of what they heuristically call the Autism Industrial Complex (AIC). The concept of the AIC brings into focus how neoliberal capitalism propagates the rhetoric of autism as an economic burden thereby requiring intervention, and justifying autism intervention, including the requisite professionals, products and services (p. 92). Autistic bodies are the crux of the AIC which in turn generate economic wealth for the AIC's constituent parts. The production of AIC is sold to non-autistic consumers based on the narrative that autistic people require these services and products to become economically contributing members of society.

### ***Neurodiversity Paradigm***

The neurodiversity paradigm is an expansion of the social model of disability and is antithetical to pathologizing models of autism. Social models of disability identify the locus of disability as an interaction between individual difference and social or societal norms (Heilker & Yergeau, 2011; Metell, 2014; Milton, 2012; Mitchell et al., 2021; Miyake, 2014; Straus, 2013; Williams, 2018). The neurodiversity paradigm frames neurological differences, of which autism is one, as one of many natural expressions of human diversity like race, gender, age, etc. (Walker & Raymaker, 2021). In this framing, disability occurs when the neuro-majority does not make space for neurodivergent ways of being. Critics contend that the neurodiversity paradigm overemphasizes the social construction of disability and does not account for experiences of impairment (Hughes, 2021). However, the neurodiversity paradigm is generated by individuals who identify as neurodivergent and who claim that expertise gained from lived-experience is essential to any discussion about autism research (Milton, 2014; Woods & Waltz, 2019). Researchers and practitioners can gain second-hand expertise in autism, by investing time and

effort to build non-therapeutic relationships with autistic adults and experience autistic culture (Milton, 2014). However, this knowledge remains second-hand and can not be considered as having more authority than lived experience.

### ***Cultural Paradigm***

A cultural paradigm of autism acknowledges the various ways autistic individuals and communities create meaning from their shared experiences. The rise of autistic community as the result of the internet through listservs, newsletters and formal organizations has a well documented history (Bascom, 2012; Kapp, 2020). Joseph Straus (2013, 2014) writes about the theories of autism generated by autistic communities and about how they could be applied to autistic creative works. Other authors write about differences in communication framed in cultural terms (Ballou et al., 2021; Bascom, 2012). For example, two autistic peers may interact with more ease than an autistic and non-autistic peer (Mitchell et al., 2021). When cultural aspects of autistic experiences are centered, the practice of limiting autistic individuals to their symptomology becomes highly problematic (Bakan, 2014a, 2014b; Bakan & Chasar, 2018; Ballou et al., 2021; Bascom, 2012; Cameron, 2014; Honisch, 2014; Onaiwu, 2020; Straus, 2013, 2014; Yergeau, 2013; Zisk, 2021).

**Autism and music.** The relationship between autism and music as a stimulus is frequently researched, and it reveals possibilities for harm that will be discussed later. There are a few important exceptions that focus on the personal and cultural experiences of music by autistic individuals (Bakan, 2014a; Bakan & Chasar, 2018; Korošec et al., 2022; Straus, 2013, 2014). Bakan (2014a, 2015, 2018, 2014b; Bakan & Chasar, 2018) used an ethnomusicological lens to explore autism and autistic experiences of music. His projects, Music-Play Project and Artism ensemble, centered the musical expression of autistic children without a specific therapeutic goal (Bakan, 2015). This specific research project led the author to explore the rich musical lives of autistic individuals with a range of interests and life experiences. *Speaking for Ourselves: Conversations on life, music and autism* (Bakan & Chasar, 2018), amplified the rich creativity described by autistic people engaged in music experiences and that music was an integral part of the collaborators' life experiences. Framing autism in cultural terms centres the experiences of autistic people and necessitates the inclusion of these experiences in discussions about autism, music therapy and harm.

## **Characteristics of Harm in Autism Intervention and Support**

Having established the paradigmatic contexts in which autism is frequently situated, the next section focuses specifically on the experiences of autistic individuals. A neurodiversity paradigm frames autism as a natural part of human diversity making it critical for music therapists to understand support needs based on autistic experiences. Here, the experiences of autistic individuals, from first-voice and allied literature, identified normalization, compliance-based intervention, pathologizing difference and professional alignments as significant areas of concern regarding harm.

### ***Normalization***

Autistic individuals are very concerned about normalization, a process of imposing societal norms for behaviour and communication on autistic individuals (Mitchell et al., 2021; Nicolaidis et al., 2015; Raymaker et al., 2020; Schneid & Raz, 2020). What is considered normal is contextual, and it fluctuates according to culture, time, and place. Normalization is particularly harmful when it forms the basis of therapeutic intervention (Kupferstein, 2018, 2019). The adverse impacts of normalizing pressures include low self-esteem, masking, burnout and suicide in autistic individuals (Mitchell et al., 2021; Raymaker et al., 2020; Schneid & Raz, 2020).

In spaces where societal norms do not embrace differences in behaviour and communication, autistic individuals feel compelled to use impression management and social camouflage, including in therapy and healthcare (Mitchell et al., 2021; Raymaker et al., 2020). Schneid and Raz (2020) used qualitative interviews in a participatory research approach to explore the impacts of impression management and social camouflage from the perspective of 24 Israeli autistic adults. Impression management is a broad set of social tools that “we use to present ourselves to influence how others see us” (Schneid & Raz, 2020, p. 2), whereas social camouflaging is a specific tool that minimizes the presentation of autistic traits in social encounters. Though impression management is a common experience in social interaction and its tools can be manipulated to relate personal interests, beliefs and traits, under normalizing pressures, it can lead to masking and camouflaging to reduce the chances of social rejection. This in turn leads to feelings of alienation and frustration (Schneid & Raz, 2020).

Ongoing impression management and social camouflaging can also lead to experiences of burnout for autistic individuals. Raymaker et al. (2020) used qualitative analysis in a community-academic partnership model to develop a definition of autistic burnout, and

identified its occurrence as a unique risk expressed by autistic individuals on multiple media platforms (interviews, blogs and YouTube videos). They define autistic burnout as “a syndrome conceptualized as resulting from chronic life stress and a mismatch of expectations and abilities without adequate supports. It is characterized by pervasive, long-term (typically 3+ months) exhaustion, loss of function, and reduced tolerance to stimulus” (Raymaker et al, 2020, p. 140). Burnout impacts the health and well-being of autistic individuals, affecting their quality of life and capacity for day-to-day living over a prolonged period of time. It also impacts autistic experiences of empathy from neurotypical people and puts them at possible risk of suicide (Raymaker et al, 2020, p. 136).

**Double Empathy Problem.** The double empathy problem, theorized by Damian Milton (2012), illustrates a possible mechanism for harm in therapeutic and healthcare contexts (Heilker & Yergeau, 2011; Mitchell et al., 2021). This problem occurs when two social communicators, in this case, one autistic and one non-autistic, have vastly different experiences of relating to one another; autistic individuals’ efforts to understand non-autistic ways of being are not reciprocated by their non-autistic peers (Milton, 2012). False presumptions of autistic social capacity have created widespread assumptions regarding a supposed lack of social interest (Mitchell et al., 2021; Yergeau, 2013). At its core, the double empathy problem is a powerful expression of normative expectations for communication, exposing the underlying ableist assumption that there exists normal communication, usually meaning spoken, direct, independent forms of communication (Heilker & Yergeau, 2011). Non-autistic individuals are often unaware of the efforts of autistic individuals to make social interactions go more smoothly. In therapeutic or healthcare contexts, where power is balanced in favour of the practitioner, the consequences of the double empathy problem may be amplified.

Mitchell et al.(2021), indicate that social camouflage results from experiencing the double empathy problem and may lead to a thwarted sense of belonging. Autistic individuals are no more or less socially motivated than neurotypical individuals; the expressions of autistic social connection are what are different and may not conform to normative social expectations. Similarly, autistic individuals have varying levels of personal insight, much like neurotypical individuals. A socially motivated autistic individual may employ impression management and social camouflage to improve social connection in neurotypical spaces. Subsequent insight into the precarious nature of these connections may lead to a thwarted sense of belonging, and a

diminished sense of belonging is a risk factor in suicidality (Mitchell et al, 2021, p. 10).

### ***Compliance***

Compliance-based interventions impose a specific way of behaving or communicating (normalization) on autistic individuals and are not responsive to autistic ways of being (Bascom, 2012; Bottema-Beutel, Crowley, et al., 2021a, 2021b; Kupferstein, 2018, 2019; Walker, 2021; Williams, 2018). Perhaps the most contentious discussions of harm in autistic communities occur around Early Intensive Behavioural Intervention (EIBI) and Applied Behaviour Analysis (ABA). Many medical professionals consider ABA as the preferred evidence-based, standardized therapy for children with autism. The practice uses intensive (25-40 hrs./week) behaviour training to replace behaviours considered inappropriate with behaviours considered acceptable (Applied Behaviour Analysis, n.d.). Because ABA is rooted in a pathologizing model of autism, it cannot be reconciled with a neurodiversity paradigm (Walker, 2021). Critics of ABA emphasize its normalization agenda, the ongoing evidence of aversive punishments, its shared foundation with conversion therapy and the significant potential for harm (Bascom, 2012; Kupferstein, 2018, 2019; Williams, 2018). Proponents of ABA defend the practice by noting its general move away from historically used aversive punishments and that it is a scientifically grounded evidence-based best practice (Kapp, 2019; Williams, 2018). Recent systematic reviews, however, have provided critique of the quality of research supporting ABA, including the frequent absence of conflict-of-interest declarations (Bottema-Beutel et al., 2021a, 2021b).

Compelling arguments against ABA and in favour of relationship- and communication-based intervention models are offered by Williams (2018) and Kupferstein (2018, 2019). Williams (2018) uses Self-Determination Theory to critique Early Intensive Behavioural Intervention and ABA. Self-Determination Theory positions itself as antithetical to behaviourism, meaning systems of rewards and punishments are unacceptable. The author argues that external motivators imposed by an ABA therapist undermine internal motivation which comes from the client themselves (Williams, 2018, p. 62). Alternatives to external motivators are rooted in relationship, connection, feedback, and choice.

Kupferstein (2018) surveyed autistic individuals, parents and caregivers about their (or their children's) experiences in ABA and screened for post-traumatic stress symptoms (PTSS). The results indicated increased evidence of PTSS in those who had experienced ABA compared

to those who had experienced other forms of intervention (including communication-based interventions). Kupferstein (2019) followed up the study with a qualitative analysis of the narrative questions from the original survey. This secondary analysis revealed that when individuals and caregivers abandoned ABA approaches it was frequently in favour of communication-based intervention that reflected an autonomy-based attitude. The survey results also suggested that those who had not experienced therapeutic intervention of any type reported no PTSS (Kupferstein, 2019, p. 77).

### ***Pathologizing difference***

Autistic individuals indicate that harm is possible and happening in their interactions with healthcare providers (Ballou et al., 2021; Biklen & Burke, 2006; Kapp et al., 2019; Kupferstein, 2018, 2019; Nicolaidis et al., 2015). Research examining the interactions of autistic adults and healthcare professionals reveals significant room for improvement; a provider's openness to considering accommodations has a large impact on the healthcare experience. Nicolaidis et al. (2015) used a community-academic research partnership to explore the patient-, provider- and system-level factors that influenced autistic individuals' interactions with healthcare providers. At the provider-level, autistic interviewees and their supporters identified providers' lack of knowledge, incorrect assumptions about individual patients' skills or needs, unwillingness to allow non-speaking forms of communication, and failure to use accessible language as barriers in interactions with healthcare providers. This is echoed in well-being research by Milton and Sims (2016) whose thematic analysis of the magazine *Aspergers United* found that "interactions [with psych-professionals] ... were often seen as extremely negative, with many reporting that their needs were not recognized or were misinterpreted" (p. 526). In their analysis of social media discussions of autistic burnout, Raymaker et al. (2020) identified that access to therapy, specifically as a resource for reducing symptoms of burnout, was often reported as limited, or the therapeutic experience was negative. This finding is an important reminder for helping professionals to identify, understand and respond to concerns from autistic individuals regarding their experiences of therapeutic intervention.

Sensory differences experienced by autistic individuals are frequently misunderstood or disregarded in therapeutic or healthcare contexts rooted in pathology (Bakan & Chasar, 2018; Ballou et al., 2021; Bascom, 2012; Biklen & Burke, 2006; Davies, 2022; Felepchuk, 2021; Robertson & Simmons, 2015; Robledo et al., 2012). Harm occurs when helping professionals do

not accommodate these differences, potentially limiting an autistic individual's capacity to communicate about or participate in their care decisions (Kapp et al., 2019; Milton, 2014; Milton et al., 2014; Milton & Sims, 2016; Nicolaidis et al., 2015; Williams, 2018; Young, 2020).

Autistic individuals have indicated that sensory differences are frequently misunderstood and that this misunderstanding limits their capacity to participate in social activities (Ballou et al., 2021; Bascom, 2012; Robertson & Simmons, 2015; Robledo et al., 2012). Changes in sensory capacity are similarly identified as one of the more common symptoms of autistic burnout (Raymaker et al., 2020).

It is important that music therapists understand how sound stimuli might affect autistic individuals. Two studies, one by Robledo et al. (2012) and one by Robertson and Simmons (2015), reported that sound stimuli may be perceived in various and contextual ways. Robledo et al. (2012) interviewed five “independently-communicating [autistic] participants,” through various methods, over the phone or via email, to gain insight into their lived experiences of sensory and movement differences (p. 3). Robertson and Simmons (2015) used qualitative analysis to gain insight into “sensory issues in ASD” through a researcher-moderated focus group of six autistic individuals (p. 571). Though the latter study was not based in the neurodiversity paradigm, its inclusion of rich verbatim quotes from the focus group reveals results that can inform a neurodiversity-affirming understanding of sensory differences. Research and self-report both indicate that sensory capacity is a non-static experience; its characteristics are unique for each person and may fluctuate based on physical, emotional and social contexts (Raymaker et al., 2020; Robertson & Simmons, 2015). Korošec et al. (2022) added to this body of research looking at autism and music (see also Allen et al., 2009; Kirby et al., 2015). Their hermeneutical-phenomenological interview research captures the two-sided nature of music experienced by their autistic interviewees. Music offered opportunities for coping with the environment, regulating mood, and creativity. Participants also identified how those opportunities could become challenges if music-induced hyperfocus was used to ruminate on negative emotions, or to induce highly stimulating emotional experiences.

### ***Professional alignment***

Autistic individuals, disability studies researchers, and music therapy researchers and practitioners have expressed concern about the consequences of aligning therapeutic and healthcare with medical practice and government institutions rooted in pathology and

normalization (Cameron, 2014; Davies, 2022; Honisch, 2014; Metell, 2014; Miyake, 2014; Pickard et al., 2020; Rickson, 2014; Rolvsjord, 2014; Straus, 2014). Healthcare practitioners, and specifically music therapists, must recognize how their assumptions about disability and pathology are influenced by societal norms and how this impacts their work (LaCom & Reed, 2014; Metell, 2014; Miyake, 2014; Rickson, 2014; Rolvsjord, 2006, 2014). As the music therapy profession continues to gain recognition and practitioners, an increasing number of music therapy scholars are challenging the humanist foundations and status quo of therapeutic power dynamics to ask questions about the future, purpose, and responsibility of music therapy work (Davies, 2022; Isenberg, 2012; McFerran, 2021; Murakami, 2021; Norris, 2020; Pickard et al., 2020; Powers, 2020; Shaw, 2022). Drawing from music therapy scholars who identify as marginalized members of the profession (Davies, 2022; Norris, 2020; Shaw, 2022) and from music therapy scholars who witness the marginalization of the individuals and groups they work with (Devlin, 2018; McFerran, 2021; Pickard et al., 2020; Rolvsjord, 2014), it becomes apparent that a paradigm shift is required in music therapy to understand difference, not as pathology, but as an opportunity rich with relationality. In the context of this current research, it is essential that these foundational examinations include the voices of autistic individuals who are impacted should the status quo be maintained (Berger, 2002; Cameron, 2014; Devlin, 2018; Honisch, 2014; Milton et al., 2014; Milton & Sims, 2016; Nicolaidis et al., 2015; Norris, 2020; Pickard et al., 2020; Rolvsjord, 2014; Williams, 2018).

### **Characteristics of Harm in Music Therapy**

Research in music therapy is only beginning to explore autistic perspectives (Davies, 2022; Devlin, 2018; LaCom & Reed, 2014; Powers, 2020; Young, 2020) and examine the dominant narratives that influence practice (McFerran, 2021; Norris, 2020; Pickard et al., 2020; Shaw, 2022; Thomas & Norris, 2021). Therefore, the literature reviewed here will draw primarily from music therapy theory rather than the lived experiences of autistic individuals. In this section, music therapy literature engaged with questions of harm will be examined, followed by an explication of the Music Therapy and Harm Model (Murakami, 2021) that frames the analysis in chapter 4.

### ***Theorizing Harm in Music Therapy***

Considerations of harm are increasingly appearing in music therapy discourse (Gardstrom, 2008; Hiller & Gardstrom, 2018; Isenberg, 2012; Murakami, 2021; Silverman et al.,

2020). Harm in music therapy has been defined at the theoretical level in commentaries by Gardstrom (2008), Edwards (2011), and Isenberg (2012). These authors caution music therapists and other music providers about the danger of considering music as always good, as non-invasive, or as non-threatening. Music therapists should understand that sound, and by extension music, is an invasive phenomenon that enters the body through a physical process (Gardstrom, 2008). It is translated into neurological and psychological information and is filtered through personal and cultural experiences. Additionally, Gardstrom (2008) argues that the nature of therapy is to work with a client through difficult processes, some which may be considered invasive, within a therapeutic framework of trust. Edwards (2011) argues that music is commodified or stripped of its holistic meaning in media representations of music interventions. Music is frequently represented as the sole vehicle for positive social change without accounting for the contextual factors leading to a general sense that music is, at worst, a benign artifact. In 2012, Isenberg illustrated possible ways music therapy could cause harm based on case examples from a number of therapists. Examples of such harms include: poor music selection leading to re-traumatization, inappropriate instrument selection leading to injury, and the therapist becoming overwhelmed by the emotional content of the client's music (pp. 73-76). Isenberg (2012) argues it is the responsibility of the music therapist to maintain safety in therapeutic contexts. As such, the therapeutic framework of trust must be one that allows the client freedom and safety to identify the potential harms in their therapeutic experience.

Music therapy theorists are also beginning to challenge the dominant narrative of humanism (Rolvsjord, 2014; McFerran, 2020; Shaw, 2022). As a philosophical theory, humanism was a departure from previously held beliefs that measured man against the divine (Ansdell & Stige, 2018). Within humanism, the *person* is the definable being, measuring humans against an idealized construct of humanity, namely White, male, able-bodied and sound of mind (McFerran, 2021; Norris, 2020; Shaw, 2022). Humanism gave rise to the empirical sciences, which generally define *being* in observable terms, and capitalism, which values the *person* in terms of productivity. As society is reaching the limits of humanism, posthumanist philosophies are emerging that emphasize the interconnections between beings, the blurring of lines between human and non-human beings, and the non-hierarchical nature of being on earth (Shaw, 2022). Hierarchy remains in humanist systems of therapy which upholds the “ableist strategy of fixing people” (Rolvsjord, 2014, p.4). Where humanism continues to reinforce binaries, post-humanist

theories struggle against binary language and attempt to understand being as embodied, relational, and indeterminate (Fritsch & McGuire, 2019; McFerran, 2021; Pickard et al., 2020).

### ***Models of Harm in music therapy***

During the development of this philosophical inquiry, two models were published providing a response to the question, how is harm described in music therapy? The Music-Induced Harm (MIH) model, proposed by Silverman et al. (2020), is a comprehensive theory of music-induced harm, attempting to consider music and harm in universal terms. The model relies heavily on visual representation and a large number of questions for consideration to communicate the relationships between its six factors. The Music Therapy and Harm Model (MTHM), proposed by Murakami (2021), is a concise and concrete theory of how to conceptualize harm in music therapy practice. It is simple to describe and uses straightforward geometry in visualizing its six factors. Both models situate music therapists as having the potential to mitigate or remediate harms related to music. Clinicians with appropriate training should be able to identify possible harms, but ultimately harm should be identified by the client and subsequently addressed by the therapist (Murakami, 2021, p. 17; Silverman et al., 2020, p. 266). Both models informed the development of this research, however the MTHM specifically provides the framework for the analysis because it is based in relationship. The model is conceptually accessible to the day-to-day music therapist and was developed through practice, observation, discussion, and modification (Murakami, 2021).

### ***Music Therapy and Harm Model***

Murakami (2021) builds her basic definition of harm from psychology focusing on the physical and psychological results of harm. Drawing on Bruscia's (2014) Client-Music-Therapist Constellation and Bronfenbrenner's (1979) ecological development model, she conceptualizes harm in music therapy as having six aspects. Harm may arise 1) from a music stimulus, 2) from the music therapist, 3) from the application of music interventions, 4) from the therapeutic relationship, 5) from client associations with music, and 6) from ecological factors (Murakami, 2021). The six areas of harm are supported with clinical examples and there is room to imagine one's own clinical experiences in the model. By combining the familiar theoretical structures of the triangular client-music-therapist constellation (Bruscia, 2014) and the concentric circles of the ecological model of development (Bronfenbrenner, 1979), the model is concise, descriptive and immediately applicable to day-to-day practice.

The MTHM provides a relational approach to the present research question. First-voice and allied literature indicate that many of the challenges experienced by autistic individuals are due to assumptions about competence, communication, and relationship (Biklen & Burke, 2006; Kapp et al., 2019; Milton, 2012; Milton & Sims, 2016; Nicolaidis et al., 2015; Raymaker et al., 2020; Williams, 2018). The MTHM is a sturdy framework that remains responsive to the nuanced relationships between client-therapist-music and the contextual factors that influence the therapeutic process. It has potential to provide a framework for dialogue between existing theories of music therapy and the lived experiences of autistic individuals.

### **Summary**

The literature review in a philosophical inquiry sets out the evidence for the argument. The experiences of autistic individuals, gathered from first-voice and allied authors, provided insights into the paradigms that contextualize autism research and described potential harms in autism intervention and support structures. Therapeutic interventions and support structures rooted in normalization, compliance, and pathology were identified in the literature as potential sites of harm. Concerns about the professional alignment of music therapy led to a review of existing theories of harm in music therapy. This chapter concluded by introducing the Music Therapy and Harm Model, which provides the framework for the analysis in Chapter 4.

## Chapter 4: Dialogue

Drawing on the groundwork laid in chapter 3, this analysis examines the themes presented in the reviewed literature through the framework of the Music Therapy and Harm Model (Murakami, 2021). The model allows for dialogue between the individual, relational and societal factors that influence autistic people and the music therapists working with them. Each factor in the MTHM will be expanded for clarity, followed by (1) a synthesis of the findings from the first voice literature and music therapy literature regarding potential harms identified by autistic individuals and (2) opportunities for reducing harm in music therapy with autistic individuals.

### **MTHM 1: Music as Stimulus**

“The potential for harm arises from the music when the psychoacoustic energy (i.e., the vibrations, sensations, or perceptions a client receives from a musical stimulus) causes physical or psychological distress for the client that is not in service of a therapeutic objective.”

(Murakami, 2021, p. 6)

### ***Expanding the Concept***

The MTHM defines music from an acoustic perspective, isolating the physical aspects of sound from its cultural or artistic meaning. Sound, and by extension music, is a phenomenon that enters and is processed in the body (Gardstrom, 2008). Evidence of harm related to music as stimulus has been generated in musicology regarding oppression and torture (Cloonan & Johnson, 2002; Cusick, 2008), in medicine related to musicogenic epilepsy (Maguire, 2012; Pelliccia et al., 2019; Tseng et al., 2018) and, more recently, in connection to music-induced hearing loss (Weilnhammer et al., 2021). Music therapy has been particularly concerned about harm related to music as stimulus in connection to overstimulation and overexposure with neonatal intensive care unit patients. The literature about the sensory experiences of autistic individuals in music therapy is less abundant (Berger, 2002; Shiloh & Lagasse, 2014; Williams, 2020).

### ***Potential Harms Identified by Autistic Individuals***

While sensory differences are implicated in the medical symptomology of autism, much of the research does not include the first voice experiences of autistic individuals. Sound stimuli was cited by many autistic research participants as having potentially negative effects, though there was no broad rule that determined what might be harmful where, when, or how (Korošec et

al., 2022; Nicolaidis et al., 2015; Robledo et al., 2012). In fact, the nature of sensory experiences is not evenly distributed across autistic individuals; specific stimuli may cause distress where others do not (Robertson & Simmons, 2015; Robledo et al., 2012; Woods & Waltz, 2019). Autistic individuals experiencing burnout may have lower tolerance for previously innocuous sounds or music (Raymaker et al., 2020). Participants in studies included in this inquiry identified sound stimuli or noise as often creating physical or emotional discomfort (Kapp et al., 2019; Korošec et al., 2022; Robertson & Simmons, 2015; Robledo et al., 2012). Unwanted or uncomfortable stimuli could cause increased anxiety prior to, during or after a sensory experience (Robledo et al., 2012). However, not all autistic individuals have sensitivities to sound or music, and music was also identified as helpful by many (Kapp et al., 2019; Korošec et al., 2022; Robertson & Simmons, 2015; Robledo et al., 2012). Opportunities for reducing the potential for harm are generated when music therapists understand there are various sensory responses to stimuli unique to each autistic individual.

### ***Opportunities for Reducing Harm***

Generally, music and specifically preferential music, were identified as exceptions to sound sensitivities. Indeed, music was cited as having more beneficial than detrimental effects on research participants (Korošec et al., 2022; Robertson & Simmons, 2015; Robledo et al., 2012). This is not to suggest there is no chance for harm; adverse sensory experiences related to music cannot be entirely anticipated by a music therapist. Importantly, music could still be a trigger for noisy thoughts, anxiety, or it could create sensory discomfort (Kapp et al., 2019; Korošec et al., 2022). However, participants in some studies identified being allowed control over the source of sound or music as a powerful tool for mitigating sound sensitivity. Autistic individuals may benefit from low-impact sensory environments where they have control over the sensory inputs (Korošec et al., 2022; Robertson & Simmons, 2015; Robledo et al., 2012).

### **MTHM 2: The Music Therapist**

“The music therapist’s role is to competently and ethically facilitate the client’s journey through the clinical process within their scope of practice... Harm can occur when the music therapist lacks self-awareness, knowledge, or judgment leading to non-musical decisions that compromise the client’s safety.” (Murakami, 2021, p.7)

### ***Expanding the Concept***

As the bearers of power in the therapeutic relationship, music therapists have an ethical

responsibility to understand the potential of harms related to music, therapy and professionalization (Dileo, 2021; Isenberg, 2012). The MTHM identifies the music therapist as a potential source of harm specifically regarding practicing out of scope, personal beliefs, and inadequate supervision. A music therapist's fundamental beliefs about personhood influence their interactions with clients. In relation to autism, the literature revealed practitioner lack of training in autism support, insufficient understanding of autistic ways of being, and inadequate supervision as possible sources of harm (Kapp, 2020; Milton, 2014; Nicolaidis et al, 2015).

### ***Potential Harms Identified by Autistic Individuals***

Music therapists hold and gain knowledge that puts them in positions of power related to their clients. This power relationship will be explored in a later section, but here we will look at the space from which a music therapist practices. Autistic adult research participants identified harm in their interactions with healthcare professionals (Nicolaidis, 2015). They highlighted the lack of knowledge around autism in adults as the primary source of harm; this means practitioners continue to engage in deficit thinking and behaviour normalization. More fundamentally, music therapists may hold potentially harmful beliefs about disability and personhood that inform assumptions about autistic people (LaCom & Reed, 2014; Williams, 2018; Yergeau, 2013), and it is the therapist's responsibility to examine deeply how their beliefs may influence their practice. As an example, weak theory of mind remains lodged in conventional thinking about autism. This hypothesis ultimately strips autistic individuals of their personhood, resulting in the general overlooking of autistic subjectivity, culture, and competence (Gernsbacher & Yergeau, 2019; Yergeau, 2013). For music therapists, this hypothesis and its implicit conclusion, made explicit here, should result in discomfort. We may not hold this conventional thinking to be true, but it is imperative music therapists examine how pathologizing assumptions influence the foundations of our profession (McFerran, 2021; Norris, 2020; Pickard et al., 2020; Shaw, 2022).

### ***Opportunities for Reducing Harm***

As professionals and experts in their field, music therapists hold a responsibility to practice in a safe and ethical manner. This requires ongoing reflection and supervision. Music therapists must look outside conventional sources of knowledge and find expertise in the experiences of autistic individuals (Devlin, 2018; Milton, 2014). For the music therapist, epistemological considerations must include a reflexive examination of who is generating the

knowledge they use to understand autism. Music therapists must be skeptical of any claims that undermine the personhood of autistic individuals. Therefore, it is necessary to include research driven by autistic participants and community priorities in music therapy training and supervision (Devlin, 2018; Kapp, 2018; Milton et al., 2017; Milton & Sims, 2016; Pickard et al., 2020). Music therapy researchers should consider community-academic research partnerships to navigate what autistic participants express as important in qualitative and quantitative research projects (Bascom, 2012; Bottema-Beutel, Kapp, et al., 2021; Kapp, 2018; Kapp et al., 2019; Korošec et al., 2022; Milton et al., 2017; Nicolaidis et al., 2011, 2015).

### **MTHM 3: The Therapeutic Application of Music**

“Harm may arise from the therapeutic application of music if the music therapist makes poor musical decisions during a session, or if they fail to respond effectively to a client’s negative reaction to the therapeutic music experience (TME).” (Murakami, 2021, p. 7)

#### ***Expanding the Concept***

Harm in the therapeutic application of music is related to poor musical decision-making, not anticipating therapeutic contraindications, and the inappropriate application of techniques (Murakami, 2021). This aspect is farthest from the client’s control since the music therapist has the training, knowledge, and techniques to design and facilitate therapeutic experiences. In their paper, *The Selection of Music Experiences in Music Therapy*, Hiller and Gardstrom (2018) assert that ethics, risk, and contraindications be considered first and foremost. Autism intervention has historically been compliance-based and coercive, therefore it is also necessary to examine how normalization influences goal setting in music therapy practice and its impact on the application of music.

#### ***Potential Harms Identified by Autistic Individuals***

The therapeutic application of music is potentially harmful when the goals of music therapy are not in the interest of the client. Musicological research demonstrates that music can be employed in harmful ways to overwhelm sensory systems or to reduce unwanted behaviours (Cloonan & Johnson, 2002; Cusick, 2008). Normalization is a common undercurrent in autism intervention, so music therapists must question the roots of their work by scrutinizing the rationale for goals and how music experiences are being used. As an agenda, normalization does not align with the expressed support needs of autistic communities (Ballou et al., 2021; Bascom, 2012; Kapp, 2019; Kapp et al., 2019). While developing certain skills may be identified as

helpful (i.e. broadening friendships, or coping with stress), a focus on normalization can lead to misplacing therapeutic energy toward eliminating benign or beneficial autistic traits. When normalization is the goal or autistic individuals are not given space to be themselves, they may experience loneliness, exclusion, masking, burnout (Raymaker et al., 2020), and/or suicidality (Mitchell et al., 2021). If the pressure to be normal is coming from (music) therapy sessions, then it is particularly harmful. Evidence suggests that compliance-based intervention reduces autonomy and intrinsic motivation (Williams, 2018). Where music is only the reward for expected behaviours, it becomes a normalizing stimulus rather than a dynamic facilitator of relationship.

### ***Opportunities for Reducing Harm***

Alternatives to compliance-based training are those that focus on communication, relationality, and make room for autistic self-determination (Bakan, 2014a; Kupferstein, 2019; Straus, 2014; Williams, 2018). Within a neurodiversity paradigm, autism does not require curative or normalizing therapeutic intervention. An autistic individual may identify areas of growth, development, or support they would like to explore. Whenever possible, the goals of music therapy should be set with autistic clients and should account for the experience and self-determination of the individual (Biklen & Burke, 2006; Milton, 2014; Milton et al., 2017; Williams, 2018). This requires the practice of presuming competence and responding to client needs as they arise. Autistic individuals must be afforded control over their therapeutic experiences and music is a flexible medium for this. Music therapists can look to the work of the Artism ensemble (Bakan, 2014) or the Musical Autist (Shiloh & Lagasse, 2014) as frameworks for therapeutic music experiences. It is significant that these two points of inspiration do not have explicit therapeutic purposes. Perhaps, music therapists can imagine their work with autistic people, not as spaces solely for therapeutic change, but as spaces where autistic individuals can simply be themselves (Kapp, 2019; Korošec et al., 2022).

### **MTHM 4: The Therapeutic Relationship**

“Harm may arise from unhealthy or inappropriate client-therapist interactions within the therapeutic relationship.... If unresolved emotions or an undesirable power dynamic between the client and therapist exist, then therapeutic progress and client welfare could be negatively impacted.” (Murakami, 2021, p. 8)

### ***Expanding the Concept***

Though potential harms identified in the therapeutic relationship are defined by boundary violations related to power, the literature also revealed that power is expressed in the communication between therapist and client (Kapp et al., 2019; LaCom & Reed, 2014; Nicolaidis et al., 2015; Rolvsjord, 2014). Conventionally, the client-therapist relationship is situational and goal-oriented; it is a non-reciprocal system of trust. Power in the therapeutic relationship is balanced in favour of the therapist, who must work to maintain rapport, while keeping professional boundaries (Murakami, 2021). The MTHM identifies where harm may occur in this relationship, but not the mechanisms that may cause its occurrence. The perspectives of autistic individuals suggest that differences in communication, and specifically a lack of understanding on the part of practitioners, can cause mistrust in therapeutic relationships.

### ***Potential Harms Identified by Autistic Individuals***

Harm occurs when music therapists do not account for communication differences between themselves and autistic individuals in therapeutic practice. This may lead to presumptions of incompetence or disregard for the individual's right to self-determination. One possible mechanism for these harms is the double empathy problem (Milton, 2012; Mitchell et al., 2021), which is generated by assumptions that require autistic individuals to work harder to understand their non-autistic music therapist. In other words, when music therapists do not make efforts to understand the communication styles of autistic clients, the double empathy problem may be amplified and the potential for harm in the forms of masking or social camouflage are present (Mitchell et al., 2021; Nicolaidis et al., 2015; Raymaker et al., 2020). In most medical and therapeutic interactions, verbal communication is prioritized, creating barriers to authentic client-directed communication in various other formats (i.e., written, facilitated, sign, non-verbal, etc.). Expectations for verbal communication constitute a dominant norm that influences much of social experience (Gernsbacher, 2018; Heilker & Yergeau, 2011; Nicolaidis et al., 2015). Communication barriers lead to experiences of the misapplication of interventions and often result in diminished trust in healthcare professionals. Autistic research participants reported that their experiences of interactions with health-care providers were poorer when communication alternatives were not available to them (Nicolaidis et al., 2015; Nicolaidis & Raymaker, 2013). Notably, autistic adults also identified frustration when health practitioners communicated with support staff rather than the autistic individual directly.

### ***Opportunities for Reducing Harm***

Music therapists should be aware of and resist normative expectations for musical and non-musical communication. Because therapists are responsible for preventing or repairing harms identified by clients, efforts must be made by practitioners to understand the various ways autistic individuals communicate. Presuming competence is a natural and essential starting point for all interactions in a neurodiversity paradigm (Biklen & Burke, 2006). Kapp (2019) citing Donnellan (1987) argues that presuming competence is the “least dangerous option” when it comes to relating to autistic individuals (p. 5). This perspective situates autistic individuals as the primary source of expertise regarding their needs within the required support structures (Williams, 2018). Music therapists must also work to address the double empathy problem (Milton, 2012). This requires intentional listening (Heilker & Yergeau, 2011) and understanding the various factors that may influence differences in communication. Ideally, music can be a sandbox for authentic communication between an autistic client and their music therapist (Bakan, 2015; Korošec et al., 2022).

### **MTHM 5: Client Associations with Music**

“This interaction is characterized by the client’s extra-musical associations to the music presented in the therapeutic session.... Harm may arise when a client’s extra-musical associations produce a negative psychological or physical response that is beyond the scope of the session’s therapeutic objective.” (Murakami, 2021, p. 8)

### ***Expanding the Concept***

Client associations with music sit furthest from the music therapist across the therapeutic triangle, meaning the music therapist cannot easily anticipate client responses to therapeutic music experiences. The client’s associations with music are unique to each individual and are not easily predicted prior to relationship development. As already explored above, music is a stimulus that elicits physical and psychological responses. The context in which a client experiences music inside and outside the therapeutic space is always present during music therapy interventions. The music therapist is responsible for monitoring the quality of client responses to music in consultation with and based on their knowledge of the individual client.

### ***Potential Harms Identified by Autistic Individuals***

Assumptions about autistic ways of being influence how music therapists interact with autistic clients. Harm is possible when music therapists do not presume competence about their

clients and if client responses to music are interpreted as behaviours requiring correction. Take, for example, stimming as a response to music. Stimming may be automatic, communicative, or simply fun (Bakan, 2014b; Felepchuk, 2021). Often perceived by non-autistics as maladaptive, stimming is cited by many autistic researchers and research participants as a scaffold for sensory integration and as a form of self-expression (Bakan & Chasar, 2018; Bakan, 2014b; Kapp et al., 2019). Conversely, Korošec et al. (2022) argue that an overly positive view of the relationship between autistic people and music overlooks the possible ways music is reported to be personally disruptive: overwhelming emotions (including too much enjoyment), inducing hyperfocus or diminished awareness of one's surroundings, or concerns about being judged by others for musical preferences or creativity. Without dialogue with autistic clients, music therapists may misinterpret associations with the therapeutic music experience by attributing assumptions of negativity or positivity to autistic client responses.

### ***Opportunities for Reducing Harm***

Music therapists should not overlook the connection between improvisation and stimming; autistic people who stim are constantly navigating novel experiences through improvisatory movement and vocalization (Felepchuk, 2021). Stimming as an improvisatory practice affords opportunities for every day creativity, explorations of environment and relationality (Felepchuk, 2021). Thus, music therapy sessions should be conceptualized as a space where authentic, autistic responses to music are celebrated and not redirected, eliminated or normalized. In fact, music therapy sessions should be conceptualized as creative spaces to support autistic self-discovery and not spaces for 'treating' autism (Bakan, 2014; Cameron, 2014; Honisch, 2014). CJ Shiloh and the Musical Autist have worked to both accommodate autistic experience (Shiloh & Lagasse, 2014) through Sensory Friendly Concerts, and to amplify autistic creativity through Elevating Autistic Musicians (The Musical Autist, n.d.). These two programs are exemplars of how music therapy can respond to expressed community needs and make efforts to work within an emancipatory framework.

### **MTHM 6: Ecological Factors**

“Harm may arise from...ecological factors when the music therapist fails to recognize or appropriately respond to client distress resulting from the contextual interactions that influence the client's experiences in session.” (Murakami, 2021, p. 9)

### ***Expanding the Concept***

The ecological factors fall into three categories: micro-, meso-, and macro-ecological factors. At the micro-ecological level, the focus is on the immediate concerns of a music therapy session, including issues around place and time. Here the music therapist has the best opportunity to respond to client-identified harms as they occur. At the meso-ecological level, the general concerns of client and therapist identity, culture, and family are in focus. The therapeutic relationship cannot be isolated from the complexities of identity that influence both client and therapist in different ways. At the macro-ecological level, paradigms influence the systems in which clients and therapists must work. The practice of music therapy and the experiences of clients are framed by these dominant narratives including prevailing assumptions of personhood and whose knowledge is valued (Yergeau, 2013; Kapp, 2019).

### ***Potential Harms Identified by Autistic Individuals***

Ableism arguably constitutes the greatest harm at the ecological level because it manifests in the fundamental relationships between client, therapist, and society. It is a political, personal, social and economic narrative that is easily taken for granted (Rolvjord, 2014). Functioning labels, pathologizing models of disability, normalization agendas, and humanism are rooted in the idea that there exists an able-bodied, able-minded, able-ideal person (Ansdell & Stige, 2018; McGuire, 2017; Shaw, 2022). These beliefs influence Western medicine, science, and society to a point where they are advanced as universal givens. Harm occurs when music therapists do not critically reflect on their practices at the individual, community, and societal levels (Nicolaidis et al., 2015). Harm is possible when music therapists work in silos, overlooking the complex lives of autistic individuals who live within complex systems of community and society. Even music is a complex artifact influenced by cultural history, personal circumstances, and current politics.

Ableism is a form of oppression and a generator of exploitation. It is enacted on autistic people through attempts at normalization and the application of functioning labels based on individual capacity to contribute to economic, social, and capital growth (McGuire, 2017). In their discussion of the Autism Industrial Complex, Broderick & Roscigno (2021) expose the circular logic of professionals defining autism in order to create autism interventions which then require product development for the intervening autism professionals. While the majority of music therapists are presumably not actively and knowingly exploiting autistic people, it is

essential that music therapists consider the ways they may benefit from the dominant narrative of ‘autism as deficit’ (McFerran, 2021; Pickard et al., 2020; Shaw, 2022). Pathologizing models of autism lead to problematic assumptions about autistic personhood, their capacity for self-determination, and the requirement of normalization.

### ***Opportunities for Reducing Harm***

It is essential that music therapists advocate for transformative societal change at the highest levels. Music therapy organizations must be accountable for their policies, practices, and critically consider their professional alignments (Cameron, 2014; Honisch, 2014). This means music therapists acknowledge the politically charged spaces in which they work (McFerran, 2021; Norris, 2020; Thomas & Norris, 2021) and take steps to celebrate the cultural expression of autistic individuals and communities (Bakan & Chasar, 2018; Kapp et al., 2019; Korošec et al., 2022; Straus, 2013, 2014). Addressing meso-ecological level harms requires openness and flexibility to respond to the complexities of individual experiences within systems of language, identity, culture, and community. As a practical example, music therapists should use terminology reflective of client preference when discussing clinical processes in supervision or presentations offering a rationale for their choice.

### **Conclusion**

Autistic perspectives on experiences of harm in intervention and support provided insight into the potential for harm in music therapy practice. Music therapy theories about harm clearly indicate that the client is the first source of information about their experiences of harm in therapy. As such, the Music Therapy and Harm Model (Murakami, 2021) was used to facilitate dialogue between the experiences of autistic people and the evolving discussions of harm in music therapy theory and practice. Each aspect of the MTHM represents a moment in the music therapy process; by engaging with lived autistic experiences, these moments and their interconnections can be more fully understood (Devlin, 2018). Indeed, the literature revealed that normalization, pathologizing paradigms, and ableism influence the therapeutic process at all levels. Prioritizing knowledge gained from lived experience, presuming competence, and embracing neurodiversity are important countermeasures for possible harms. Prevention of harm in music therapy with autistic individuals ultimately requires music therapists to examine the influence of ableism and pathologizing paradigms on their beliefs about personhood and knowledge creation.

## Chapter 5: Discussion

The experiences and perspectives of autistic individuals are essential sources of knowledge when considering the potential for harm in music therapy with autistic people. In the literature explicated in chapter three, articulated concerns about potential harms in autism intervention and support contexts stemmed from discourses around autism rooted in ableism and pathology. It is necessary to examine music therapy practice in light of these concerns and through the lens of neurodiversity. This philosophical inquiry aimed to reveal new possibilities for anti-ableist practice by drawing into dialogue the seemingly disparate fields of autistic experience and music therapy theory (Burbules & Warnick, 2006). The Music Therapy and Harm Model (MTHM; Murakami, 2021) provided a strong framework for facilitating dialogue between first-voice and allied literature about autism and music therapy theories about harm.

First, autism research is frequently based in the pathologizing paradigm, meaning the experiences of autistic individuals are overlooked and undervalued (Nicolaidis, 2015; Yergeau, 2013). This results in therapeutic strategies that prioritize normalization and compliance which can lead autistic individuals to masking, social camouflage and/or suicide (Mitchell et al., 2021; Raymaker, 2020). Additionally, the lack of autistic perspectives in research about autism may lead to missed opportunities for relationality, authenticity, and creativity in therapy spaces (Devlin, 2018; Williams, 2018; Woods & Waltz, 2019).

Second, music therapy scholars identify the client as the best source of information regarding experiences of harm in music therapy (Isenberg, 2011; Murakami, 2021; Silverman et al., 2020). As such, it is necessary for music therapists to center autistic individuals as experts by experience regarding the potential for harm in music therapy practice. For example, the affective quality of a sensory experience may fluctuate for an individual from one situation to another. So, the potential for harm can be difficult to anticipate. This challenge can be mitigated by giving autistic clients control over the frequency, intensity, or quality of the music experience.

Finally, the MTHM was used to center autistic experiences and perspectives on potential harm as reported in the literature. This revealed many potential harms as well as opportunities to reduce or prevent harm. The potential for harm in music therapy with autistic people results from the dominant narratives of ableism, pathology and normalization that influence Western society, medicine and therapy. By centering the experiences of autistic individuals, music therapists commit to understanding their own relationship with neurodiversity and disability.

In the course of writing this philosophical inquiry, I became increasingly aware of the dominant narratives that influenced my understanding of music therapy with autistic people. This struggle was particularly salient as I navigated centering autistic perspectives in this research and it ultimately meant refining my research question to make space for these perspectives (St. Pierre, 2018). This process is far from complete, as I continue to examine the ways in which I unintentionally participate in normalization and ableism.

### **Limitations**

The topic of harm in relation to autistic experience is nuanced, complex and evolving. Presenting these nuances in a linear fashion means other potential harms may have been barely touched upon or unintentionally overlooked. Though I took a particular neurodiversity-affirming stance and took steps to center the voices of autistic individuals, it was not an attempt to speak for autistic individuals or about a universal experience. Data were drawn from scholarly literature and commercially published books, which limited the breadth of experiences engaged for this inquiry. Many perspectives of autistic people do not enter academic spaces (Davies, 2022; Milton, 2014; Pickard et al., 2020). Most saliently, non-speaking autistic individuals, whose writing is infrequently included in academic journals, were under-represented here.

### **Implications**

#### ***Music Therapy Practice***

This research revealed that music therapy, at organizational and practitioner levels, could benefit from regular critique and reflexive analysis in order to better serve clients. It was also made evident that the separation of therapeutic spaces and political spaces may be more illusory than realized (Norris, 2020; Shaw, 2022). In order to reduce ableism in professional spaces, music therapists must confront how ableism influences their day-to-day practice with autistic clients and the world around them.

#### ***Music Therapy Education***

Students and educators alike could benefit from taking up the challenge of looking outside academic literature and engage with first-voice literature when learning about autism. It is essential to go beyond the biomedical definitions of autism and include the definitions of autism based on autistic experiences (Bakan, 2014; Straus, 2013).

### ***Social Justice and Music Therapy***

This research highlights how important it is for music therapists to recognize past harms that autistic people have experienced as the result of pathologizing paradigms and to identify how ableism continues to influence therapy practice today (Davies, 2022; McFerran, 2020; Pickard et al, 2021; Shaw, 2022). Additionally, music therapists have an important role to play in championing access to music and creative experiences for autistic clients outside therapeutic spaces (Cameron, 2014; Honisch, 2014) and promoting universal access to the arts (Bakan, 2014; Shiloh & Lagasse, 2015).

### **Recommendations for Future Research**

This research revealed the challenge of including and focusing on the experiences and contributions of non-speaking autistic individuals. There is a need for research projects and methodologies that include non-speaking autistic individuals. Participatory and emancipatory forms of collaborative research are also necessary. Music therapy researchers are well-positioned to engage in community-directed, arts-based research with autistic individuals and communities.

Music therapy, as a profession, benefits from critical perspective-taking and should embrace critical autism and critical disability scholarship. Along with anti-oppressive, anti-ableist, post-structural and post-humanist theories, these perspectives provide ideas of relationality, indeterminacy, and interdependence that are mirrored in therapeutic ideas of music as communication, as improvisation, and as performance.

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