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## Exploring the Lived Experience of Disabled Music Therapists: A Literature Review

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**Exploring the Lived Experience of Disabled Music Therapists: A Literature Review**

Capstone Thesis

Lesley University

May 5, 2022

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Music Therapy

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### **Abstract**

Music therapy and the mental health field are publicly praised fields dedicated to helping those who are in need of services. Music therapy in particular is especially praised for the work that is done with people with disabilities. Although this work is extensive and important, there is an underlying tone of ableism that runs through the profession. This ableism points to the clients served, but also the therapists who are disabled themselves. This literature review examines the history of disability studies, disability statistics, disability competencies, as well as the lived experience of three different disabled therapists. Far more research is required in this area of the field, however, there is enough research out there to instigate a need for change.

*Keywords:* disability, disability studies, music therapists, mental health, ableism

## Exploring the Lived Experience of Disabled Music Therapists: A Literature Review

### **Introduction**

Accounting for the population of the globe, approximately 15% of the population has some form of disability (The World Bank, 2021). In the U.S alone, 26% of the population is disabled (Center for Disease Control and Prevention [CDC], 2020). This means that in the U.S, one in four people have a disability of some kind (CDC, 2020). What does it mean to have a disability? The Americans with Disabilities Act (n.d.) defines disability as “someone who has a physical or mental impairment that substantially limits one or more major life activities, has a history...of such impairment, or is perceived by others as having such an impairment” (para 2). It is important to note that not all disabilities are visual to outsiders. Disabilities can come in the forms of learning disabilities, debilitating mental health struggles, or chronic illnesses. Approximately 10% of Americans are diagnosed with an invisible disability and 96% of people with invisible disabilities do not use any assistive devices such as walking aides or communication devices (Disabled World, 2015). This, unfortunately, leads to further marginalization for the population of those with invisible disabilities due to them being able-bodied passing thus not being taken seriously by employers, healthcare providers, and potentially family and friends as well.

The field of music therapy has been a perceived champion for people with disabilities since the start. Students training to be music therapists are often shown example sessions between a music therapist and disabled client, assigned book chapters and articles to read about music therapy with children and adults with disabilities, and learn how to hone the craft to help those who would benefit from gait training, or utilizing communication, or learning how to live effectively or overcome their mental illness. Unfortunately, for those students in training who are

disabled, the same kind of advocacy and passion simply is not there in the literature, and may not even be there among colleagues, professors, and fellow students. Music therapy at its core can be very ableist when discussing the role of the therapist. The competencies include a mastery of the voice, piano, and guitar. If the therapist has limited or no mobility in their arms or if they struggle with their speech, they may not meet competencies required, even though there is a host of other instruments out there that can be better utilized for that individual that still contribute to a meaningful therapeutic practice. This of course, comes from a place of wanting cohesion in the profession, but does not come without its downfalls.

The topic of disabled music therapists is a topic that has little exploration in the literature as well as in conversation in the field. Looking at the professional organizations in the region of New England, which are the New England Region of the American Music Therapy Association (NER-AMTA), and the New England Region of the American Music Therapy Association Students (NER-AMTAS), neither organization has a specific chair on the board, or a task force dedicated to advocating for people with disabilities. The NER-AMTA board holds a task force for diversity, equity, and inclusion, however, as listed in their duties, this chair is solely to promote anti-racism in the field, which is necessary and important. However, when holding a position of equity and inclusion that needs to include all communities that face oppression, including, but not limited to, the disabled community (New England Regional American Music Therapy Association, n.d.). Additionally, the NER-AMTAS do not have a chair member responsible for diversity, equity, and inclusion for students in the region (New England Regional American Music Therapy Association Students, n.d.). On a national level, the American Music Therapy Association (AMTA) also does not have a chair member responsible for diversity, equity, and inclusion to advocate for music therapists across the country.

This thesis focuses on exploring the world of music therapy and mental health counseling from a disabled person's perspective and critiquing the internalized ableism that exists in not only music therapy but throughout the expressive arts therapies and other mental health professions.

I will be exploring different models of disability studies and the role music therapy takes within each of these models. The most prominent and widely used model of disability studies, and a model that will be explored, is the biomedical model, which is referred to in this paper as the medical model (Disabled World, 2010). Other models that will be explored include the social model, and the human rights model. These models will be explored through the lenses of their definitions in health care as well as their definitions as they relate to the disabled population.

Through this process, I hope to explore in depth other experiences of disabled therapists to expand my view on the world beyond my biased opinions. I hope to learn more completely the different models of disability studies and how they influence the work being done in the field of music therapy and mental health counseling. Within the exploration of disability studies and experiences of those in the field of music therapy, I will also make recommendations on further research in the field and how the field of music therapy and mental health can call to action further change to allow therapists with disabilities to be able to succeed fully within their professions without inherit bias from employers and professional associations.

This research is important, not only to the field of music therapy and the larger mental health profession, but also to myself. I live with Ehler's Danlos Syndrome (EDS), Functional Neurologic Disorder (FND), Postural Orthostatic Tachycardia Syndrome (POTS), and endometriosis, all disorders that affect my mobility, my cognitive functioning, and cause chronic widespread pain. As a graduate student in the experience of a disabled body, I have found it

challenging to navigate through my education as well as my health journey. This experience made me curious about what living with a disability looks like after graduation. As a student in internships, there is a safety net. I have been fortunate enough in both of my internships to have supportive supervisors who understand what I live with. This, however, is not always going to be my experience. Interns and professionals have different roles. Post internships, more responsibility is placed on the employee and unfortunately not all employers are as accommodating as my experience has been. I wanted to hear from the disabled music therapist community and listen to and reflect on their stories. I also wanted to dive into disability studies to find out how we got to where we are today and how far we need to go when it comes to disability rights. This literature review is not a comprehensive history of disability rights as a whole but rather a history of disability rights as it relates to my research topic. All of the research done is through the lens of language used in Western society and job accommodations.

### **Literature Review**

In order to dive into the lived experiences of people with disabilities, the history and contents of disability studies first needs to be explored. Disability studies is a field that emerged to advocate for the societal needs of people who have physical or intellectual disabilities, who are neurodiverse, and people who have invisible disabilities or chronic illnesses (Goodley, 2013). Understanding disability studies and the different methodologies within disability studies provides a framework for understanding the viewpoint of people with disabilities and how they interact with and react to able-bodied society. Understanding these viewpoints further helps amplify the voices of those who have lived experiences of being therapists who are disabled.

This literature review is intended to provide a comprehensive background on the history of disability studies and define and critique different methodologies within disability studies. The

literature review is also intended to discuss and critique the role of disability in music therapy, as well as look into the lives of three disabled therapists.

### **A History of Disability Studies**

Disability studies is a relatively new area of research. The earliest record of an organization dedicated to disability studies is 1982 with the Society for Disability Studies (Ferguson & Nusbaum, 2012). Disability studies originally “reflected the efforts of scholars with disabilities (and some non-disabled colleagues) to conceptualize and interpret the common complaints of people with disabilities and their families” (Ferguson & Nusbaum, 2012, p. 71). In the 1990s, disability studies grew as conferences emerged, journal articles and special editions were published, and groups and professional organizations were formed (Garland-Thompson, 2013). In the 1990s, the Americans with Disabilities Act (ADA) was passed by congress, opening up a whole new world of possibilities for people with disabilities specifically surrounding public accessibility, employment, and education.

At its core, disability studies emphasize disability as a fundamental part of the human experience. It grounds itself in the political, economic, and social parts of society for disabled and able-bodied people (Ferguson & Nusbaum, 2012). Disability studies has many nuances in it as well that assist in the overarching definition of disability studies. Ferguson & Nusbaum (2012) defined five key concepts of disability studies. First, disability studies must be social, meaning that any research done on disability studies must be done in the social model rather than the widely used medical model. Second, disability studies need to be foundational, meaning that disability is a foundation for understanding the whole of the human experience, not just one aspect of it. Third, disability studies need to be interdisciplinary, meaning that it must not be looked at through only one lens. Fourth, disability studies must be a participatory field, meaning



that the community of people with disabilities and their families must be involved in the progression of the field. Fifth, disability studies must be values-based, meaning “reporting social validity within traditionally quantitative and behavioral research” (Ferguson & Nusbaum, 2012, p. 74). These five frameworks help not only researchers, but the disabled community have valuable research out there promoting progression in the field as well as societal understanding of disability.

Disability studies are made up of a number of different models and different models are emphasized more or less depending on organization or country. With respect for the wide variety of different methodologies of disability studies, the three main methodologies that will be explored in-depth are the medical model, social model, and human rights model.

## **Models of Disability Studies**

### ***The Medical Model***

The medical model is the most widely used version of disability studies in Western society (Disabled World, 2010). This model focuses on a person’s impairment being able to be diagnosed, and cured or rehabilitated, by modern medicine and/or technology, and that these treatments will be provided by “all-knowing professionals” (Jackson, 2018, p. 3). This model is beneficial when it comes to understanding biology and/or anatomy of medical diagnoses, chronic illnesses, mental illnesses, brain injury, neurodiversity, among other diagnoses. However, the benefits of this model do not necessarily go beyond the benefits of understanding a diagnosis.

The medical model views disabilities as problems that need to be dealt with and cured. It takes the person out of the context of the whole and focuses on what is, medically speaking, wrong with them, rather than their strengths, abilities, and ways to improve quality of life in a way that embraces the person for who they are. Take for example, perhaps the most widely used

behavioral health intervention used to correct behaviors of those with Autistic Spectrum Disorder (ASD), Applied Behavioral Analysis (ABA). This approach is heavily rooted in the medical model of disability and is built upon the notion of achieving normality (Shyman, 2016). Shyman (2016) argued that ABA focuses on “maintaining an outcome goal of attaining normality or some approximation of it, in intellectual, social, and/or behavioral functioning, is the main treatment goal, as such model treats conditions such as ASD as a medical problem that interferes with ‘normal’ functioning” (p. 367). The medical model emphasizes the focus of ABA therapy and minimizes the experience of neurodiverse people (Shyman, 2016). This does not undercut the successes that people have experienced with this model. However, if there is an expectation of viewing disabled and neurodiverse people more positively, these practices that unnecessarily medicalize necessary treatment are harmful.

As a society, we are taught to view and judge those with disabilities based on how they present to the world. Shyman (2016) criticized the model in relation to neurodiverse individuals by saying:

At its core, the medical model of disability is centered on the dichotomous categories of ‘disabled’ and ‘non-disabled’ in order to frame acceptable levels of intellectual, behavioral, and social functioning, as well as determines which individuals should be required to receive ‘treatment’ in order to ameliorate the consequences of their disability. (p. 368)

The adoption of the medical model in Western society teaches that certain people are less fortunate than others and that those who cannot be fixed be pitied. If someone is too disabled, they are labeled a lost cause, and if someone is not disabled enough, they are faking their

condition which on either side of the coin does not constitute equity within the disabled community.

### ***The Social Model***

The social model of disability is rooted in the notion that people with disabilities experience social oppression and that social practices need to be put into place to allow people with disabilities full societal integration (Gross, 2018). This model emerged in the 1980s but was not widely adopted until the 1990s. Although this adoption may seem relatively late, it may stem from the reasoning that “practically no one consciously professes to be against disabled people” (Gross, 2018, p. 2). The social model strays away from the medical models’ notion of disability being something that needs to be fixed towards the societal shift into empowering disabilities and to push for society to adapt to the disabled community, not for the disabled community to adapt for an inaccessible society.

The social model, however, does not come without its downfalls and criticisms from the field of disability studies. The concept of the social model fails to see that even without social barriers, disabled people are still disabled, so even with full social integration and societal acceptance, barriers will still exist (Thomas, 2008). Thomas also suggests that the social model has been adopted for political gain rather than for social acceptance. This framework of disability studies also reduces disabled bodies into only socially oppressed, and disregards other barriers that may arise since a world that is barrier free is not completely possible. That being said, the social model opens up more possibilities for disabled people than the medical model can. The social model focuses on the disabled person in the context of society and functioning within society whereas the medical model suggests that disability is a fundamental flaw in the human existence that needs to be cured.

### *The Human Rights Model*

The human rights model of disability studies is, in a sense, the underdog of disability studies. This model emphasizes social model concepts such as people with disabilities being integrated fully in social settings. The difference is this model adds a layer of advocating for people with disabilities having rights and that they should be able to have a say in their lives in the same way able-bodied people experience (Lawson & Beckett, 2021). This model was first brought into discussion at the United Nations Convention on the Rights of Persons with Disabilities (CRPD) which occurred in 2006 (Lawson & Beckett, 2021). The idea behind the human rights model was not to replace the social model, but rather to merge with and improve upon it with the hopes of straying away from the medical model (Lawson & Beckett, 2021). Much of the human rights approach is the social model approach with the social model to create a more rounded view of disability and to hopefully allow people who are in the disability community a voice as well as social acceptance.

Just like all models, however, there are criticisms of the human rights model of disability studies. The largest criticism, outlined by Jackson (2018), discussed how although laws can be put into place to allow the disabled community autonomy within the systems of government, local, national, and global, these laws face the risk of not being enforced and misinterpretation among these laws. There can also be a risk of segregation of the disabled community by creating access in built environment, but that these access points only allow the disabled community to engage within itself. However, as seen in Western society having access in built environments as stated by the ADA, this may never be an issue in the Western world but could become an issue in other societies where something similar to ADA is already put into place, especially in third world countries where resources are not always available to have that level of accessibility.

## **Disability Studies Within Music Therapy**

Music therapy encompasses a host of methodologies that have a heavy influence within disability studies and working with developmentally disabled children and adults. One of the most well-known methods that has this focus is Nordoff Robbins Music Therapy. Nordoff Robbins is an approach that focuses on improvisation and recently has adopted "psycho-socio-cultural epistemologies" (Tsirir, Spiro & Pavlicevic, 2018, p. 6-7). Along with Nordoff-Robbins, other methods that greatly support the disabled community include resource-oriented music therapy and community music therapy. Resource oriented music therapy is a method of music therapy that emphasizes each individual's resources within themselves for a maximization of self-worth, advocacy, and independence. Community music therapy focuses on social inclusion, equitable resources, and collaboration to nurture the social and emotional health of members in the community served (Pickard, Thompson, et. al., 2020). These approaches, among many others, emphasize the disabled population as a whole and allow the clients that come into music therapy find their voice and independence that they may not have been able to access otherwise.

While the intentions of music therapy and most music therapists are good and genuine, it is important to remember that this field was birthed by a society that widely accepted the medical model of thinking. Music therapy has been historically progressive, for example, Nordoff-Robbins music therapy first began in 1958, a time where disabled people were still largely being institutionalized. This external view of progressiveness, however, does not excuse the ableism and bias that has been passed down from generation to generation and is inherently taught to us at a young age in Western society. Pickard (2020) argued that even though music therapy is looked at as a progressive profession, that there are deep rooted aspects of medicalization and the idea that disability needs to be changed. This deep-rooted ideology of medicalization of

disability really stems back to the fact that nobody is inherently taught to feel sorry for disabled people. We learn how to navigate the world through the actions of those we look up to. When caregivers comment on a disabled person's inabilities, or when media hyper fixates on a person's disability, the young mind learns that those comments and interactions are okay. This ableism may not be born out of ill-intention, but it is still ableism, nonetheless.

This ableism and surface level viewpoint of not only disabled people, but clients as a whole, still stands in the code of ethics for the American Music Therapy Association (AMTA). The AMTA code of ethics (2019) is an extremely vague document that primarily emphasizes empathy and compassion for clients. Although these principles are vital to the work, there is a lot of grey area in the code of ethics as none of the sub-principles go into detail about what exactly these principles entail. Additionally, the code of ethics stated that "this Code of Ethics describes the highest ideals for music therapists as an aspirational guide to professional conduct. It is equally intended to educate and guide music therapists in ethical practice, as well as inform those outside of the profession" (AMTA, 2019, para 4). If the intention behind the code of ethics is to provide a comprehensive education to those both in and outside of the music therapy profession, the code of ethics needs to be far more comprehensive and specific than it is currently written. The ambiguity in the code only makes ambiguity in the way that music therapists conduct their work okay and that method of practice is not set up to completely serve clients the way they deserve to be served. Cameron (2014) criticized music therapy's relationship to disability studies:

The things that music therapy aspires to in order to be recognized as a serious clinical profession are the very things that make it from a disability studies perspective a questionable enterprise. It is not that I believe music therapists are not good or well-

intentioned people but that, in supporting a medicalizing, individualizing, normalizing ideology, I believe they are complicit in the oppression of the very people they intend to help. (p. 11)

It is important to note that this quote is criticizing music therapy from the perspective of music therapy in the United Kingdom, however, it is relevant to the AMTA as well. Medicalizing language needs to be eliminated from vocabulary, not just in music therapy, but in everyday vocabulary where it is unnecessary. Treating people with disabilities as a nuisance to society that needs to be corrected is only harming the community.

Additionally, Straus (2011, as cited in Pickard 2020) challenged the practice of music therapy by stating “music therapy is a normalizing enterprise, bound up with the medicalization and attempted remediation of disability” (p. 84). If this is the underlying intention behind music therapy when working with clients, it is impossible for the field of music therapy to adequately advocate for the disabled music therapists in the field. This practice of normalization is not isolated to music therapy. Garland-Thompson (2013) criticized the larger field of health sciences and the underlying ableism by viewing disability as a problem that needs a solution. With these criticisms in mind, Gross (2018) reminded us that “disability critique is not a true/false binary” (p. 4). The lived experience of disability is incredibly individual and there is grey area in disability studies, laws, and social norms. However, the way that disabled people are able to live their lives, interact with society, and work within society in meaningful ways should not be a grey area. Disability does not make it okay to strip rights away from a person or create situations in which the disabled person cannot have the same access as able-bodied people.

In order to undo this internalized ableism in the profession, music therapists, expressive therapists, mental health counselors, social workers, and any other human services worker needs

to shift their views on what it means to be disabled and live with a disability. Hadley (2014) speaks to this need in a shift by critiquing the way music therapy students are educated. In music therapy programs, there is an emphasis on methodologies such as community music therapy, anti-oppressive practices, and feminist studies, “there are so many ways in which our required coursework reinscribes ableist principles and norms” (para 9). There is a shift in the way that the profession and how its taught is moving towards, however, the underpinnings of ableism in music therapy education need to be recognized and corrected in order for the real change to occur.

Currently, the philosophical view of disability in music therapy involves analyzing the diagnosis, assessing what the person can and cannot do, and focusing on what they cannot do in order to correct those areas of functioning. There is a time and a place for pieces of this ideology, such as working with a stroke patient on gait training and speech. However, there needs to be the added framework and question of “what if music can be used not to overcome, not yet to accommodate something wrong, but rather to reveal what simply ‘is,’ an ‘equality of condition’ that demands acceptance on its own terms” (Honisch, 2014, para 5). What if, as a field, there is a shift from fixing to enhancing and building off of people’s strengths to become the best version of themselves. The child who is neurodiverse and cannot sustain their attention long enough to be in a classroom, maybe needs different ways of engaging that take into consideration their need for breaks. The adult with intellectual and physical disabilities that uses a communication device with eye gaze and occasionally vocalizes can still engage in singing by utilizing their communication device and their vocalizations. The clients do not need to adapt to the music, the music needs to adapt to the client.



## **Disability Competence Among Mental Health Professionals**

Looking at the competency of disability among mental health professionals, one qualitative study was conducted which aimed to analyze the extent of competence that mental health professionals have when it comes to people with disabilities (Strike, Skovholt & Hummel, 2004). Seventy-five women and thirty-three men participated in this study with 89% being Caucasian, and 12% being Persons of Color. Of the participants selected, 94% had already completed their doctoral or master's degrees while 61% of participants were currently enrolled in a graduate program. All participants had personal experiences with people with disabilities of varying kinds, although some participants had more exposure to people with disabilities than others.

This study used the Counseling Clients with Disabilities Survey (CCDS) which was developed in 2001 due to no other measures of disability competence for mental health professionals available (Strike, Skovholt & Hummel, 2004). This survey looked at each individual's understanding of what it is like to be disabled or able-bodied, factual knowledge about disability, and behaviors that people with disabilities find desirable when working with mental health professionals. This survey was designed to highlight different types of disabilities, universal experiences, and differences among individuals. Each section of this survey contained 20 questions which participants answer agreement or disagreement on a 6-point scale, 1 being strongly agree, and 6 being strongly disagree. A measure of social desirability was also included in this study which was a self-report of social desirability and disability status.

Study results found four key themes in the results. The first theme was that mental health professionals who have experienced more exposure to people with disabilities had higher disability competencies compared to those who did not have as much experience with people

with disabilities. The second theme was the group that has had more experience with people with disabilities had higher competencies with self-awareness, their knowledge of the community, and their skills for working with the community. The third theme was the group who had the least amount of experience with the disabled community reported gaps in their self-awareness and perceived skills as well as their perceived knowledge and self-awareness. The fourth theme in the findings was that these scores were likely not a result of social desirability and that no matter the experience of the mental health professionals with the disabled community, the social desirability was not affected in these scores (Strike, Skovholt & Hummel, 2004). Additional findings demonstrated that self-awareness was the highest self-reported competency in the study and perceived skills was the lowest reported competency which was consistent with findings from prior research.

This study was conducted primarily to identify gaps in knowledge and create a link between multicultural counseling and disability studies. The authors recommend that graduate programs implement multicultural education as well as disability studies into the core curriculum. Since this study was conducted in 2004, there have been major shifts in the curriculum of higher education programs, not just graduate programs. An example of this is Lesley University including not only a class for graduate expressive therapy students for multicultural education and exploring power, privilege, and oppression in society, but also multicultural practices included in classes beyond that. Although these implementations are not perfect, it is still a shift in the right direction. And as far as education has come, education has a long way to go as far as including disability studies in core curriculum classes. The authors of this study also emphasized that students and professionals increase their exposure to the disabled

community to increase their knowledge and competence of the community and how to better support the community.

### **The Lived Experience of Therapists with Disabilities**

Through the discussion on models of disability studies, music therapy and the disabled community as clients, and competencies of mental health professionals in regard to the disabled community, the most important voice to hear is the voice of disabled therapists themselves. It is difficult to know exactly how many people in the mental health field have disabilities. Collier (2015) discussed the difficulty surrounding finding accurate statistics on professionals in the mental health field who are disabled themselves. Collier (2015) stated that “not only is there no consistent definition of ‘disability,’ but there is no reliable or comprehensive measure to track the number of psychologists who might meet that definition” (para 2). Despite not having a clear idea of how many people in the field have disabilities, there is a small handful of articles written by therapists with disabilities themselves. These articles discuss the barriers to being disabled in this field as well as the benefits that disabled therapists can experience.

Mohesky (2020), who is diagnosed with cerebral palsy, talks about her experiences as a disabled student and the challenges along with the benefits of being a disabled counselor. Mohesky (2020) discusses our society having two views on the disabled community: the view that the disabled community is an inspiration and that they are hero’s for overcoming what life has given them, and the view that the disabled population is completely disposable and is a waste. In turn, the disabled population also faces high rates of mental distress and mental illness. The CDC (2020) estimates that 32.9% of adults with disabilities experience mental illness of some kind. In combination of the feeling of being disposable along with the high rates of mental illness among the disabled population, people with disabilities unfortunately can develop a belief

that nobody wants to help. Although there is an uptick in multiculturalism, authenticity, and unconditional positive regard being taught in higher education programs, that does not undo years of internalized ableism that is present in the field.

A potential client who is disabled may not feel comfortable with an able-bodied therapist because of the prejudices held against the community, even if the therapist does not hold those beliefs. Mohesky (2020) argued that “even though I cannot speak, there are many people in the disability community that may benefit from my services because they know I can relate to them, in some way” (Mohesky, 2020, para 5). She continued on “even though I will not be able to completely relate to every client since everyone is different, I foresee a lot of commonalities between clients and me, which can potentially bridge the gap between mental health services for people with disabilities” (para 6). There is a great need for disabled therapists, teachers, and professionals everywhere. Humans learn from modeling and seeing others who share a likeness with us be in the field that we want to be in or want to receive services from. Rhapp and Arndt (2012) discussed modeling in an education setting and how showing students’ behaviors that are appropriate responses to situations results in students later having a similar response in a similar situation. This theory translates beyond an educational setting and into everyday life. When a disabled person who wants to be a therapist receives services from, gets supervised by, or gets taught by a disabled person, it has the capability to reinforce in that person’s mind that there are people on their side and that they can comfortably be in those jobs or receive those services.

Beck (2020) discussed her experiences while in graduate school for art therapy and working with disabled populations as a disabled therapist herself. She explored her identity as a disabled person growing up and struggling with her identity as well as trying to find therapists, but no therapist she could find was disabled and could not relate to her experience. She shared

experiencing able-splaining, a term in which people who are non-disabled “speak for and to disabled people based on living assumptions about the lived experiences of disabled people” (Beck, 2020, p. 62). These experiences in therapy and exploration of her identity through both the medical and social models of disability led her into the field of art-therapy where she interned in graduate school at two organizations who work with disabled people. Through her work as an art therapy intern, she was able to make a significant impact in the disabled community in Chicago. She also emphasized:

It cannot be assumed that just because I work with a disabled client, we both have the same story to tell. The stories and meanings of disability vary among different identity groups; therefore, it’s important to refrain from overgeneralizing the experiences of disabled people. (p. 68)

This is similar to what Molesky (2020) discussed, that although it is important for disabled people to be in the profession of counseling and art therapies, that does not give disabled professionals the right to assume the experiences of their disabled clients and able-splain in sessions. Disabled clients have the right and autonomy to discuss their lived experiences and it is the therapist’s job to use self-disclosure as appropriate.

Kalenderidis (2020) explored her identity as a person with a disability in conjunction to her studies and practice in music therapy using arts-based research in the form of music composition. This was in response to interviews conducted with other registered music therapists who are members of the Australian Music Therapy Association. Kalenderidis (2020) noted that “at the time of commencing this research, there was no known available literature exploring the professional experience of disabled music therapists” (Kalenderidis, 2020, p. 5), and even two years after this article has been published, there continues to be a dearth of research on this topic.

Kalenderidis (2020) concluded that there was an overwhelming theme in the disabled community of “not feeling ‘disabled enough’” or “feeling ‘too disabled’” (p. 8). There was also an overwhelming theme of stigma of self-disclosure which greatly impacted future decisions of disclosure even if the disclosure was needed, as well as the fear of only being seen as disabled in professional settings. Kalenderidis (2020) also questioned the teachings in the music therapy profession of having to always be there for clients, but also needing to take care of herself and her disability. She elaborated by saying “if I am experiencing a flare of my chronic condition and share with the music therapy participants that I need to sit down in a music therapy session, is this impairing my effectiveness, or am I simply being human?” (Kalenderidis, 2020, p. 12). This question emphasizes the polarizing feeling of self-disclosure and needing to be authentic with clients.

Although these are experiences between three different modalities of therapy, there are similar themes that come up in each of these articles. The most prominent theme is that there is a need for disabled therapists out there. The presence of disabled therapists can validate disabled clients and establish stronger trust from the disabled community because of the common ground shared. Another overwhelming theme is the adoption of the social model of disability over the medical model. It is clear that the social model, although not perfect, embraces the lived experiences of the disabled community far more than the medical model does, and advocates for social change. Although the social model has gained momentum over the last few decades, society as a whole has a long way to go in terms of breaking free from the medical model and allowing the medical model a time and a place to exist.

Within the community, there is also a theme of frustration from the lack of disabled voices being heard in research, specifically peer-reviewed research; whether it is from

gatekeeping by journals or not wanting to speak up from a fear of being judged based on disability or lack of visible disability. This is a fundamental flaw in the research community and just like the birth of disability studies creating an uptick in journal articles and special editions, disabled therapists need to have the space to have their voices heard in these journals. It is unknown why there is such a small number of studies out there based around the lived experiences of disabled therapists along with research on able-bodied therapists' competence with the disabled community, but research cannot grow until opportunities arise for it to be allowed to grow.

### **Discussion**

This literature review has been a tool for highlighting how society views disability, as well as the fundamental gaps in the way our society functions when discussing marginalized communities. Disability studies has come a long way, and still has a long way to go. While laws like the Americans with Disabilities Act in place and the United Nation Convention on the Rights of Persons with Disabilities taking place, the practice of these important historical shifts for the disabled community have not been implemented completely or seamlessly. We see this gap in knowledge clearly in Strike et al. (2004) with their qualitative study and how the mental health professionals who have had exposure to people with disabilities demonstrate more competencies surrounding the community than those professionals who have not. This study shows that exposure is integral to narrowing the gap of knowledge between able-bodied individuals and the disabled community.

In the literature, there are several articles have discussed people with disabilities hiding or downplaying their disabilities in order to not be discriminated against in their jobs. Willison

(2019) discussed the burnout and failed systems that are set up for people with disabilities that ultimately fail them. She stated:

There is no shame in having a disability. What is shameful is that people with disabilities are constantly questioned and doubted, forced into poverty and must jump through endless hoops just to survive...America supposedly rewards able-bodied people who work hard; it unquestionably punishes disabled people who do the same. (Willison, 2019, para. 19-20)

Kalenderidis (2020) discussed this stigma in great length regarding “feeling ‘too disabled’” and “not feeling ‘disabled enough’” (p.8) as well as the confusing and isolating pressures felt in the music therapy profession to always show up for clients and help clients advocate for what they need, and not being allowed to take breaks or sometimes use self-disclosure when needed. This is a fundamental flaw in the system of music therapy and mental health professions and is discussed in the bulk of the literature. If music therapy truly wishes to advocate for the clients as well as the music therapists, music therapists should be allowed to take care of themselves without the fear of stigmatization from their supervisors or even losing their jobs.

Music therapy and mental health professions also need to shift their language beyond medical model language and adapt social model language as well. This is not a linear shift as medical model language does have its place, such as in intakes and assessments trying to see if a client is a candidate for services and how the therapist can address their needs. However, once those assessments are done, the medicalizing language needs to be shifted into a social model language. Clinicians need to highlight client strengths and needs and focus on areas where the client can grow, not areas that need to be fixed. If language shifts in the way therapists speak of



their clients, that language may bleed into how supervisors and employers speak to their employees.

In order for these changes to really be solidified in the profession, the AMTA code of ethics needs to be updated with stronger principles and less ambiguity in the principles. Less ambiguity leads to more accountability in music therapy which in turn serves our clients and music therapists in a fair way. The way the code of ethics is written as of now, offers loopholes that music therapists can use in order to practice in a way that they believe is ethical rather than following a code of ethics that is explicit in its definition of ethical practice.

The critiques of the field do not mean that the field of music therapy or mental health are always doing harmful work. In fact, as reviewed in the literature, the fields of music therapy and mental health have done and continue to do good for the people served and the critiques do not fall on individual music therapists or mental health professionals. These critiques fall on the larger systems put in place that are set up to fail the people they claim to help. The Americans with Disabilities Act is a perfect example of this as discussed in the literature, that the advocacy for people with disabilities primarily comes from people with disabilities (Markham, 2021). This is the system failing the disabled community and unfortunately those larger systems that say it's okay to marginalize and discriminate only make it okay for smaller systems, such as the AMTA or the American Psychological Association, or individual workplaces to marginalize and discriminate.

For further research, workplace satisfaction in music therapists with disabilities could be an important topic of research. This could show the field of music therapy how disabled music therapists navigate their jobs through the internalized ableism that is rooted in our society as well as how to better advocate for music therapists as a whole and their wellbeing. This research

would also amplify the voices of the disabled community which are voices that truly need to be heard in this conversation. General experiences of disabled music therapists as well as other mental health professionals would also be extremely beneficial in allowing these fields to shift to become more inclusive and grant a space for people with disabilities to feel safe to work in. As Molesky (2020) mentioned, the need for disabled music therapists is great because it allows disabled clients to have spaces where they may feel more comfortable talking about and expressing their experiences. The field of therapy, music therapy or otherwise, advocates for safe spaces for clients to come and process, and a part of those spaces is having therapists from similar backgrounds in them to allow for that full safety of the clients.

The history of the way we view disabilities has come a long way, but still has a long way to go. Despite the great strides in disability studies over the past 40 years, there is still a lot that is lacking in literature, laws, government implementation, and in education. These gaps can lead to disabled voices being silenced which then slows down the progression on necessary change. As of today, 26% of the United States population is disabled with 10% having invisible disabilities (CDC, 2020; Disabled World, 2015). That is a significant amount of the population that is disabled, yet there is still a huge stigma surrounding this population.

Music therapy has spent the majority of its time as an accredited practice advocating and providing services for individuals with disabilities. There is a plethora of literature surrounding music therapy for people with disabilities showing the positive implications of this work on the population. While the clients with disabilities are being heard in most literature, the disabled music therapists' voices are not being heard in the same capacity. Music therapy needs to provide working environments that feel safe for those with disabilities that also allow people with disabilities to thrive. Music therapy also needs to reevaluate its code of ethics so that it is

clear to professionals, clients, and those looking from the outside, that this is a field that respects all involved and puts in the work to maintain that respect.

Large scale shifts such as changing laws, changing a code of ethics, or dismantling years of internalized ableism is not an overnight fix. These changes take time and work put in from everybody, not just the disabled community. Change can also be small, such as evaluating one's language used in conversations and changing words or phrases that are medicalizing or harmful to words or phrases that are respectful to the disabled community. As seen in Strike, Skovholt & Hummel (2004), exposure is the key for competency. Exposure comes from reading, watching videos by people with disabilities, or asking questions.

The experience of the disabled music therapist, although scarce in peer reviewed literature, is not the experience of a small group of people. There is a large community dedicated to disabled music therapists around the globe in which peer support and professional advancement is advocated for. It is time for professional organizations like the AMTA to listen to marginalized communities and act on policies to create change for the benefits of the clients and the therapists.

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**THESIS APPROVAL FORM**

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In the judgment of the following signatory this thesis meets the academic standards that have been established for the above degree.

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