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THE EXPLORATION OF CLINICAL WISDOM OF MUSIC THERAPISTS WORKING WITH ADULTS WITH SEVERE AND PROFOUND INTELLECTUAL DISABILITY: A MULTIPLE CASE STUDY

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THE EXPLORATION OF CLINICAL WISDOM OF MUSIC THERAPISTS WORKING WITH ADULTS WITH SEVERE AND PROFOUND INTELLECTUAL DISABILITY: A MULTIPLE CASE STUDY

THESIS

A thesis submitted in partial fulfillment of the

requirements for the degree of Master of Music in the College of Fine Arts

at the University of Kentucky

By

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Lexington, Kentucky

Director: Dr. Elaine E. Reschke-Hernandez, Assistant Professor of Music Therapy

Lexington, Kentucky

2022

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ABSTRACT OF THESIS

THE EXPLORATION OF CLINICAL WISDOM OF MUSIC THERAPISTS WORKING WITH ADULTS WITH SEVERE AND PROFOUND INTELLECTUAL DISABILITY: A MULTIPLE CASE STUDY

Research on the severe and profound intellectually disabled adult population is sparse due to several factors including difficulty in acquiring consent for research, lack of funding, and difficulty in interpreting behavioral responses. Music therapists providing services to this population are faced with sparse resources to guide evidence-based practice with severe and profound intellectually disabled (ID) adults. It is vital to document how seasoned professionals work with this population effectively to improve the evidence base for music therapists. This project used a multiple case study approach. Four music therapists provided an in-depth exploration of their clinical wisdom from years of working with the severe and profound ID adult population. Interview information was analyzed and coded to provide a depth of information to inform music therapy clinical practice. The emerging themes delivered a wealth of information including practice techniques, instrument and music choice and adaptation, suggested goals and objectives, and how to observe and interpret behavioral communication. This study assists in advancing the available resources on work with this population as it pertains to the clinical wisdom of experienced practitioners.

KEYWORDS: Severe profound intellectual disability, adults, music therapy, evidence-based practice, qualitative

Courtney Elise Catron

[03/28/2023]

Date

THE EXPLORATION OF CLINICAL WISDOM OF MUSIC THERAPISTS WORKING WITH ADULTS WITH SEVERE AND PROFOUND INTELLECTUAL DISABILITY: A MULTIPLE CASE STUDY

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[03/28/2023]

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DEDICATION

To my clients, who have taught me the value and significance of things too often overlooked.

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CHAPTER 1. INTRODUCTION

Music therapy is an evidence-based practice in which a credentialed professional uses music to address non-musical goals inside a therapeutic relationship (American Music Therapy Association [AMTA], 2023). In evidence-based practice the music therapist relies on three main sources for practice or "pillars": current research, the unique needs and input of the client, and the music therapist's own clinical wisdom (Pearson, 2011). New music therapists who work with severe and profound intellectually disabled adults lack information from all three pillars to build evidence-based practice due to the unique challenges of working with this population.

Intellectual disability (ID) is characterized as a below average IQ which originates before 18 years of age. Key components of ID include limitations in intellectual functioning and adaptive behavior. Intellectual functioning, sometimes referred to as intelligence, encompasses learning, problem solving, and reasoning. An IQ test of around 70 or lower may be categorized as a limitation to intellectual functioning (American Psychiatric Association, 2013). Adaptive behavior involves activities of daily living such as social skills, personal care, safety, and so on. Various evaluations that include community support, environment, and peers are used to identify and determine severity of ID (American Association of Intellectual Disabilities, 2020). ID may be categorized as mild, moderate, severe, or profound. The current study focuses on persons with severe and profound ID.

Existing studies with this population tend to focus on school-aged participants, due to the availability of services and resources provided for this age group. Furthermore, research with adults with ID includes more inherent difficulties as compared with adults

with normal intelligence (Walton & Ingersal, 2012). These difficulties include gaining assent from individuals with limited communication and consent from legal guardians (who may not even know the individual with ID). Research is particularly limited regarding adults with severe and profound ID. The lack of research demonstrates the exclusion and discrimination against this population. Participants with severe and profound ID are often left out of studies, as researchers may assume persons with less severe forms of ID will provide better communication and make more meaningful contributions to the study (Mietola et. al, 2017).

According to the American Music Therapy Association, 2.6% of the member music therapist workforce serve the ID population (AMTA, 2021). Although a substantial percentage of music therapists provides services to this population, research remains sparse. As with more general research involving individuals with ID, existing music therapy studies with this population tend to focus on school-aged participants. Research is particularly limited regarding severe and profound adults, both within and outside of music therapy, likely leading music therapists who work with this population to lean largely on their own clinical wisdom. Given that music therapists currently work with adults with ID, yet there is very limited research within and outside of music therapy with this population, an important starting place is to explore the clinical wisdom of those with in-depth experience.

In my clinical experience, the more severe the disability, the more challenging it can be to design and implement music therapy interventions and evaluate their effectiveness. Musical preferences are challenging to assess when communication is limited. It is difficult to determine age-appropriate goals and objectives for adult clients

with more severe disability. Additionally, developing the therapeutic relationship (e.g., trust, shared decision making, agreement on the therapeutic work, etc.) can be more challenging when communication is limited. As previously mentioned, music therapists practicing with this population who are facing such challenges are also at a loss regarding resources to inform best practices (Lee, 2014). Furthermore, information regarding how to effectively approach treatment and the therapeutic relationship with these clients has largely remained absent from the literature. Given that such clinical wisdom is an important component of evidence-based practice, a qualitative exploration of the clinical wisdom of music therapists could help fill an important gap in the literature.

Rationale

As previously described, research and resources about working with adults with severe and profound ID is scarce. Music therapists working with this population appear to rely mostly on their own clinical wisdom. Music therapists who are just beginning work with this population have very little clinical wisdom to drawn on, coupled with the unique challenges this specific population brings to forming the therapeutic relationship. A qualitative study that explores the clinical wisdom developed by music therapists who have substantial experience working with this population would offer an important resource to help to fill out the evidence base. Therefore, the purpose of this qualitative multiple case study was to explore the clinical wisdom of four experienced music therapists who have worked with adults with severe and profound ID. In the next section, I review the theoretical framework for this study, namely the Social Model of Disability (Inclusion London, 2022).

Theoretical Framework

Widely Used Disability Models

The term “disability” can take on different meanings when viewing it through different lenses. Three widely used models are the Moral Model, Medical Model, and Social Model (Olkin, 2022). The moral model proposes that a person’s disability is somehow caused by their lack of moral efficacy. Perceived causes may include moral failing on the part of the disabled person, a religious judgment of that person or their community, or a condemnation of the actions of parents imposed on their child. Historically, this model of disability has been pervasive. Although researchers today largely disregard the moral model as uninformed and driven by prejudice, beliefs and stigma informed by this model still exist today, particularly in areas where disability education is lacking (Jost, 2021). For example, ideas that are grounded in the moral model of disability can still be found in subtle differences between modern Hollywood non-disabled heroes and disabled villains (e.g., Scar from the Lion King, Captain Hook, or the general malformed appearance of “bad witches;” Johnson, 2020).

The medical model of disability gradually began to replace the moral model in the 1800s as medical science advanced (Retief & Letsosa, 2018). The medical model asserts that disabilities are a deviation from a socially defined norm, which causes impairment to the person. These impairments solicit the need for intervention to cure, rehabilitate, or teach the disabled person to adapt to conventional society. Several limitations exist with this model. The determination of disability hinges on a societal or cultural definition of “normal.” For example, societal norms may be unaccepting of mannerisms that often accompany autism, such as sensory-seeking behaviors or lack of eye contact. Through the medical model lens, the idea of autism as an illness reinforces barriers and stigmatization.

In reality, autism is lifelong and does not stem from pain or illness. Autistic self-advocates assert that autism "isn't a bad thing. Autism is a developmental disability, and disability is a natural part of human diversity. Autism is something we are born with, and that shouldn't be changed" (Autism Self Advocacy Network, 2022, para. 16). Interventions which intend to "fix" autism may function as unnecessary stress and mental or emotional harm to an autistic person (Art of Autism, 2022).

An additional limitation of the medical model is that it fails to account for personhood. According to the medical model, a disabled person is largely defined by their disability. This viewpoint promotes an attitude of exclusion, undervaluation, and pressure to conform to societal standards of what is considered normal (Goering, 2015) and promotes ableist mindsets. Ableism is a set of discriminatory biases or behaviors against people with disabilities often leading to undervaluing or excluding the disabled population from society (Center for Disability Rights, 2022). When society defines a person only by their disability, rather than approached holistically as a multifaceted individual with rich lived experiences, they may be viewed as needing outside help to escape what society views as an unbearable existence. By contrast, disabled people may view their disability as integral to their identity—not a condition to trade for more typical heath (Goering, 2015). Indeed, many disabled individuals take pride in the unique ways they experience and contribute to the world (Ameridisability, 2019).

Social Model of Disability

While the moral and medical models of disability attribute the cause of disability to functional limitations, the social model of disability points to society's failure to adapt to humankind's diverse needs as the ultimate cause of disability. The Social Model of

Disability, also known as the "barriers approach," proposes that societal barriers, such as ableist mindsets, bias, and environmental design, cause impairment rather than disabilities themselves (Cigman, 2010). The Social Model of Disability was born from the Disability People's Rights Movement of the 1960s and 1970s, as disabled people began to question societal views of their limitations (Lawson et al., 2021).

According to the Social Model of Disability (Lawson et al., 2021), society excludes those with disabilities rather than creating inclusive environments and opportunities. These barriers may be structural, attitudinal, or knowledge-based. Structural barriers may include public buildings only accessible by stairs, or intercom systems without access to video or text for people who have a hearing impairment. Attitudinal barriers may include stigmas and pervasive inaccurate views, such as a societal view of persons with ID as "childlike," and they are often perpetuated by the media and medical model of disability lens. This common bias leads to adults with ID being excluded or shamed for participating in typical adult activities. Knowledge barriers may include the lack of exposure to the general population, due to the structural and attitudinal barriers restricting adults with severe and profound ID to nursing facilities and care home (Inclusion London, 2022).

Societal conditions that specifically limit the severe and profound adult ID population may include caretakers' lack of basic knowledge of how to provide appropriate care (knowledge barrier), understaffed and underfunded care facilities which may lead to low-quality care (structural barrier), and limited provisions for therapeutic and recreational services (attitudinal barrier) (Goering, 2015). These remaining societal limitations have been perpetuated by lack of education and normalized societal exposure

to the adult ID population, creating a lingering bias and therefore little incentive for change.

This study views severe and profound ID from the lens of the social model of disability. The lack of resources and education provided to therapists working with this population stems from a pervasive societal bias that lowers perception of the population's value and significance. In other words, society has failed to provide adequate resources to allow this population to thrive. This study attempts to address some of these limitations within the music therapy profession by exploring the wisdom of music therapists who have many years of experience confronting their own implicit bias through time and exposure to the population, forming relationships, and developing and testing therapeutic tools.

Additional Models of Disability

Although the social model of disability adds another dimension to our understanding of disability, viewing disability only from the social model contains flaws. For example, the social model in some ways overlooks the negative sides of impairment which may be assisted by a medical model frame through therapies and intervention. Additionally, the social model fails to incorporate the factors outside of society which contribute to disability such as biological, psychological, and cultural factors (Rickson, 2014). Two additional models of disability assist in rounding out these overlooked aspects of the social. These are the affirmative model and the cultural model of disability (McCormak & Collins, 2014). Although the framework for this study is the social model of disability, these additional models are also incorporated when needed to reflect nuances in the viewpoints of participants.

The affirmative model of disability recognizes the potential negative sides of impairment while also recognizing that impairment is not always undesirable, and may not always be associated with pain or illness (McCormak & Collins, 2014). It encourages individual and societal identities build around specific disabilities. This model also acknowledges the social model of disability through recognition of the reality of living in a society which often causes impairment and oppression through lack of provision for the disabled community.

The cultural model of disability states that specific cultures have the power to marginalize groups by creating a diagnosis which views certain traits as undesirable or inferior (Waldschmidt et al., 2017). This goes past the social model of disability in that it takes specific disabled groups into account and their marginalized place in society such as deaf or autistic people. The cultural model, like the social model, often rejects the need for intervention and instead focuses, like affirmative model, on disability pride.

Person and Identify First Language

The social model of disability generally promotes person first language, or, referring to the person before the disability (i.e., individuals with severe and profound ID) (Disability Rights UK, 2022). Advocacy groups, however, have expressed desires to be referred to with identify first language, such as an intellectually disabled person. According to the American Association on Intellectual and Developmental Disabilities, in most cases, person first language is most appropriate, although some people with ID prefer identify first language (Joint Position Statement, 2023). Due to this lack of consensus, both person first and identify first language will be used periodically in this study.

Subjectivity Statement

I am a white, 34-year-old cisgendered woman originally from New England, now living for 16 years in Kentucky. I received my undergraduate degree in music education and taught elementary general music for seven years before returning for my equivalency (2014–2017) and master's (2017–2023) in music therapy at the University of Kentucky. I completed my internship in a medical setting (2017) and have now practiced as a board-certified music therapist for seven years. During this time, I have worked in medical care, individual and group sessions with adults with severe and profound ID, and children's developmental groups. My training in music therapy was grounded in a biopsychosocial and client/patient-centered models, but I have also been exposed to various lenses of disability through my work experiences, more recent coursework, and thesis experience.

In my responsibility for transparency as a researcher (Glense, 2006), I will further stress my personal connection with this topic. The adults with severe and profound ID with whom I have worked sparked my interest in further examination of this phenomenon, vis-à-vis the clinical wisdom of music therapists working with this population. I have worked with this population in both group and individual sessions in residential group homes and skilled nursing facilities since 2018. While I strive to inform my work with research evidence, I have found limited research to build on. I found the uniqueness of each of my clients in their needs, environments, and communication styles to be challenging without the guidance of research to help me learn to address their continuum of strengths and needs. Furthermore, I had limited time as a new professional to meet experienced clinicians and build collaborative relationships to learn from them. I

pursued this qualitative research to learn more from the skill and expertise of others so that I may enhance my own practice to better serve the needs of my clients.

My Implicit Bias

In my experience as a non-disabled person, when I was first introduced to clients with severe and profound ID, I held a deeply implicit bias of "less." That is, I often immediately assumed that because a client communicated through behaviors that I did not readily understand, they had "less" to say and "less" need to be heard. I presumed that clients that appeared inattentive or immobile from my perspective had "less" need for stimulation and movement. These clients did not make eye contact and did not initiate engagement with other residents at their care facility; therefore, I implicitly thought that they had "less" desire for social interaction.

My bias was implicit. Where explicit bias comes with an understanding and ability to identify and act upon one's beliefs, implicit bias occurs without conscious awareness, as though it has been hardwired into the way one understands the world. Implicit bias can occur from the repetition of prevalent ideas embedded within society or from lack of experience (Pelleboer-Gunnik et al., 2019). As my experience grew over time, I noticed subtle changes in behavior and facial affect as I played specific songs. I started to recognize consistency in responses over the course of many sessions and began to interpret those responses with greater nuance. The more experience I gained with individuals with ID and the more I engaged in reflexive practice, the more I identified my implicit biases, assumptions, and subjective interpretations and how I had been limiting my clients. For example, I had not offered opportunities for decision making assuming my clients were not capable. After developing awareness of this implicit bias, I offered

opportunities and found that all my clients could make many choices using affect changes, communication boards, eye gaze, and other methods outside the limits of spoken language.

With one non-speaking client, I began to slowly identify his preferred music over the course of two years though studying his subtle affect changes in response to different songs. This client's mother became a resident in the same care facility three years after I began sessions with her son. In our first joint session, I hesitantly presented the client's mother with the songs I had believed to be his favorites, and her eyes filled with tears. "Those were the songs his daddy used to play him on the guitar," she told me. This experience assisted me in developing greater conviction, not only in the existence of a complex inner world of my clients, but in my own ability to recognize these complexities.

As my experience and recognition continues to grow, so does my recognition of my own limitations. I can now understand that my clinical wisdom greatly impacts my clients' ability to demonstrate their capabilities. This growing awareness of my biases, and my subjective lived experiences, in conjunction with my theoretical framework, informed my thesis from its conception through analysis and interpretation. This qualitative multiple case study grew from my desire to advance my clinical wisdom to enhance music therapy services, provide appropriate levels of support, and further shift my mindset from implicit bias of limitations to presumed competence.

Purpose

The purpose of this qualitative multiple case study was to explore the clinical wisdom of experienced music therapists who have worked with adults with severe and profound ID. My research questions were:

1. How do music therapists define effective treatment with adults with severe and profound ID?

2. How do music therapists carry out evidence-based practice with adults with severe and profound ID?

3. How do music therapists promote engagement in adults with severe and profound ID?

4. How do music therapists promote psychosocial well-being in adults with severe and profound ID?

Glossary

I have included a glossary of terms to aid your understanding of this thesis. This list is not exhaustive, and it does not represent every disabled individual's lived experience.

Ableism: A set of discriminatory biases or behaviors against people with disabilities often leading to undervaluing or excluding the disabled population from society (Center for Disability Rights, 2022).

Case Study: A research approach which explores an event or phenomenon in-depth in its real-life context, rather than the controlled trails of experimental design. A multiple case study presents several carefully selected cases to make comparisons or expand the multi-faceted study (Crowe et al, 2011).

Explicit Bias: Discriminatory attitudes towards a specific group of which the individual is aware (Vela et al, 2022).

Implicit Bias: Automatic and unintentional beliefs and thoughts that impact judgments, decisions, and behaviors (diversity.gov, 2022).

Intellectual Disability (ID): Defined by the DSM-5 as a neurodevelopmental disorder initiated in childhood and characterized by deficits in intellectual functioning and adaptive functioning (Boat & Wu, 2015). An individual with severe ID requires assistance with self-care and safety daily. Individuals with profound ID require 24-hour supervision and care.

Quality of Life: A measurement of the overall wellbeing of a person, including social, emotional, physical, and spiritual factors (Bharwaj, 2022).

Social Model of Disability: Views impairment as separate from disability and finds that lack of disability education, appropriate accommodations, and prejudiced attitudes are often the cause of impairment rather than the disabilities themselves (Goering, 2015).

Spiral Method: A process of coding data through which the researcher first becomes familiar with the interview content through many readings, then categorizes topics, sorts topics into codes, and continues to sort and condense codes by repeating the processes until the broad themes emerge (Creswell, 2016).

Therapeutic Relationship: A connection with a healthcare professional perceived as comforting, caring, supportive, non-judgmental, and safe, often employed during stressful times or while exploring stressful topics (Kornhober et al., 2016).

CHAPTER 2. REVIEW OF LITERATURE

In this chapter, I will define severe and profound intellectual disability (ID). I will describe the current lack of therapeutic services and research available for adults with severe and profound ID and the challenges that contribute to this shortage. I will also outline current research on music with adults with severe and profound ID and available music therapy research and resources for this population.

Intellectual Disability

ID is characterized as a below average IQ which originates before 18 years of age. Key components of ID include limitations in intellectual functioning and adaptive behavior. Intellectual functioning, sometimes referred to as intelligence, encompasses learning, problem solving, and reasoning. An IQ test of around 70 or lower may be categorized as a limitation to intellectual functioning (American Psychiatric Association, 2013). Adaptive behavior involves activities of daily living such as social skills, personal care, and safety. Various evaluations of levels of community and support as well as the living environment are used to inform the severity of ID (American Association of Intellectual Disabilities, 2020), which may be categorized as mild, moderate, severe, or profound. The current study focuses on individuals with severe and profound ID.

Terminology and definitions for this population have gone through many changes through the years. Historically, treatment of this population has included forced withdrawal from society and severe abuse (Trent, 2016). Although society has made progress in the treatment and understanding of individuals with ID since the 18th century, much work remains to be done. Stigmatization, access to quality education and long-term care, and adequate funding for services all present ongoing barriers for these individuals

and their families. Litigation and societal views of the inherent rights of those with ID have shown some progress since the introduction of the Social Model of Disability (Pollack, 2011). Individuals with ID now have legal protection, access to health services, and are generally not as feared by society as they once were (Pollack, 2011). Despite these advances, funding that supports these new societal views remains sparse, especially in the adult population.

Due to communication limitations, choices are often made for the individual with ID by family members, social workers, and care providers (Jacobs, 2018). The wishes of the individual may be easy to overlook when that person is unable to verbally communicate their desires or advocate for their own needs. Financial constraints and lack of options and assistance often further limit the choices afforded these decision makers (Pollack, 2011). Such limitations mean that most individuals with severe and profound ID are living in residential facilities composed of staff that is often not trained or available for services beyond basic care with ID residents (Woodman et al., 2014). This leads to low-quality care due to low-quality work conditions for those providing direct services.

Despite the low quality, the financial cost of this care is still high as individuals with severe and profound ID require complex full-time care, including full support of daily self-care activities and comorbid physical limitations (National Academies Press, 2015). Additional funding for therapeutic services (e.g., physical therapy, occupational therapy, recreational therapy, music therapy) is often not available to adults with severe and profound ID (Carminati et al., 2016; Pollack, 2011). Today, both therapeutic services and research associated with ID largely focus on school-aged clients or mild to moderately intellectually disabled adults. Once these individuals have aged out of public

education, societal means to fulfill the basic needs of adults with severe and profound ID are limited.

Barriers to Research

There are several considerations to research with this population that make studies difficult to carry out. These considerations include barriers to communication, reliance on proxy reports and observational data, and complex ethical considerations.

Communication Barriers

Brisbon (2021) described in her article, "Valuing the Lives of People with Profound Intellectual Disabilities," how she was unsure how to act when meeting Sesha, an individual with profound ID. Brisbon described how, she learned to communicate effectively and develop a deep connection with her with help from Sesha's parents. Brisbon's lack of knowledge and skills to communicate with an adult with profound ID may have been derived from the reality that this population remains largely invisible in society. Opportunities for communicating with and understanding even the tone of voice to use when speaking to a non-speaking adult are largely nonexistent.

Building interpersonal relationships with individuals with severe and profound ID can prove difficult when faced with non-spoken communication. Behaviors that can be difficult to interpret and a lack of functional ability to initiate social interaction (Lee, 2014) make building rapport a lengthy and intensive process. An individual's repeated efforts at communication may continue to be ignored and dismissed as meaningless behavior. In time the individual may stop efforts to communicate, and lack of engagement with others may become engrained behavior (Swaney, 2020).

Reliance on Proxies

Research with this population becomes a daunting task when considering the difficulties in interpreting reactions to various stimuli and the lack of verbal communication to facilitate the participant's responses. While efforts can be made to include communication by persons with severe and profound ID, responses must still be interpreted by a proxy, who may or may not be familiar with the participant and their communication style. It is challenging to determine the accuracy of these interpretations and therefore difficult to evaluate the reliability of a study involving these interpretations.

Ethical Considerations

Another consideration for the sparseness of research is the ethical considerations of gaining consent. As previously stated, decisions are typically made for an adult with severe and profound ID by a guardian. The guardian may be a family member who is familiar with the individual, their needs, and communication styles, or it may be a person appointed by the state without much knowledge of or experience with the individual (Carminati et al., 2017). Gaining consent for research requires asking such legally authorized representatives to agree to participation in the study on the individual's behalf. The researcher must trust the ability of the guardians to appropriately assess the client's wishes for study inclusion.

According to the American Music Therapy Association (AMTA) Professional Code of Ethics, Section 1.5, the music therapist must obtain informed consent from the client or legal guardian and in cases in which the client is unable to provide consent, assent will nonetheless be sought. This consideration, in conjunction with many other sections within the Code of Ethics, becomes complex when working with individuals without spoken language and who often have enigmatic behaviors. These provide

potential barriers to research with difficulties in obtaining consent, which simultaneously creates barriers to greater understanding, as considered by Section 1.8, which asserts a music therapist must acquire knowledge and information about the specific cultural group(s) with whom they work, seeking supervision and education as needed (AMTA, 2018).

Music and ID

The presence of music has been documented throughout all known human history, playing an integral role both in intra- and interpersonal development (Koelsch, 2011). Inherent within the structure of music are opportunities for expression, regulation, and autonomy, as well as cultural and interpersonal connections (Swaminathan & Schellenberg, 2015). The human brain demonstrates the ability to perceive and form these musical connections even before birth (Granier-Deferre et al., 2011). While individuals with severe and profound ID demonstrate severe limitations in adaptive functioning, they can respond to and engage with music (Hooper, 2016).

Despite limited research, anecdotal and emerging research evidence supports music as an effective means to engage and connect with individuals with severe and profound ID (Carminati et al., 2017). Responses to music by this population may include decreased stress response (e.g., as measured by cortisol levels; Hooper, 2016), motivation, opportunity for social interaction (Johnels et al., 2016, Debedout & Worden, 2006), and means to communicate with others outside of functional boundaries of verbal speech (Bergmann et al., 2019). These characteristics of music make it a valuable tool for therapeutic interactions (Busoom & Schwaiblmair, 2010; Thompson & McFerran, 2015) and may in turn enhance quality of life. Additionally, music provides multiple means for

expression, choice, and autonomy—opportunities that people with severe and profound ID are not frequently afforded (Ward et al., 2021). Each of these aspects support the addition of music into the lives of those with ID.

To reiterate, the environment created by music can be engaging and provide structure that may supply opportunities for communication beyond spoken language (DeBedout, 2006; Thompson, 2015😉. An additional component of the therapist is added in the context of music therapy. A music therapist provides an opportunity for manipulation of the attributes of music, individualized assessment of responses to music, development of supportive experiences using all manner of music engagement (e.g., instrument play, singing, moving, listening), and an interpersonal relationship with the client (AMTA, 2023; Gfeller, 2008). Opportunities to engage in music therapy may support the client more so than the presentation of music alone.

Music Therapy and ID

Music therapy is the evidence-based practice of musical interventions to achieve therapeutic goals within a therapeutic relationship with a credentialed professional (AMTA, 2020). According to AMTA, 2.6% of music therapists work with individuals with ID or developmental disability (AMTA, 2021). The workforce analysis did not ask participants to clarify if they worked with adults or school-age clients in this population. Research on music therapy with this population remains scarce, which leaves this percentage of professionals at a loss of resources to best serve these individuals.

Available research and anecdotal accounts indicate that music therapy may improve social interactions (Thompson & McFerran, 2006), impact arousal (Bergmann, 2016), and evoke a relaxation response (Hooper et al., 2016). While music therapy

research with individuals with ID is emerging, research focused on adults with ID and those specifically with severe and profound ID has largely remained absent for reasons previously mentioned (see Barriers to Research). Where research is available, it focuses mostly on the school-aged population (i.e., those 21 years and younger with support through the public education system), and regardless of age group, the literature often does not include those with severe and profound ID. In the past 20 years, only six articles have appeared in the *Journal of Music Therapy* (the leading research-based journal) and *Music Therapy Perspectives* (a longstanding practitioner journal in the United States) regarding the ID population. Although five of these articles included adults, only one included those with the severe and profound designation. Little research appears to exist in other journals and scholarly publications (e.g., *Journal of Intellectual Disabilities, Journal of Applied Research in Intellectual Disabilities, American Journal on Intellectual and Developmental Disabilities).* The following sections contain summaries of said articles.

DeBedout and Worden 2006

DeBedout and Worden (2006) used a quasi-experimental study to determine what music interventions best motivate school-age children with severe ID. They recorded the difference in behaviors among children using switch-activated recorded music versus participating in music therapy. Recorded behaviors included head movement, vocalizations, and changes in affect. The researchers found the students gave greater attention to music therapists versus switch-activated toys, concluding that music therapy was more effective in evoking response than other sound-making stimuli. The study highlights the importance of music therapy as a motivational tool for this population.

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Hoyle and McKinney 2015

Hoyle and McKinney (2015) adapted a study from 2007; a multiple case study to explore the use of music therapy for bereavement in adults with ID. Participants were recruited from a residential facility to attend once a week music therapy sessions in a group setting for nine weeks. Sessions included educational material on death in coping with emotions surrounding bereavement. The Brief Psychiatric Rating Scale for Developmental Disabilities (BPRS) (Bodfish, 1995) was used to determine whether "negative" behaviors (as identified by the BPRS such as blunted affect, emotional withdrawal, and motor retardation) had decreased after this nine-week period. Though the researchers noted a reduced level of negative behaviors in one of the participants who had lived in her family home the longest, no change was noted for the other participants.

The researchers speculated that the participant who lived longer in her family home had developed a stronger relationship with the parents for which she was grieving, and therefore showed a greater change in her decrease of negative behaviors. The other participants had lived away from their family homes since childhood. The researchers speculated it is likely they did not have a close relationship with their parents who had passed, and therefore did not show a significant change in behaviors after the music therapy sessions.

Hooper and Colleagues, Parts One and Two, 2016

Hooper (2016) explored the use of music with the ID population through a review of the literature. Most of the articles Hooper reviewed were case studies like Hoyle and McKinney's study on bereavement, or what Hooper referred to as philosophical writing.

Common themes among the case studies included using music therapy to improve quality of life, self-expression, and development of relationships. Hooper concluded that while case studies helped prove the viability of music therapy work with this population and promote further research, more quantitative research for evidence-based practice was needed.

In part two, the researchers examined musical aptitude in those with and without ID. They studied the societal perception of the "musical savant" and found that those with ID or Down syndrome do not necessarily have improved aptitude towards music in comparison with the general population. They also compared responses to active versus receptive music therapy interventions and found that active music therapy interventions were more effective in decreasing unspecified "unwanted" behaviors. Hooper noted that while case studies and philosophical writings are of value, more quantitative data was needed to better understand the responses of those with ID to various music stimuli and music therapy interventions.

Staab and Dvorak 2018

Staab and Dvorak (2018) used a phenomenological study to explore direct care staff's perceptions of music therapy with adults with ID. This study demonstrated the beginnings of leaning toward the a more social model of disability approach to music therapy in the expressed viewpoints of direct care staff. Where previous studies have focused more on behavior and behavior modification, this study's results put more importance on quality of life. Each staff member had observed a minimum of one music therapy session with a client. The researchers used semi-structured interviews for staff to share their perceptions. The themes that emerged from the analysis of the interviews

included: a) staff believing music therapy to be effective in improving social, physical, emotional, and cognitive functioning, and b) staff believing music therapists should focus on physical, emotional, and social functioning instead of cognitive functioning of older adults with ID. Direct care staff also asked music therapists to understand the individualism of each client and asked direct care staff for help in understanding each client's behaviors. Direct care staff reported they found enjoyment in connecting and participating in music therapy experiences. They also believe that connections with knowledgeable staff helped the music therapist's flexibility and intuition with individual clients.

Swaney 2020

Swaney (2020) presented a conceptual framework for music therapy with the severe and profound ID population using Carl Rogers's person-centered theoretical framework, furthering the direction of music therapy practice to a more affirmative model. Swaney stated that there are four key relational experiences that drive the therapeutic process with this population: curiosity, invitation, celebration, and recognition. Swaney highlighted the importance of using music therapy to improve emotional health through these relational experiences, as the severe and profound ID population often has their emotional needs overlooked. The therapeutic relationship can provide individuals with the freedom of "unconditional positive regard, empathy and genuineness," which should be afforded to all people regardless of their ability level.

Swaney practiced Nordoff-Robbins music therapy, using improvisational experiences to build the therapeutic relationship. Through improvisation, the therapist and client build a shared creative language. Swaney pointed out the temptation to

overlook the “other mind” present in the room due to the difficulty in reaching the severe or profound ID person. “Many [. . .] times throughout my clinical practice [. . .] I would be reminded of this thought; there are two minds present in the therapy space—despite what may appear to be absent.”

Beebe 2022

Beebe (2022) studied music therapists currently working with individuals with an intellectual disability and a developmental disability using a survey questionnaire. Beebe’s survey questioned the amount of self-determination individuals with ID were given in music therapy sessions. The study explored the benefits of including self-determination in sessions, and how a music therapist’s experience level correlated with the frequency and perception of opportunities provided for self-determination.

Beebe found that many participants highlighted the idea that the individual’s competency played a role in the amount of self-determination provided. Beebe noted that it may not be reasonable for music therapists to provide self-determination for clients with limited communication skills. Beebe’s research highlights the progress still needed in the field of music therapy to provide self-efficacy and non-limiting services for this population.

Further Resources

The remaining resources on music therapy for persons with ID are mostly contained within book chapters. These chapters reflect the experience of clinicians working with this population, with the focus continuing to be on school-aged children. Content includes potential interventions, goals and objectives, and case studies. For example, one chapter suggests goals that target building conceptual skills, social skills,

and practical (functional) skills. Suggested interventions include using music for multimodal stimulation, to reinforce desired behaviors, to support other educational learning, to structure activities and social interactions, and to improve memory and attention span (Wheeler, 2001).

Although most resources focus on school-aged individuals, Laurie Farnen's chapter in "Music Therapy, An Introduction to the Profession" specifically addresses adults with severe and profound ID. Ms. Farnen, who has more than three decades of experience with this population, discussed music therapy in residential settings and offered case studies along with a brief section on guidelines for clinical work. She advocated that a music therapist's focus with this population should be on client choice and preference, such as the use of client-preferred music, and that goals should be identified by client need. She outlined a few general recommendations for working with this population, including allowing greater processing time, keeping interventions age appropriate but simple, describing what will happen before acting, and focusing on the acquisition of functional life skills (Knight et al., 2018). This chapter offers a glimpse of her clinical wisdom derived from years of experience working with this population.

Measuring Effectiveness

Most occupational practices that seek to best serve clients strive to be guided by evidence-based practice to provide effective treatment (Kitson, 2003). Evidence-based practice consists of the best available research, the strengths, needs, and desires of the client, and clinical wisdom (Pearson, 2011). As previously discussed, there is a dearth of research on adults with severe and profound ID, assessing their strengths is challenging, and, given the lack of literature available for guidance, accurate assessment requires

experience with the population. Furthermore, individuals with severe and profound ID have limited functional ability to communicate their desires. Current practice within music therapy and other professions seems to be driven by individual clinical wisdom and transfers made from related research. This combined lack of guidance from the literature and clients makes evidence-based practice difficult for emerging professionals.

As the severe and profound ID population often communicates without speech, and frequently with enigmatic behaviors, evaluating the effectiveness of interventions derived from individual clinical wisdom is also challenging. While the non-verbal aspects of music may assist in reaching non-speaking clients, the music therapist must still interpret their responses and non-verbal communication. In the case that the client reaches the intended goal of the intervention, the goal itself may do injustice to the client's capabilities, particularly if they are viewed through a medical model lens.

As the Social Model of Disability suggests (refer to Chapter 1; Carminati et al., 2017), few with severe and profound ID are afforded consistent high-quality care and therapeutic services, and therefore little is known about the potential for their growth and capability. This context exacerbates a music therapist's own assumptions and biases and, in turn, may limit what the music therapist may try when developing goals and interventions. Additionally, due to funding constraints, severe and profound ID adults lack the frequency and availability of therapeutic services, leaving a smaller base of professionals from which music therapists may draw experiences and share clinical wisdom. As previously discussed in Chapter 1, in my own clinical experience, the more severe the disability, the more challenging it is to design effective music therapy experiences. For example, musical preferences are difficult to assess when

communication is limited. It is difficult to determine age-appropriate goals and objectives for clients with more severe ID. Additionally, developing a therapeutic relationship can be more challenging when communication is limited. Music therapists practicing with this population who are facing such challenges in helping their clients are also at a loss regarding resources to inform best practices (Lee, 2014).

The Role of Clinical Wisdom

Despite the barriers faced by individuals with severe and profound ID (i.e., lack of therapeutic services, diminished communications skills, lack of research), no study has appeared to address these complex challenges faced by professionals who seek to provide quality person-centered care for this population. As previously stated, available literature mainly centers around case studies or school-aged clients. Each individual with severe and profound ID has unique needs, communication styles, and private inner worlds. These unique challenges coupled with limited literature and lack of clinical guidance means that music therapists working with this population must use trial and error to inform their practice. This approach leaves music therapists with a stark lack of resources to inform best practices (Lee, 2014). Documenting clinical wisdom through multiple case studies helps fill some of these gaps.

Due to the complex nature of ID and its many inherent difficulties in conducting research with participants with severe and profound ID, a starting point may be to study those most familiar with this population. In-depth exploration of clinical wisdom on how to effectively approach treatment and the therapeutic relationship, specifically with adults with severe and profound ID, has appeared to remain mostly absent from music therapy and related literature. Studying the clinical wisdom of several music therapists

experienced with this population can broaden the scope of this limited research, filling in the considerable gaps with experience and intuition guided by evidence and insight (Pearson, 2010). Clinical wisdom can offer insight on work with the population without the complex issues of consent or proxy report required by other study types.

To improve the evidence base for music therapists who work with individuals with severe and profound ID, it is vital to document how seasoned professionals work with this population effectively. Because the phenomenon of music therapy clinical work with adults with severe and profound ID is not well documented or studied, a qualitative approach is warranted. The purpose of this qualitative study was to explore the clinical wisdom of experienced music therapists who have worked with adults with severe and profound ID. I used a multiple case study design to gain a well-rounded perspective of music therapy practice with this population and specific wisdom of four experienced clinicians (Creswell, 2018). In the next chapter, I describe the study methods.

CHAPTER 3. METHODS

The purpose of this study was to explore the clinical wisdom of music therapists experienced with working with adults with severe and profound intellectual disability (ID). Current research on clinical work with this population is sparse, mainly limited to book chapters outlining broad possible interventions and goals and a handful of articles. This study seeks to add to the base of current research by providing an in-depth look at the wisdom that four music therapists amassed over many years of work with this population. In this chapter, I provide detailed information regarding the research methods for this qualitative multiple case study. The research questions are as follows:

1. How do music therapists define effective treatment with this population?
2. How do music therapists carry out evidence-based practice with nonverbal adults with severe and profound ID?
3. How do music therapists promote engagement in nonverbal adults with severe and profound ID?
4. How do music therapists promote psychosocial well-being in nonverbal adults with severe and profound ID?

Research Design

The study was approved by the University of Kentucky Institutional Review Board (see Appendix A). The research questions aligned with a qualitative approach, which is ideal when analyzing personal narratives and determining how they fit together (Glense, 2006). A case study is an in-depth exploration of a particular person, group or event from many different angles in order to give a rich picture with many insights

(Thompson, 2016). The case study format allows for detail with insights into each practice, seen from multiple angles. A multiple case study, as used in this study, is an exploration of several people, groups, or events similar, or parallel, to each other so they may be compared (Thomas, 2016). This research design allowed me to explore each music therapist's unique clinical wisdom and then compare the cases. I utilized semi-structured interviews to explore multiple aspects of each music therapist's experience, which allowed me to collect detailed and specific qualitative data.

Participants

To address the research questions and given that clinical wisdom was my primary interest, I aimed to recruit three to five credentialed music therapists with extensive experience working with adults with severe and profound ID. Inclusion criteria were as follows: (a) 10 or more years experience working as a music therapist, (b) caseload includes adults with severe and profound ID, (c) speak and understand English as a primary language, (d) currently practicing or retired, and (e) most or all of their clinical practice completed within the United States. Accepting clinicians working mostly within the United States gives the greatest possible chance of appropriate transfer of wisdom when working within the systems of the culture and government.

Participant Recruitment

I recruited participants for four months beginning in February 2021. I used purposeful, response-driven sampling (i.e., "snowball sampling") to recruit participants. My thesis advisor (Dr. Alaine Reschke-Hernandez) and Director of the University of Kentucky Music Therapy Program (Dr. Olivia Yinger) sent recruitment emails to colleagues whom they believed to be eligible candidates. Participants also forwarded the

recruitment email to their own colleagues they believed to be eligible. Interested candidates contacted me via email. I then sent an email response that included the details of the study and offered a phone conversation so that interested parties could make an informed decision regarding their participation.

Participant Selection

I provided the candidates who remained interested with directions for completing a Google Forms prescreening questionnaire (see Appendix B). The purpose of the questionnaire was to confirm eligibility and try to ensure a diverse representation of music therapists with the greatest amount of experience with adults with severe and profound ID. I wanted to make certain that participants had adequate experience with this population, but also that the sample was diverse in terms of clinical approach, gender identity, and ethnicity. Nonetheless, only four candidates expressed interest in the study and therefore prescreening was mostly to ensure candidate eligibility. All four candidates met eligibility criteria and provided verbal informed consent to participate in this study. The participants completed the Google form and a time was set up for an individual Zoom interview (one with each participant). Participants were then emailed consent documents and given an opportunity to address any questions they had before the interview. At the close of one of the participant's interview she offered to email two other colleges she believed would meet the inclusion criteria. Laura sent emails connecting these colleagues with me, both of whom also completed the Google form and interview. The study had four participants in total.

Participant Characteristics and Anonymity

When one presents a depth of information about the clinical wisdom of those who are well-known for working with a particular clinical population in their field, it is challenging to convey information in such a way to both preserve anonymity and answer the research questions. Given the relatively small size of the music therapy profession in the United States and few with significant expertise with this population, the potential for readers of this thesis to discern the identities of my participants is high. Participants were aware of this risk when they consented to participate. All names were changed to pseudonyms to minimize any risk of confidentiality breach. Names of facilities and geographic locations were also changed to further protect information by minimizing the risk of participants being linked to a specific facility. Finally, all identifying information within the stories that participants shared of their clinical experiences were also changed to protect the anonymity of clients and participants.

Participant demographics are summarized in Table 1. All four participants were white cisgender women and ranged in age from 63–70 years (M= 66.25). Participants ranged in years of music therapy work from 25–40 (M=34.75) with a combined 131 years of experience in work with adults with severe and profound ID. Three worked within the same geographical region, which is likely reflective of the sampling method. Three of the participants have a master's degree in music therapy with one participant also holding degrees in music education and special education. Several additional certifications held by participants included Neurologic Music Therapy (NMT), and Licensed Creative Arts Therapist (LCAT). Participant stated approaches, collected from the prescreen questionnaire, are quoted in Table 1.

Table 1

Participant characteristics

Characteristic	Number of Participants
Education	
Bachelor's Degree	4
Master's Degree	3
Age in years	Mean = 66.25 (range = 63-70)
Race	
White/Caucasian	4
Gender	
Female	4
Years spent practicing	Mean = 34.75 (range = 25-40 years)
Years spent with the study population	Mean = 32.75 (range= 20-40)
Clinical approach (from prescreen questionnaire)	"The use of live music, goal oriented, multisensorial" "Provide for age-appropriate, active participation in making music, to promote social, sensorimotor, and cognitive development, using methods and adaptations that correspond to each student's developmental level and cultural background" "Music-centered music therapy" "Neurologic music therapy; live music approach to support clients to develop functional life skills"

Data Collection

Each of the four participants completed one semi-structured interview over the teleconferencing software Zoom. Total interview time ranged from one hour to 90 minutes. A research assistant transcribed each interview verbatim; transcripts were collected through Zoom recording software. Field notes on non-verbal behavior were

recorded in my research journal entries while reviewing the interview videos. Interview answers were coded manually using the data analysis spiral method (Creswell, 2013). The pre-screen questionnaires provided to participants via Google forms included data on participant demographics, approach to music therapy, and levels of education. Complete data from the study included information provided on the pre-screen questionnaire, interview transcripts, recorded observations of non-verbal behavior during interviews, notes provided by the interviewee, and my own researcher journal.

Interview Protocol

I created an interview script with questions designed to allow exploration of each interviewee's vast and complex wisdom as well as to address each research question in depth. The semi-structured interview format allowed for interviewees to initiate discussions on areas of wisdom I may have lacked the knowledge to inquire towards. This format also allowed for topics to flow with fluidity and questions to be moved or skipped to conserve time and limit redundancy (Patton, 2015). I first drafted the interview questions based on my theoretical framework and research questions, then received input from my thesis advisor. The final questions are as follows:

1. What inspired you to work with non-verbal adults with severe and profound ID?
2. Tell me about the theoretical framework and philosophy that guides your practice. How has your practice changed as you've gained experience?
3. In what ways do you adapt assessments, goals, and interventions across clients with severe and profound ID, across settings, or over time with the same client?

4. Take a moment to imagine a typical session with a non-verbal adult with severe and profound ID *(wait a slow count to 10, or until they indicate they are done imagining)*. Please describe this session.
5. Please take a moment to imagine a go-to intervention in your music therapist toolbox that you use with this population *(wait slow count to 10, or until they indicate they are done imagining)*. Please describe this intervention and why you like it.
6. In what ways do you measure or evaluate your therapeutic effectiveness with this population? Please consider factors that indicate music therapy may not be appropriate or is no longer effective for a client.
7. Take a moment to think about different ways you communicate with this population and how you try to objectively interpret their responses (*wait slow count to 10, or until they indicate they are done imagining).* Please describe these communication and interpretation strategies.
8. What is your approach to music selection with this population, and what methods do you use to determine their music preferences? How does age-appropriateness factor into your decision?
9. What readings or other resources do you suggest that could help me understand your approach or the clinical wisdom involved in working with this population?
10. Is there anything else you'd like to add that we haven't covered?

The following prompts were used alongside interview questions when needed:

1. Prolonged silence

2. Take as much time as you'd like to reflect on this question.
3. Could you please further describe what you said about . . .
4. Please explain what you meant by . . .
5. Could you give me an(other) example?
6. It sounds like you're saying . . . is that a fair summary?
7. What would that look like?

Trustworthiness

I kept thorough notes in my researcher journal reflecting on my own thoughts and biases throughout the research process. I also kept regular meetings with my thesis advisor, sending regular drafts of the research process for check-ins. After interviews were transcribed, each participant received a copy of their interview to check for errors (i.e., member checking). This process helped maintain the integrity of the data over potential connectivity and audio issues during the online call. Before beginning to code data, I familiarized myself with the interviews by reading the transcripts several times while logging my observations in my researcher journal. This ensured greater familiarity with the content of each interview to increase the trustworthiness of the coding process. Throughout the analysis, I checked in with my thesis advisor to debrief, and I also requested input from my committee member with qualitative expertise (Dr. Vasil).

Analysis and Coding

Each participant's interview was transcribed and sent to the interviewees to review for clarification (i.e., member checking). Due to Zoom communication being sometimes difficult to hear, two of the interviewees wrote back with small revisions to the transcriptions to fill in words that were lost to audio quality or malfunctioning internet

signal. Once the transcriptions were clarified for accuracy, I went through and separated each answer into smaller topics, changing bullet points each time I perceived a shift in topic. These bullet points were then distilled to individual codes. The codes were then sorted by topic using the spiral method outlined by Creswell (2016). As themes emerged from the interview data, I would take a step back, returning to the codes with each new theme to check that the arrangement continued to be effective and make the most sense. As I finished one interview, I would revisit the others to determine similarities and differences across each case, and among emerging themes and recheck the codes against the themes. In the next chapter, I present the results of this analysis. In Chapter 5, I interpret the analysis and relate it to existing literature.

CHAPTER 4. RESULTS

The purpose of this study was to explore the clinical wisdom of music therapists experienced in working with adults with severe and profound intellectual disability (ID). The research questions were:

1. How do music therapists define effective treatment with nonverbal adults with severe and profound ID?
2. How do music therapists carry out evidence-based practice with nonverbal adults with severe and profound ID?
3. How do music therapists promote engagement in nonverbal adults with severe and profound ID?
4. How do music therapists promote psychosocial well-being in nonverbal adults with severe and profound ID?

This study was a multiple case study, using semi-structured interviews of four participants. This chapter presents the results of the spiral analysis from each interview with the four music therapists. I begin this chapter with an overview of each case, their experience, and work context.

Participant Overview

I gave each case its own metaphor to tie all the cases together as well as differentiate them (Patton, 2015). The metaphors were developed based on each participant's unique strengths and themes they continued to return to during their interviews. As stated in Chapter 3, all participant names have been changed to pseudonyms.

Laura

Laura's metaphor, both figuratively and literally, is singer/songwriter. Laura proclaimed that she had always wanted to "be a hippie," which included having long hair, engaging in songwriting and guitar playing, and doing coffee shop gigs. She had songwriting skills from before her music therapist days where she learned to write music that could "work a crowd." Laura eventually moved those skills into her music therapy career with individuals with severe and profound ID, writing music specifically catering to the population.

Laura did not actively pursue work with severe and profound ID adults, instead taking the population on because she was offered and "needed a job." The sentiment of not actively seeking a career in work with this population is one that is shared by all the music therapists in this study. Laura has 36 years of experience providing music therapy services for adults with severe and profound ID. Laura worked primarily in in the upper mid-west at an intermediate care facility for individuals with ID, which focused on improvement of functional life skills. The facility provided short-term care for residents, outlining an intensive treatment program with a discharge date planned at the start of a resident's stay, the goal being to give clients the tools to live in their community with the greatest amount of independence possible. At the start of her career, the center housed around 900 residents with Laura being the sole music therapist in employment. By her retirement, the center consisted of three full-time music therapists and three interns and had downsized to around 200 residents on average. In accordance with the goals of the facility, Laura's music therapy practice focused on goal-oriented functional life skill improvement.

Melissa

Melissa is the crafter of the participants. Melissa has enjoyed sewing costumes for middle school musicals during her retirement. She has, in fact, been sewing throughout her career. As a working music therapist, she enjoyed employing her crafting skills in creating adaptive instruments for the severe and profound ID adult population. Like the other interviewees, Melissa did not "seek out" music therapy work with the severe and profound ID population. Melissa's journey appears somewhat similar to Laura's, as they worked together for many years. Melissa has a bachelor's degree in both music education and music therapy and also completed a master's in special education. Like Laura, Melissa's practice was informed by her workplace, and she focused on goal-oriented improvement using live music and multisensory adaptions. Melissa also worked primarily in the upper mid-west at an intermediate care facility for individuals with ID, giving clients the tools to live in their community with the greatest amount of independence possible

Diane

Diane is the advocate. Diane was also not initially "drawn" to work with the adult ID population but developed her practice over the course of her 40-year career. She is trained in Nordoff-Robbins, an improvisational and music-centered form of music therapy. Unlike the other cases, Diane's sessions were primarily one-on-one, with some small group work. Diane's work was funded by the state of New York with ample resources for purchasing instruments and even more advanced equipment such as

Somatrons[1]. She continues to supervise students at a small northeastern university. She is drawn to the depth of story behind the stigma and mistreatment of the ID population throughout history, even describing how the facility where she worked for years had originally been established as a "State Custodial Asylum for Feeble-Minded Women of Childbearing Years." Diane's work was mainly with individuals who traveled to her office to receive services. In alignment with a Nordoff-Robbins approach, her practice focuses on the music-centered experiences shared by the client and the music therapist.

Faye

Faye is the educator. Although Melissa and Faye have similar educational backgrounds (Faye has bachelor's degrees in music therapy and music education and a master's degree in special education), Faye's career was mainly established in self-contained public schools, working with both children and young adults. The main school she worked in served around 270 students and included services such as occupational therapy, physical therapy, speech therapy, and nursing. It ran and functioned in the same fashion as surrounding public schools, but self-contained in parallel. Faye's job was to integrate music education with music therapy. The school sought her out due to their need for a music therapist who also had a teaching license. Faye has the unique perspective of working with younger adults who have not yet passed what is often

[1]The Somatron vibroacoustic products were created by Dr. Philip Brotman and distributed by Biofeedback Instrument Corporation. Their products consist of many different speaker-infused materials includes chairs and mattresses that allow listeners to experience tactical and vibrational sensations of the music to increase calming or stimulation (https://www.biof.com/somatron/products.asp).

described as “the services cliff”[2]. Her practice focuses on providing age-appropriate and active music making to encourage social, sensorimotor, and cognitive development.

Interview Themes

As described in Chapter 3, I used Creswell’s spiral analysis to determine the main themes of the study. Briefly, this involved becoming familiar with the interview content through many readings, creating bullet points for each topic line by line in the transcripts, sorting bullet points into codes, and continuing to sort and condense codes by spiraling through readings until the broad themes emerged (Creswell, 2016). Eight primary themes emerged from this analysis: 1) theoretical framework, 2) stigma, 3) practice intention, 4) practice techniques, 5) considerations of effectiveness, 6) observation of communication, 7) music selection, and 8) instrument adaptations. Each theme was explored by each participant during their interview. Additionally, seven of the eight themes were further divided into subthemes. The subthemes help further delineate important points of each main theme. Table 2 outlines the themes and subthemes of this analysis.

[2] A term often used to describe aging out of special education (typically around age 22) and no longer being eligible for educational services. Funding for adult services is described as uncoordinated, underfunded, and not focused enough on giving participants meaningful lives (Bagenstos, 2015).

Table 2

Themes and Subthemes

Theme	***Sub Themes***
Theoretical Framework	Variety of Frameworks
	Goal of Collaboration/Equality
	Power Dynamics
Stigma	Viewpoints of Others
	Terminology and Other Barriers
	Underestimation
Practice Intention	
Practice Techniques	Specific Interventions
	Session Formatting
	Further Considerations
Considerations of Effectiveness	Records
	Eligibility
Observation of Communication	Behaviors
	Adaptations
	Hints and Types
Music Selection	Selection
	Songwriting
Instrument Adaptations	Instrument Types
	Instrument Adaptations
	Further Considerations

In the following sections, I describe each theme and subtheme. Each participant's contributions to the theme and subtheme will be included in the descriptions. These collective answers will assist in developing a thorough understanding of how the collective wisdom of these experienced music therapists provides insight into these essential questions of music therapy practice with adults with severe and profound ID.

Theme 1: Theoretical Framework

This theme outlines the personal philosophies that drove each participant's practice. This theme had three sub-themes: variety of frameworks, the goal of collaboration/equality, and power dynamics.

Subtheme: Variety of Frameworks

A variety of frameworks were represented by the four research participants. A prevalent theme was the exploration of ideas in practice. Laura described this exploration as the "theory, research, practice" triangle. Being unafraid to attempt new ideas and record their effectiveness, whether good or bad, is important to the overall development of effective practice with this population. Melissa described this view as an "attitude of trying new things" and being open to the possibility that they may or may not be effective. The prevalence of the participants' suggestions to explore one's own ideas may be due to the lack of research, shared wisdom, and small number of music therapists practicing with this population from which to draw pre-established effective techniques. Invention, intuition, and experimentation become essential components to productive work as a music therapist with this population. Faye stated she would "throw out

whatever came to me and record the results." "Try things and experiment," she said, "don't think anything is a dumb idea."

Subtheme: Collaboration

All the participants described the importance of collaboration as a key to informing their practice. Most collaboration occurred with physical and occupational therapists, as these specialists were also peers of the music therapists in this study and would often accompany residents to group therapy. Music therapists collaborated by using music to assist in meeting goals developed by the occupational therapists, but they also developed their own interventions based on the needs identified by other therapeutic specialties. It is also important to develop collaboration as a model to inform professionalism. Being involved in staff initiatives, learning about departments, and connecting with colleagues are valuable tools for reaching clients. Faye stated that she developed her theoretical framework by watching other professionals provide care. In other words, the participants of this study mainly used their collaboration with, and observation of, experienced professionals to inform their own practice.

Collaboration as a cornerstone of the development of theoretical framework was not limited to professional colleagues. Collaboration was also important between the therapist and the client. The amount of collaboration varied greatly among the research participants. Diane described her practice as a complete collaboration between client and therapist:

> The essence of my work with my clients is those moments in sessions where we are creating the music, moment to moment together, and neither of us really know where it's going to go, but we're willing to trust each other enough to find out.

Participants agreed that the client should be involved in the process as much as possible in whatever way they can be involved. The importance of letting this population, many of whom do not have spoken language, experience having a "voice" in their therapy is meaningful to a population whose "voice" is often overlooked, stripped away, or believed to be irrelevant.

Subtheme: Power Dynamics

The person-centered approach is another prominent theme among the theoretical frameworks of the participants. Diane cited Maslow's theories of self-actualization, growth, motivation, and peak experiences as key elements to her own theoretical framework. Humanism and collaboration also informed the framework of the power dynamics. Many of the participants stressed the importance of keeping a balance of power between client and therapist. In a population that is historically stripped of power and importance, the therapists must keep the framework mentally present to ensure that the therapist is not putting themselves in a place of power or prominence above the client. Diane prefers to use the word "experience" instead of "intervention" for this reason. An "experience" makes the therapeutic process feel more of a collaboration, whereas an "intervention" sounds as if the therapist must "intervene" for the client to progress. Both Melissa and Laura referred to releasing instruments to a "neutral zone" such as a box to lessen the feeling that the music therapist is the "keeper" of the instruments, thereby giving the music therapist a feeling of more power than the client. Laura mentioned that it is key to be able to vary your therapeutic style to match the needs of your client. This is also helpful to establish the balance of power within the therapeutic relationship for a population that is viewed as "less."

Theme 2: Stigma

This theme explores various biases around the severe and profound ID population and how these biases affect music therapy practice. This theme had three sub-themes: viewpoints of others, terminology and other barriers, and underestimation.

Subtheme: Viewpoints of Others

Each participant spoke about slightly different aspects of how stigma and bias affected the ID population and those who work with the ID population. Not one of the participants initially sought out this population for their work; they fell into the work through various connections and jobs. Laura stated that this population is simply "not so glamorous" as others and not as well promoted through school or experiences during practica. Each participant's understanding and appreciation of the population grew along with their wisdom over the course of their work.

However, according to the participants in this study, not all professionals working with this population demonstrated growth in their understanding or a decrease in unconscious bias. Diane described how staff would convey amazement that specific clients with severe and profound ID would have the ability to participate in music therapy. On the opposite end of the spectrum, staff sometimes assumed that someone was appropriate for music therapy services simply because they enjoy playing with "noise-making toys." Staff sometimes claimed that a client preferred the same music as them, when in fact that client was unable to verbally advocate for their own preferred music. This assumption might have been due to staff playing their own preferred music around the person with severe and profound ID, thereby causing the person to develop more

familiarity with this type of music, while staff remained unobservant of the initial preferences or developing musical interests of the person.

Diane also spoke about staff reactions during teletherapy sessions at the start of the COVID-19 pandemic. Often staff were required to "help" participants during their telehealth music therapy session. At times this help would be riddled with assumptions and unconscious bias which Diane stated illustrated "how much work is still left to change people's perspectives." Staff would often be required to sit with clients, as it was assumed clients could not be left alone with a telehealth device. During these sessions, some staff would try to encourage clients to play instruments if they choose to put instruments down to listen rather than play. Their perspective on therapy for this population was focused on engagement rather than choice. Diane said:

> We've come a long way, but we're still not there. Even the people that work in some of these settings with the people we serve don't get it. There's still that perspective, that I'm going to go in and make this person do this, and they're going to be better for it. And that doesn't work for anybody. You know, if you want something to be meaningful, first they have to want it themselves, and they have to experience it.

It was not just staff that demonstrated lack of awareness when it came to understanding and working with the severe and profound ID population. Faye discussed how parents of young adults with severe and profound ID would make damaging assumptions about their children, assuming that they would be unable to participate or accomplish many things of which they ultimately proved to be capable. Parents would also appreciate their children's participation in music therapy as it seemed to be an

activity for a “normal” child, thereby decreasing some of the stigma and isolation from their typically 49tigmatping peers. Melissa spoke about visitors who came to the center and seemed surprised when staff would describe a client as having a “good” or “bad” day. “I’m sure people looked at the individuals we worked with and thought, ‘Really? You think they have a personality?’” Melissa said that leaning into the “real little” things helped key into a person’s mood and accomplishments, such as seeing a client smile as a critical interaction.

Subtheme: Terminology and Other Barriers

Laura stated that labels continue to change due to their tendency to become insults over time. However, labels remain a necessary part of providing services to those with ID, as Laura stated, these “descriptors are tied to funding.” Diane stated the importance of how labels are used, saying, “words matter so much in terms of how a person feels about themselves, and how then that person relates to others.”

Subtheme: Underestimation

All participants spoke about the power of the music therapist’s assumptions when working with this population. Assumptions can cause you to underestimate a person’s ability to understand or their ability to gain understanding through familiarity. Diane stated that even staff working in direct care can underestimate the “power of a person.” Faye shared stories of how students demonstrate the ability to anticipate chord changes without prompting from the music therapist. Faye emphasized the importance of encouraging innovation and doing what would be considered “normal” in any other circumstance, such as putting on performances and inviting participation in traditional musical activities without being biased based on their perceived ability.

Theme 3: Practice Intention

This theme explores how each music therapist viewed the function of music therapy with the severe and profound ID population, or the intention of their practice. Practice intentions could also be referred to as goals and objectives. Specific interventions that the participants in this study used will be described in the next section on practice techniques. In practice intentions, participants described what behaviors they asked for from their clients to improve functional skills and quality of life.

Laura's focus on neurologic music therapy was important in developing goals and creating interventions. Specific neurologic goals included vestibular system stimulation, proprioceptive stimulation, movement of cerebrospinal fluid, and bringing clients to a state of alertness, in collaboration with occupational and physical therapists. Laura stated that her objectives often emphasized the client's ability to regulate. Goals, therefore, included sensory stimulation and processing, arousal, orientation, and pattern sensory enhancement.

Melissa, Laura, and Faye participated in co-treatment sessions with physical therapists and would often include physical therapy goals in music therapy sessions. These goals included grasping and releasing objects, reaching to touch, desensitization to touch/raising the tactile threshold, hand opening, extending the range of motion, and turning the head toward a sensory target at either side.

Melissa also worked on localization and further spoke of removal of the tonic neck reflex (i.e., "fencing" reflex in newborns), which often remains in individuals with severe and profound ID into adulthood. Melissa also looked for clients to demonstrate reactions, showing some kind of behavior to acknowledge a change in the environment

such as music stopping or starting. Melissa spoke of providing stimulation to stave off lethargy and combat the side effects of some needed medications such as anti-seizure medications, which sometimes left clients in a state of perpetual drowsiness.

As a Nordoff-Robbins music therapist, Diane's practice intention overlapped but did not completely mimic that of the other three music therapists. Diane looked at the domains of development, sensory-motor, communication, cognitive skills, and emotion by reading a client's musical communication using the Nordoff-Robbins categories of responses. These responses focus on two scales: musical communicativeness and client/therapist relationship. The music the client creates reflects their own changes and growth over time. Growth is shown when a client adds a new musical skill. Diane stated, "I do believe that paying attention to changes in a person's music is how you can determine growth just as easily and in some ways in a more meaningful way than how long did they maintain grasp."

Theme 4: Practice Techniques

This theme outlines specific interventions used by the music therapists. This theme had three sub-themes: specific activities, further considerations, and session formatting.

Subtheme: Specific Activities

Each of the music therapists discussed specific activities they may use to address the above goals. In collaboration with occupational and physical therapists, Laura used "sit and spin" wheelchair dances for the movement of cerebral spinal fluid. She also used contrabass bars for vibrations, scarves for tactile stimulation, combining instrument sounds with computer visualizations for combined auditory and visual stimulation, and

instrument play for object manipulation. Laura also discussed the importance of listening as an intervention in itself.

Melissa used boomwhackers and other instruments, walking around the circle of gathered clients to encourage tracking and localizing sound. She used “vibrations a lot” with drums tables, tone bars, and wooden sound floors that encourage the transmission of vibrations. Melissa picked instruments and adapted instruments for clients that allowed them the “biggest bang for your buck,” allowing the most amount of sound for the smallest movement to encourage reactions to the sound.

Diane used the term music “experience” rather than “intervention.” She views this as a more collaborative and patient-driven vocabulary. Diane explained why she found this terminology shift important:

> An intervention to me sounds like, I’m the only one that can do it. As the therapist, I must intervene. And I’m going to do this intervention. But the experience, to me, is more a collaborative way of thinking. It might just be semantics, but to me, it makes a big difference in how, especially a young therapist, thinks about relationship, and especially with this population, there’s so much still thinking of developmental disability as an illness, and as such a barrier to independence and independent thinking and autonomy.

Diane’s experiences engaged clients in musical conversations with question-answer formats or vocal improvisation. Diane presented clients with a wide range of instruments without instruction, allowing them to play and explore. These instruments included drums, hand percussion, tone chimes, and Nordoff Robbins Reed Horns. “It’s a very exciting instrument [reed horns], and I find a lot of people who are nonverbal seem

to love this big sound coming out of their mouth." Diane also spoke of discovering uses for the Somatron, an adaptive chair that incorporates speakers and allows the listener to feel physically immersed in the music.

Faye talked about using music to encourage clients to turn their head, or promoting the use of communication devices that were already being utilized by the client's other therapists or teachers. Faye discussed the use of the 53tigmatiz[3] and having students use a switch to change chords to perform music. Faye often discussed the importance of trying many different things, or "throwing it out there" and "whatever came back to me, I would record the results." In terms of the 53tigmatiz, Faye said,

> "I found out that several children knew in two chord songs, when to hit that switch. It amazed me, because sometimes, sometimes people who learn guitar don't know when to change. So that to me, you know, that was a musical skill, but it also showed how those students had something special that no one would ever know about."

Subtheme: Further Considerations

Melissa pointed out the importance of being aware of how the environment may be impacting the client. Some of her suggestions included: a) covering lights with fabric to soften them (especially for people who cannot turn their heads away from harsh lighting), b) if possible, try not to pair loud clients with clients who easily startle when working in a group, and c) move staff to the same side of the group and move yourself

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[3] An electronic musical instrument developed by Suzuki using a sensor which you can touch to creating a strumming sound and buttons for chord changes (suzukimusic-global.com).

next to a window or light if you are attempting to encourage localization to a sound. Melissa recommended using changes in the environment, such as silences and sounds, to build opportunities for communication. Laura and Melissa discussed using the environment to "level the playing field" between therapist and client, such as the previously discussed box for release of instruments. Additionally, Laura discussed keeping visuals in the environment which outlined the session format and allowed the client to potentially move the manipulatives to create the session order themselves.

Several of the music therapists also discussed how changing the music's arrangement could help move a session forward. Laura used extended strumming as a sound cue which mimicked the motion of reaching to encourage a client to reach for an instrument. Laura also stated that instruments could be chosen that are incompatible with an undesirable behavior. Melissa discussed how to combine light and instruments, such as creating a prism on a tambourine to combine visual and auditory stimulation and encourage participation. Diane stated you can simplify music or instruments if someone appeared "stuck" during a session or if they were "pulling back." Diane also noted that keeping improvisation in the same key as a person's vocalizations helped encourage participation.

The music therapists further discussed the nuances of communication and how the music therapist's focus could drive success. Diane said, "ask direct questions and interpret the response." "Take any response they have. Take it and go with it," said Melissa. Laura phrased all communication to encourage participation.

> You never asked, “yes, no.” You never say, “Do you remember?” You never say, “Do you want to?” You say, “Let’s see you, let’s see you do this.” Keep the focus on the person and their response … There is always a response to be ferreted out.

Subtheme: Session Formatting

All participants referenced session formatting as something important to working with ID clients. Laura stated that consistent formatting helped set clients up for success in demonstrating understanding built on comfort and familiarity. Melissa reiterated this idea, using repetition and sameness in a session format to build anticipation and familiarity. Laura built her session plans around creating an engaging and interactive musical environment for all, even involving staff whenever possible.

Laura, Melissa, and Diane all discussed beginning sessions with a musical greeting. Diane switched to a verbal greeting when more appropriate for the session. After the musical greeting, both Laura and Melissa followed their session plan using the principles described above. Diane focused on musical improvisation in her sessions, allowing the client to decide where the session goes, following with the music that she was observing from the client. Faye stated it was important to start interventions by matching the client’s current mood. “Find them where they are and pick up on that.” Faye then moved the session to focus on each domain outlined in the client’s IEP.

Theme 5: Considerations of Effectiveness

This theme discusses how music therapists defined and measured effectiveness. This theme has two sub-themes: records and eligibility.

Subtheme: Records

Diane explained that while her view of what makes music therapy effective has remained consistent, documentation of effectiveness has changed as employer regulations have changed.

> When I started out, I was writing very sort of behavioral, quantitative goals and objectives, because that's what my employer required. Although my work, has always in music centers [*sic*], so I can document how it needs to be documented and still do the work the way it seems to make sense for the clients. Now at work, even though it's same employer for 40 years, now they don't want any numbers from—it's all person-centered language.

Diane most recently used "valued outcome states," which uses broad person-centered language. She gave the example, "Susie wants to participate in music therapy experiences that provide opportunities for cognitive stimulation, self-expression, and to maintain emotional and physical ability." Documentation would then build on skill areas that are witnessable even if they are not being numerically measured, such as, "Susie is engaging in cognitive stimulation experiences, and working towards self-expression." Diane used treatment plans that consisted of the style of music and clinical techniques that may be implemented in a session. The treatment plan kept up with the client's needs, adding or taking out techniques as the client experiences changed. Diane completed monthly summaries for each client, including what music was used and any unusual things that happened in sessions, as well as mentioned specific successes. Every six months an updated report on the original assessment was completed and the treatment plan was reviewed. Diane stated that changes in this population typically happened over a

long course of time. Diane explained her process for reviewing assessments and creating treatment plans:

> I do look at things in the major domains of development, sensory motor skills, communication, cognitive skills, affective emotion, development. I also, as part of that, include the Nordoff-Robbins categories of response . . . because those really can help inform a lot of what I'm going to initially consider for treatment plans. Measuring the categories of response measures, looking at changes in somebody's rhythmic stability is, to me, a real measure of growth. So I look at all the areas, generate a report that talks about what I've seen musically in all of those domain areas, and then that sort of generates, is the person an appropriate candidate or not, and then, if so, what, what the initial focus in therapy would be.

Both Laura and Melissa used objective measurement-focused assessments using short- and long-term goals. Laura gave the following example (Laura used the names "Sue" and "David" as pseudonyms):

> David will use his tactile senses following relaxation. That's the long-term goal. Short-term objective: Following relaxation procedures. Sue will maintain contact with textured objects using an open hand pattern for 10 seconds, 60% of the trials by 5/21/21. Some long-term goals. Sue will use her tactile senses. Short term: Sue a reach to touch an instrument, drums, maracas, bells, tambourines, guitar, etc. presented to her in midline once per session 60% of recorded trials by XYZ date."

Faye also discussed using assessments to record measures of effectiveness. Faye used measurable assessments along with the "human dignity element that you can't always measure." Practically, this looked like keeping observation checklists such as time

measurements alongside anecdotal progress reports. Faye stated the purpose of keeping records was not just for informing the music therapist of a client's progress, but also communicating to staff and parents "the what I'm doing and why I'm doing it of music therapy."

Subtheme: Eligibility

Eligibility in this case referred to determining if music therapy was appropriate for a client. Laura asserted that as long as the client was demonstrating gains in functional skills while participating in music therapy the service was considered appropriate. If a client began to show adverse reactions, rather than discontinue music therapy the music therapists would work on adjusting the session to better serve the client. Laura also stated that while music therapy may not be recommended for everyone, there were very few times someone would be discontinued from music therapy services.

Melissa agreed with Laura's approach. Melissa may adapt music therapy to fit the client by removing certain stimulations such as vibrational or tactile or limiting loud instruments to avoid startle responses. Melissa added a reminder that responses in this population are often small. "It may take two years for someone to start turning to look at a sound." Persistence and adequate time were therefore also important to determine the effectiveness of music therapy and deciding on continuing services. Both Laura and Melissa worked for an intermediate care facility for intellectual disabilities. Laura described below how the facility's overarching goal affected the view of eligibility for music therapy services.

> One of the main requirements of an ICF [Intermediate Care] facility versus a skilled nursing facility is that people are there for an intermittent period of time.

> They’re going to improve, and they’re going to go somewhere else. . . And one of the services that is required by the regulations for ICF MR [Intermediate Care Facilities for Individuals with ID] Facilities is that a person receives a specialized program of active treatment. So as long as music therapy is looked at, as a way to gain functional life skills, it’s deemed you know, we’re a player in the active treatment arena. So there were very few times where we would discontinue somebody, because we could demonstrate active treatment really well and [document it].”

Diane leaned heavily on her treatment plans to determine effectiveness and eligibility. The six-month plan determined if a person was still experiencing growth and positive sense of self. Though some clients remained long term, some also achieved a determined goal from music therapy and communicated in their own way that they did not need to continue services. At times Diane may have implementd a “music therapy vacation” using collaborative contracts with the client who was able to verbalize their wants and needs for their music therapy achievements, or by listening to the “clear message” a client might be communicating through behaviors that they needed a break. These behaviors could include repeated refusals to come to therapy, repeated leaving of the therapy space, or repeated intentional destruction of music therapy property such as instruments (different from cases of momentary extreme distress or agitation). Diane had experienced times when people other than the client believed the client wanted to be in music therapy when Diane felt that person was not in need of services. “It’s not the right thing for everybody, that’s certainly true.” Diane gave an example of misconceptions that may cause inappropriate services recommendations:

> He loved holding noise-making toys. So people thought he needed music therapy. You get the referrals, like, "well, so and so loves music." Well, I'm very happy to know, that does not necessarily mean, you know, an entry into therapy.

Theme 6: Observation of Communication

This theme explores how music therapists communicated with the severe and profound ID population. This theme had three sub-themes: behaviors, adaptations, and hints and tips.

Subtheme: Behaviors

Interpreting behaviors as communication, according to all the music therapists, was an exercise in noticing details. Table 3 lists behaviors the music therapists would look for while watching the client's response to music therapy and their intended communication according to the clinical wisdom of the music therapists.

Table 3

Behaviors and Communications

Communication	*Behavior*
Interest/Arousal	Turning towards a sound Picking up head Pupil dilation Tongue movement Eye movement Change of smile Change in body position Change in breathing pattern Reaching for instrument Change in facial affect Vocalization increase Opening eyes wider Attending eye gaze Synchronizing with therapist
Relaxation	Deep breathing Opening posture Dropping of the abdomen after cessation of swallowed air Change in breathing pattern
Aversion/Overstimulation	Change of smile Change in body position Rapid Blinking Change in facial affect Vocalization increase Refusing to synchronize (evasive beat keeping/vocalization)

As many of the behaviors can communicate multiple states of being, Faye noted it was important to take all behaviors as a "whole package" to better understand their meaning.

> I mean, crying isn't necessarily a sign of sadness. It's an emotional reaction. So I had to take everything as being part of a big picture. And that whatever it was,

> turning the head you know, if they liked a particular song, a smile or some kind of opening the eyes wider, [it] was all part of the communication.

Subtheme: Adaptations

Faye discussed several adaptations she incorporated from school age to younger adult students. These adaptions assisted students with communication. They were sometimes implemented in music therapy to reinforce what was being utilized in the classroom. These adaptations included communication boards, yes/no signs or buttons, writing language or spelling (for students with language but not speech), boards with buttons with pre-recorded phrases, cards for comprehension questions such as "is the music fast or slow?," and cards and instruments to indicate different parts of songs or to assist students in pointing out preferences.

Subtheme: Hints and Tips

Each music therapist had several hints to assist with communication between therapist and client. Faye brought her knowledge of early childhood into her work with adults with severe and profound ID. "When you're working with adults, a knowledge of childhood physical, sensory motor, cognitive development is really important to find what makes cognitive attention fire and respond."

One aspect of childhood development that Faye carried into her session in an age-appropriate manner was the use of narration in sessions. Faye found it important to narrate what was going on while working with a client, including what she was doing or planning on doing, and what communication she was seeing from the client.

> [Narrating] came out of my experience working with three-, four- and five-year-olds. Because that's what you do with little kids. "Oh, you're holding a flower in

your hand." You're developing their language sense. Teaching them words, but also teaching them communication. . . Also, it helped me put a framework around what was going on in the session, and describe it for myself as well.

Laura, Faye, and Melissa discussed using choices as opportunities for communication and presenting clients with them often. Choices were built into sessions as a communication tool as well to preserve autonomy and allow the client to collaborate.

Allowing time and looking for and responding to subtle behaviors were two factors reiterated by Faye and Melissa. "Look for the really minuscule kinds of responses and see [those] for the significance that [they are]," Faye stated. Melissa added, "Take any little response and go with it …allow a great amount of processing time for responses." Faye shared that some of her students may have responses so delayed that they are seen by the teachers well after the end of the music therapy session. "The teacher would tell me, 'she started singing or humming after you left.' So it's important to recognize [the response] is not going to be always within that half hour that you're with them." Melissa used the example of "head shoulders knees and toes." Using the repetition of the song assists in the processing delay. By the time the client is moving to touch their head, the second repetition of the song may have begun.

Theme 7: Music Selection

This theme discusses how the music therapists selected music for the severe and profound ID population. This theme had two sub-themes: selection and songwriting.

Subtheme: Selection

Laura had a clever method of selecting music to help introduce current music and explore client preferences. During these explorations, she would use recorded music,

specifically the Grammy sampler, which includes current music in five different genres. She would then watch for differences in behavior for specific music as compared to others to determine preference. Laura mainly used live music and would implement songwriting. Live music is important for the flexibility it brings to a session. Melissa, like Laura, used mostly live music, occasionally allowing individuals to bring in recorded music. As long as the music therapists were familiar with the songs, they could play along to a song during a session.

Faye often used instrumental music because of the range of tones and timbers and promotion of movement. A local orchestra would perform a string quartet of interactive classical music at Laura's center. This allowed clients to hear live instrumental music in a concert-style format that they may otherwise not have been able to experience due to wheelchair tolerance times and accessibility of concert halls.

Faye also spoke of using a client's preferred music as a reward for participating in something less familiar, or as a jumping off point for improvisation. She also utilized the 12-bar blues to communicate someone's mood or found one-chord songs that could be played by clients on the Q-chord/64tigmatiz to encourage participation. Faye used camp songs and traditional folk music, which is "age appropriate for people of all ages." Faye stated that sometimes a person may get "stuck" developmentally in an era that was most important to them, and their music choices reflect that era. She may use the melody of preferred music and adapt the words to indicate what a person is currently doing or change the style to feel more in line with the person's age.

Diane had a slightly different viewpoint on the age appropriateness argument for music selection.

> If somebody loves a song, they love the song, and if it's a child song and the person is 80 and they still love that song, it's 'appropriate' for them. I try to always respect and value the music that clients seem to indicate in whatever way they do, what's meaningful for them.

Diane assessed the client's responses to different musical styles, sometimes also using recorded music to assess preference. She used her full repertoire to see what makes someone "sit up and say 'oh!'"

Subtheme: Songwriting

Laura, the songwriter of the group, discussed different methods for writing that encouraged clients to demonstrate functional skills and meet objectives. She wrote songs with specific behaviors in mind, using the melodic line to mimic the desired movement and repetition to allow for moments of synchronicity despite delayed processing times. Laura also used repetition as a timer to measure occurrences or durations of behaviors for assessments. Creating music where any responses sound harmonious, such as utilizing the pentatonic scale or fluidity or rhythms, encourages client participation and a positive sense of self. Meter is a tool Laura used to indicate different types of movement (3/4 for rocking motion) or to cue a change in movement with a change in meter. Laura also stressed the importance of precise language when writing music. She would use "positive" lyrics–language that asks for a desired behavior rather than stilting an undesired behavior. Laura sometimes teamed up with a client and co-wrote songs in the client's preferred style using the client's exact words for lyrics to promote self-expression and autonomy. Melissa used original music to preserve age appropriateness while implementing interventions with the population. Melissa warned that while popular,

“piggybacking” songs by changing words to popular melodies, rather than writing original melodies, can often cause confusion as the melodies are often most recognizable (i.e., changing “jingle bells” to “fourth of July”).

Theme 8: Instruments

This theme presents how instruments were chosen and implemented in each participant’s practice. This theme had three sub-themes: instrument types, further considerations, and adaptations.

Subtheme: Instrument Types

Laura used instruments of varying diameters for opening the hand. The size, timbre, and maneuverability of the instruments are all important when considering their effectiveness and the client’s ability to use them. Melissa discussed specific instruments she found to be most easily adaptable for the severe and profound ID adult population. Handbells (easy cylindrical grasp as well as option to make a sound if you cannot grasp them), cabasas (easy to hold, provide tactile stimulation), shekeres (can be self-made with knots and beads and therefore timbre is adaptable), boom whackers with or without activators (can hold or strike and observe colors), and drums (vibrations).

Subtheme: Further Considerations

Faye stated that even for younger students she did not use “toy” instruments due to their difficulty to grasp and play. To Faye, the instruments chosen needed to be age appropriate to preserve the dignity of the young adults playing the instruments. Melissa used instruments mostly tuned to the pentatonic scale to create harmonious sounds. Melissa also discussed instruments that have been manufactured, and often used, without their effectiveness being considered. For example, shape drums are difficult to hold and

have no place to hold that does not dull the vibrations to play. Fruit-shaped shakers can cause confusion as they look as if they should be eaten. “A maraca is a maraca, leave it at that,” Melissa said. Melissa also shared that instruments do not have to be limited to being played by the client with their hands. She would unstrap the client’s legs from their wheelchairs and set them on the guitar as she played to provide stimulation.

Subtheme: Adaptations

The following is a list of adaptions created or utilized by Melissa that have proven effective in her practice with the population: extra large guitar picks to keep from hurting hands with strumming or dropping small picks into the guitar, tuning the guitar to a single chord and using the capo so clients can grip the guitar lower on the neck without muting the sound, attaching ribbons to triangles for the client to hold while staff plays the instrument (allowing the client to feel the vibrations), T-shaped mallets for ease of playing, jump rope handles with springs attached to mallets to allow for rebound without requiring the client to pick up the hand after the strike, rhythm sticks to hold drums off of wheelchairs to allow for resonance, and shorter mallets that are easier to stabilize.

Summary of Findings

In this chapter, I discussed each theme and subtheme, explaining how participants contributed to each theme with their own unique wisdom. The themes included the music therapists’ theoretical frameworks, the goals and objectives they focused on with this population, specific interventions used, how they decided and documented effectiveness, how stigmas impacted their practice, their ways of communicating with their clients, how they selected music and instruments, and what they believed demonstrates effectiveness.

In the final chapter, I will discuss how the themes answer the research questions. I will identify key differences and similarities among the music therapist's collective wisdom. Finally, I will relate information presented in the themes to the theoretical framework.

CHAPTER FIVE

The purpose of this study was to explore the clinical wisdom of music therapists experienced with working with adults with severe and profound intellectual disability (ID). The first chapter outlined the lack of research and societal problems which have contributed to the isolation and underfunding of this population. The second chapter outlined current research, the effectiveness of music with this population, and the impact of further research specifically regarding clinical wisdom. In the third chapter, I described the research methods and presented the results in Chapter 4, reporting on the clinical wisdom of each of the four interview participants and categorizing their experiences into a thematic structure. In this chapter, I will present results of this study according to my research questions, relate the themes to current research and the social model of disability, and discuss limitations of this study and directions for future research.

Discussion of the Research Questions

How Do Music Therapists Define Effective Treatment with Adults with Severe and Profound ID?

Session Effectiveness

All the music therapists agreed that attuning to the client's behavior and using it to drive the session is key to providing effective treatment. For example, Diane stated, "Sometimes the responses are so subtle and if you miss it, you might have missed the whole session." Faye echoed this sentiment, "look for the really miniscule responses and see [them] for the significance that [they are]." Laura shared the importance of keeping the focus of music therapy on the "person and their response," and Melissa pointed out the value of using the responses to move the session forward, "any response they have,

take it and go with it." These small behaviors not only drive the session, but also determine if music therapy is functioning effectively throughout the session. Laura explained thatthe music therapist's response to these small behaviors determines the effectiveness of the session.

> Turning towards sound, reaching, changing position, turning away might be a response and important response to and could be that you're approaching you too loud when you're approaching. . . Rapid blinking means they're overstimulated. They're trying to self-regulate the sensory input, it's too much too, too loud, too close too fast. Unwelcomed . . .And then I have to step back, take a deep breath, calm myself down. . . . So as a therapist, know how to turn on a dime [when] it's all racing through your head and nanoseconds of, "okay, how do I how do I, this isn't working? What do I do?

This idea held by the participants supports the research of DeBodout and Worden (2006), where greater engagement was found while using live music therapy versus recorded music. Although DeBodout and Worden did not speculate on the exact components that may have been causing the improvement in engagement behaviors, it is possible it is due to the music therapist attuning and responding to the clients, as the participants in this study cite.

While the attunement to small behaviors and using them to adjust one's approach determined the effectiveness of the session, it is also essential to determine effectiveness over time. All the music therapists used the careful selection of goals and objectives combined with documentation to determine the effectiveness of music therapy over time. However, the chosen goals and documentation type, and therefore the idea of what

constituted effective treatment, differed according to each music therapist's unique worldview. Various models of disability were reflected in each participants perspective on effective treatment.

Reflected Models of Disability

Both Laura's and Melissa's definitions of effectiveness fit best with the medical model. The medical model means of determining effectiveness focuses on assessing behaviors that translate into functional life skills. The music therapists documented these behaviors numerically, by duration or instances of occurrence. For example, turning the head to localize a sound, timing maintaining a grasp of an instrument, or counting the number of times a client releases an instrument back to a bin without assistance. These behaviors may translate to non-musical tasks such as attending to a conversation (head turning), holding eating utensils (maintaining grasp), and releasing painful contractions (releasing grasp). Laura stated, "putting an instrument back in a box . . . it's really a functional skill of manipulation of objects."

Faye appeared to fall into the affirmative model when determining what assessments indicated effective music therapy. Faye used both specific interventions and measured behaviors by duration or the number of occurrences to provide intervention to assist with client's limitations, while also being sure to note the importance of including the "human dignity element that you can't always measure" by providing equal opportunities for persons with ID within the community. "Providing something that gives joy, pleasure, comfort, or memories is very significant, though the significance isn't always obvious." Faye also stressed the importance of considering the emotion and motivation behind the behavior she requested of the client. She stressed the importance of

taking in the “whole package” while counting behavioral instances. The “whole package” includes affect changes, vocalizations, perceived effort, and so forth. For example, how far the head turns when localizing to a sound must include any change in affect for the client such as a smile or a grimace.

Diane stated her approach is humanistic[4], and her view of what makes music therapy effective has informed her lens as evidenced by the goals she created for her clients. Diane appears to fall under a cultural model of disability, viewing persons with ID as being marginalized by society and highlighting their unique abilities by honoring their individuality. Stated that where behavioral observations focus on a person’s functional skills, she prefers to look at the person as a whole. She focuses on broad quality-of-life goals with opportunities provided through music for stimulation and development. She used narrative accounts of specific breakthroughs alongside general session documentation to demonstrate the value of continued services on her clients’ psychosocial well-being. In keeping with her approach, Diane chose to use the terminology “experience” rather than “intervention.” This change in terminology creates a different intention in the clinical space and has implications for determining effectiveness. The choice of the term “intervention” (consciously or unconsciously) implies that the music therapist must intervene to fix, whereas an experience is a collaborative engagement with the music therapist. Diane strove to create opportunities

[4] The humanistic approach asserts that people are inherently good and well-meaning and will tend towards self-actualization (the complete realization of one’s potential), given the correct environment and opportunities (American Psychological Association, 2023).

for development through musical experiences and tracked the client's musical changes over time.

Impact of Work Environment

There appears to be a correlation between the music therapist's definition of effectiveness and their work environment, which has been described by Gfeller (2008).Gfeller stated that a music therapist's approach to treatment consists of their personal philosophy, their experiences with the population with which they work, and the "established policies and treatment models" required from the facility in which they work. Facilities, rather than the music therapist, often determine what constitutes effective treatment and how effectiveness should be documented. Where Laura, Melissa, and Faye's approach seemed to reflect the framework of their workplace, Diane discussed how her employer's philosophical view did not always match her own.

> My documentation has changed over time in response to employer requirements, but my actual clinical engagement with my clients really, I think, just deepened over the years, simply because I've grown as a musician and therapist, so it's, it's just expanded tremendously in that regard. But the foundations are the same.

Both Laura and Melissa worked in a facility that appeared to hold a medical model approach. The facility's stated intention is to improve personal skills to allow clients to reach their full potential. As Laura shared, "One of the main requirements of an ICF (Intermediate Care Facility) facility versus a skilled nursing facility (SNF) is that people are there for an intermittent period of time. They're going to improve, and they're going to go somewhere else." The focus is therefore on motivating clients to perform

specific behaviors. Documentation through time or frequency measurements are used to measure occurrences of behaviors.

> One of the services that is required by the regulations for ICF ID facilities is that a person receives a specialized program of active treatment. So as long as music therapy is looked at, as a way to gain functional life skills, it's deemed you know, we're a player in the active treatment arena. . . We could demonstrate active treatment really well and document it . . . The music therapy department never got cited for when the surveyors came through. Surveyors come through once a year and check records, follow people and observe.

It appeared that Laura's and Melissa's method of documentation and definition of effectiveness was defined by their employer. Laura's and Melissa's philosophies on effectiveness also appeared to mirror the model presented by their facility.

Faye worked in a school setting with children and young adults. Her goals and objectives, and therefore markers of effectiveness, were based on individualized educational plans (IEPs) created by teams of educators and therapists working with the students. Faye used checklists and time/occurrence measurements for specific behaviors, which reflected the educational model of the school. However, Faye's "human dignity" element included qualitative goals and objectives such as normalization, autonomy, and self-expression. "Providing opportunities for providing something that gives joy, pleasure, comfort or memories is very significant, though the significance isn't always obvious." Faye stated that therapeutic services were included on students' report cards, which included sections for anecdotal notes as well as quantitative assessment data. It seems Faye's eclectic philosophy, much like the documentation required by her facility,

also mirrored that of her employer, and Faye saw effectiveness as both demonstrating increase in occurrence and duration of functional behavior as well as providing experiences that may be supported anecdotally.

Diane did not always see eye to eye with her employer's view of effectiveness. Diane related a case in which her employer continued to push for services to be provided to a client for whom Diane believed music therapy would not be appropriate. The client's travel to her office caused much distress and the client gave several indications they were not interested in services. It was not until the client began screaming for the entirety of the commute to and from music therapy that the team agreed to terminate services. According to Diane, her view of what is most effective for her clients has remained consistent throughout her career, despite at times contradicting her employer's philosophy. Diane did state that her employer has transitioned to a more Humanistic approach over time.

Diane believed music therapy is not always effective for everyone and the assessment process is fundamental to determine if services may be effective for the client. On the other hand, Faye, Laura, and Melissa thought there are few instances where music therapy cannot be effective for a client, as music and interventions can always be adapted to the client's specific needs. These differences in viewpoint on providing services and determining effectiveness could be influenced by the types of clients served by a music therapist's facility and how the employer's expectations function for the population they serve.

Workplace Trends and Models of Disability

There appears to be no research from the past 20 years on how music therapists' perception of effectiveness correlates with their work environment or their own philosophy and approach to practice. There also appears to be no research in the past 20 years on how the philosophical views of music therapists or their work environments have changed over time. Beebe (2022) and Swaney (2019), whose focus (like Diane's) is around experiential and improvisational music therapy with a Humanistic approach, tended to share the same view of effectiveness as Diane. This also happens to be the most current music therapy research on work with this population. Earlier research on music therapy with this population largely endorsed objectives focused on measurable behaviors to either increase functional skill or tolerance of stimulation (DeBout, 2006; Hooper, 2008). It is possible the view of what makes music therapy effective is trending toward a more Humanistic approach, paralleling American society's trend toward the social model of disability and away from the medical model.

Staab and Dvorak (2018) seemed to demonstrate this trend towards the social model of disability in the viewpoints of direct care staff. Direct care staff stated that they preferred to see music therapists working on goals relating more to quality of life and less on increasing functional skill. Swaney (2020) also reflects this trend, moving toward an affirmative model approach, using music to build therapeutic relationship and provide "unconditional positive regard" and self-affirming experiences.

Summary: Effectiveness

In summary, the participants of the study perceived effectiveness in accordance with their practice philosophy and approach. Those whose focus appeared to be more medical model-based used increase in functional skill measured by time or occurrence of

specific behaviors to demonstrate effectiveness. Those with a affirmative or cultural model approach focused on client experience and anecdotal, or person-centered, language in their documentation to demonstrate improvements to the sense of self, normalization, and other broad outcomes over time. The music therapists' view of effectiveness appeared to be heavily influenced by their workplace. The employer sets the goals and what constitutes effectiveness, which in turn shaped the way the music therapists measured and documented their effectiveness.

Further implications arise when framing these findings within the Social Model of Disability. It appears that facilities, and perhaps also music therapists, may be trending toward a Social Model of Disability when considering effectiveness of services. There appears to be a potential for moving away from measuring segmented behaviors and towards more anecdotal, broad quality of life measurements in documentation. The Social Model of Disability asserts that it is society's lack of provision and understanding that causes impediments to those with ID. When we view effective treatment through this lens, it appears we move from increasing skills toward expanding opportunities for persons with ID to have normalized experiences and personhood. Further research is needed to determine what is truly most effective in improving the quality of life for our adult clients with ID.

How Do Music Therapists Carry Out Evidence-Based Practice with Nonverbal Adults with Severe and Profound ID?

Practicing in an evidence-based way involves using the most sound and current research alongside one's own expertise (i.e., clinical wisdom) informed by the uniqueness of each client to provide the best possible care (Larson, 2018). The music therapists

discussed using their own expertise, writing and presenting their own informal research, and allowing the individual client to inform their practice, but did not speak of using current research on the ID population. Melissa, Donna, and Laura described using research from other populations and adapting the information to serve their client base.

Research

As described previously in the literature review (Chapter 2), research with the severe and profound ID population is starkly lacking, and even more rare when attempting to find specific applications to music therapy. Hooper et al's (2016) review of literature on the population showed mostly case studies and some quantitative data on active music therapy being more engaging than passive recorded music making up the majority of the research base. Therefore, research as a reference point for providing evidence-based practice is often adapted from other populations. Melissa shared, "I was a big conference goer, and I remember learning early on that because for this population, there are very few sessions." Laura described using current research on the neurotypical brain to transfer to potential interventions for her clients, such as vestibular stimulation and movement of cerebral spinal fluid. Faye stated it is essential to understand child development and apply it to better understand the intellectually disabled brain. "When you're working with adults, a knowledge of childhood development, physical, sensory motor, cognitive development is really important to find what makes cognitive attention fire and respond."

Clinical Wisdom

Three of the four music therapists described using the clinical wisdom of other professionals, such as occupational and physical therapists, in their own practice. Laura

and Melissa described how they would often co-treat with physical therapists to assist with grip and opening of hands.

The main way music therapists were informed was through their own clinical wisdom developed through experience and what they believed to be the desires and needs of their clients. Types of identified needs and clinical wisdom varied with session type (group or individual) and setting (residential, educational, or private practice). For example, Faye worked as both a music educator and a music therapist with her population. Therefore, interventions and engagement revolved around providing opportunities for clients to have normalized music making experiences as would be seen in the schools of their peers. Faye would create opportunities for her school-aged and young adult clients to perform at concerts. Melissa and Laura's clients were often in their residential facilities for a short period, and goals focused on improving functional skills, leading their wisdom and client need to be driven by marked behavioral improvements. Diane's adult clients were often seen in individual settings, and she focused on providing opportunities for individual expression and relationships. Each type of setting led to unique ways in which each music therapist carried out evidence-based practice, whereby clinical wisdom and client need were the most accessible means for informing practice.

The participants also described having an attitude of experimentation as an important tool in growing their clinical wisdom. Faye stated, "I'd throw it out there and whatever, whatever came back to me, then I would record the results," Melissa said, "it's an attitude, too, that you bring to it, trying new things. And, and you know, they work, or they don't work. Who knows?" Donna's work, which focused on improvisational experiences in particular, leaned on this attitude. As she stated,

> sort of the essence of my work with my clients is those moments in sessions where we are creating the music, moment to moment to moment together, and neither of us really know where it's going to go, but we're willing to trust each other enough to find out.

Client-Informed Practice

The unique needs of each client were a large part of the information utilized for evidence-based practice for all participants. This included moment by moment observations of nuanced client behavior as well as the client being as involved as possible in decisions regarding services. This might be especially difficult with non-speaking clients, but as Diane said, "It's on us to do our best interpretation, our most informed interpretation of facial affect, body posture, body position, movement, all of those things to determine [communication]."

In the moment, the therapist must observe behaviors, interpret to the best of their ability, and quickly react to a client's needs. Melissa related the importance of meeting the client where they are, adapting to what a client "brings to the room" or what type of day they are having. Faye shared that if a therapist perceives resistant behaviors, they may need to try another time of day or another day all together.

> My intervention was kind of multi-faceted. I had to see where they were, that day, at that moment. You know, if they were fussy or crying or in pain, or, you know, or happy or, like I said, asleep, or feisty or whatever. I had to match to that and pick up on that. Find them where they were.

Laura shared that a music therapist might need to change their leadership style according to the information the client is giving.

> It's too much too, too loud, too close too fast. Unwelcomed that that's a very important sensory cue to pay a lot of attention to. And then I have to step back, take a deep breath, calm myself down. So [have] a wide range of leadership styles and approaches in your repertoire. Maybe [they] need a really quiet, slower, deliberate approach and could be sitting next to somebody who really is a more high energy person. [Know], as a therapist, how to turn on a dime. It's all racing through your head and nanoseconds of, "okay, how do I how do I, this isn't working? What do I do?"

Giving clients long-term control over a session also informed the participants' practices. Laura stated, "Involve people in the process as much as possible for whatever they could do." Faye seconded this sentiment stating, "make sure they have a voice…in how things proceeded." Donna related some specifics on how to include the client's unique information in the treatment process.

> Depending on who they are, we'll collaboratively like design a contract. Like, this is a six-week music therapy vacation. Or it might be a six-week music therapy achievement contract. I have people that want to be in music therapy, and I do not believe that they need to be in music therapy. So, then we'll have to put something in writing that's pretty specific [like], we're going to meet once a week for eight weeks, or 12 weeks, or whatever it is, and here's what we're going to work on, and at the end of that time, we're going to review where we are now. There are other times when I have to make the decision because the person can't engage in that kind of collaboration, but their message is clear. Either repeated refusals to come to therapy, or coming into therapy and refusing

to stay or being destructive, while in music therapy, and not because of a moment of extreme distress, or agitation, but intentional sort of destruction or aggression. Those are different ways different people have of communicating when they're, when they're done.

How Do Music Therapists Promote Engagement in Adults with Severe and Profound ID?

Promoting engagement depends on the selection of interventions or experiences for the client as well as the music therapist's interpretation of the client's response to interventions. Each client has their own unique way of communicating. Determining whether the individual with severe/profound ID is engaged relies on the interpretations of behaviors by the music therapist. The music therapists in this study spoke of some potentially "universal" signs of engagement as well as the need for the therapist to be aware of more enigmatic and individualized behaviors. For example, to the inexperienced eye, behaviors that look like withdrawal may be signs of engagement. These behaviors may include closing their eyes when the music starts or appearing to turn away from a sound, while they are actually moving one ear closer to the sound source. All participants noted the importance of vigilant observation over time to better understand everyone's communication methods and, therefore, their signs of engagement.

Determining Engagement

The following is a list of more common signs of engagement indicated by the participants: eye gaze (tracking), eye movement, pupil dilation, facial expression, tongue movement, turning of the head, a slight change in smile type, a deep breath or change in breathing pattern, a drop in the abdomen after allowing the release of swallowed air, a

change in body position allowing for posture opening, reaching or turning towards sounds, or synchronizing sounds or movements with the music therapist. Faye noted the importance of considering these behaviors collectively as a "whole package" rather than individually. For example, if a client turned their head away from a sound while simultaneously smiling and changing body position to be close to an instrument, they might be demonstrating engagement, switching to a preferred ear with which they would like to hear the sound. If the music therapist isolated the behavior of turning the head, the behavior could easily be misinterpreted as the client withdrawing from sound rather than greater attendance to it.

Behaviors that may indicate withdrawal, lack of engagement, or overstimulation include rapid blinking (overstimulation), intentional refusal to synchronize with the music therapist, moving out of the therapy space, or intentional destruction of property. Diane, Laura, and Faye noted that throwing an instrument may be demonstrating a lack of engagement, overstimulation, or happy excitement. To interpret this behavior, one must look at all the behaviors collectively as well as interpret the energy behind the behavior.

Allowing processing time is also essential to determining if a client is engaged. Faye discussed how some students would appear unengaged throughout an entire session, but hours or even days later the student's teacher would mention to Faye that the student had begun humming a tune introduced in a session. It may take singing an entire song before a behavior appears in response. Repetition allows for greater processing time along with opportunities for synchronicity with the music therapist.

Promoting Engagement

Primary to interpreting behaviors is recognizing them. The therapists noted the importance of recognizing minuscule behaviors, or taking every small behavior offered and "running with it," even when the cliente seemed to not be communicating anything. This is essential to promoting engagement. Responding to behaviors opens channels for communication, demonstrating one's efforts to understand and enter the other person's world. Eventually, the small behaviors which one notices may become less minuscule, and greater communication attempts may arise as the individual recognizes one's attempts to honor their expressions of autonomy.

The interviewees also discussed clinical skills the therapist can use during a session to improve engagement levels. These skills included: narrating what one is doing, giving choices to increase opportunities for engagement, using sound to cue a behavior, finding a way to be at eye level with someone to neutralize the balance of power, using silence strategically to gauge response, simplifying the music or instrumentation if someone appears to be pulling back, staying in the tonality of vocalizations, trying to walk the fine line between startling and putting someone to sleep, keeping consistent formatting to promote familiarity and comfort, and repeating music so clients can become familiar and recognize more nuances.

Engagement with this population required the music therapists to be in tune not only with small behavioral differences but also with the environment. It was important to note environmental distractions that might be pulling the client's attention and creating communication behaviors in response to the environment rather than the music. This might include the placement of windows or a favorite direct care worker, the type and location of lighting, outside noises which may be triggering (such as other residents

crying in nearby rooms), and even lack of outside noise (a television which is typically left on being suddenly turned off) that may make a client uncomfortable in a setting. The nuances of everything the client and the music therapists do were essential for successful engagement.

The Hazards of Interpretation

As individuals with severe and profound ID often do not utilize spoken communication, music therapists are left to interpret their behaviors and are therefore always at risk of misinterpreting these behaviors. For example, I had a client who would smile when she was upset with a stimulus. While staff would interpret her smile as engagement or enjoyment, as I developed a therapeutic relationship with her and learned that she was bearing her teeth and clearly communicating "I don't like that." This client's engagement hinged upon my ability to be aware of my assumptions, take time to interpret this response, and adjust my practice accordingly. However, it is possible that both the staff and I are incorrect in our interpretations.

My favorite story that came out of these interviews was told by Diane, and I have found myself retelling it frequently. Diane spoke of her sessions with a young man who had received a traumatic brain injury from a car accident. This young man engaged in music therapy with ferocity, playing instruments with harsh loud sounds and appearing to thoroughly enjoy wearing himself out in each session. At each session's close, Diane would sing a short goodbye song, and each time the young man would begin to cry. Diane initially interpreted this behavior as the client being upset that music therapy was ending. One Christmas morning, the client improbably woke up with spoken language (which some might call a "Christmas miracle"). Diane stated he came to the session

talking as fast as he had played the instruments with words like a “drunken sailor,” ready to play and engage. They went through the session as they always had until the very end. Diane shared:

> And he says, “Wait . . .I have something to tell you.” So, I said “okay.” He said, “you know, I cry through the goodbye song every week.” I said, “Yeah.” He said, “I hate that fucking song.” I’m like, “Oh, oh, my god, I’m so sorry. I never- I thought you were just sad the session was over.” He was like, “No, it’s the worst song. Don’t ever play it again.”

It is oft’n difficult to interpret behaviors even of those we know well who have spoken communication. Severe and profound ID adds a whole new dimension to interpreting the behaviors of those without speech. We can only determine engagement from our own perspective, and at times that perspective may indeed be flawed despite our best intentions and efforts.

Summary: Engagement

The participants in this study spoke very little of specific interventions or experiences they found to be engaging, instead referring to communication and experimentation as the driving forces behind keeping a client engaged. They discussed key behaviors to be aware of to assist in interpreting responses. They also discussed being aware of environmental factors and manipulating the environment to best motivate engagement. To recognize these behaviors and environmental stressors, one’s ability to engage with the client’s inner world is of the most importance.

I have personally found this to be true in my own practice. I feel as if my ability to engage with clients and interpret behaviors has improved with time and experience. As

emphasized by all four participants, taking note of small behaviors has given me the ability to develop strong therapeutic relationships with my clients—noticing a turn of the head when I start a song, a tiny grimace when a note is slightly too high, or eyes that travel up and down from a light on the ceiling that is too bright. If I note the behavior and reach to turn off the light, I may even gain a small smile in response, although I am mindful of how I interpret each of these responses through my own lens. The small things build and build to form a new language between the music therapist and client as they learn from each other. However, as discussed by Diane, even as a therapeutic relationship is built with clients, music therapists must continue to be aware of potential errors in interpreting behaviors and responses.

How Do Music Therapists Promote Psychosocial Well-Being in Nonverbal Adults with Severe and Profound ID?

The participants of this study often spoke of promoting psychosocial well-being as the element of music therapy that was most essential with this population and often cannot be measured. It is the human element—providing dignity, self-efficacy, socialization, and opportunities for experiences and relationships outside the realm of basic physical care. All participants mentioned providing opportunities separate from strict functional skills, such as experiences that promote socialization, relationship building, self-expression, and personhood.

Both Diane and Laura discussed the importance of viewing the therapeutic relationship as two equals working together, rather than the therapist choosing what is in the best interest of the client. All participants felt it was important to involve the client in determining what would bring them improvement in quality of life. In relatively current

literature, this notion is often considered “unreasonable” for a music therapist working with someone with a severe and profound intellectual disability (Beebe, 2022). According to the Social Model of Disability, this belief could be due to society’s overall lack of education about or experience with this population. Faye stated, “just because of xyz [lack of spoken language, mobility, etc.] doesn’t mean that we can’t enrich someone’s life and involve them in decisions.”

In promoting psychosocial well-being, all the music therapists appeared to lean toward the Social Model of Disability. Specifically, they mentioned attempts to minimize societal barriers to an enriched life of self-efficacy. For example, Laura spoke of bringing symphony musicians into the residential facility to perform a concert. Most of the individuals she worked with had limits on how long they could sit up in a wheelchair, and therefore would not have been able to endure both transports to a concert hall and sitting through a concert. Melissa spoke of adapting instruments so clients could play independently. Laura spoke of regularly introducing new and popular music to her clients. Diane spoke of using client-preferred music regardless of what may be considered “age appropriate” to honor the client’s individual preferences. “Value and respect the music that the clients indicate, in whatever way they do, that it is meaningful for them.” Faye spoke of providing opportunities for her clients to perform for their parents. “Do things that that would be normal in any other school that nobody would ever think of having kids [with severe and profound ID] put on a show or to play the piano or the trumpet.”

All these seemingly small opportunities for individual expression that are automatically afforded to those without ID are often missed opportunities for those with

ID. With thoughtful planning, music therapy can provide opportunities for self-efficacy and self-expression and promote psychosocial well-being through inclusion and respect for individualism. As Diane stated,

> There's so much still thinking of developmental disability as an illness, and as such a barrier to independence and independent thinking and autonomy. [. . .] We've come a long way. But we're still not there. Even the people that work in some of these settings, with the people we serve, don't get it.

Implications for Future Research

I found that music therapists who are experienced with working with this population demonstrated a more informed view of this population, which included much more respect and thought towards dignity than what I have found both in literature and among societal perceptions. The longer someone works with this population, the more they seem to view people with severe and profound ID as equals, enabling them to have their own voice, recognizing behaviors as meaningful communication, and being passionately convinced of the importance of providing opportunities for engaging in the world that may been seen by society as unnecessary or underappreciated.

Unfortunately, emerging music therapy professionals, including myself, begin their careers with engrained social stigmas, unknowingly biased toward this population. I have become more aware of my biases and aspire to continue to be reflexive and develop further awareness, knowledge, and skills in my practice. The music therapists in this study had to develop such reflexive clinical wisdom through years of experience to understand things that should be inherently known, such as presuming persons with severe and profound ID as capable. It is my hope that adding to the clinical base of

wisdom will help propel music therapists to begin work with this population to create a better foundation of understanding. Future researchers may explore ways to educate emerging professionals through unconscious bias training specifically on the severe and profound ID population. This education could assist in addressing baseline stigma surrounding this population, allowing greater awareness of the “two minds” present, and creating greater opportunities for the self-expression and self-efficacy for the severe and profound ID population.

It is essential that as we continue our work with this population, we also continue to build research evidence so we may better serve these clients. Implications for future study are vast considering the spareness of current research. The studies that do exist rarely reflect the clinical wisdom amassed after years of working with this population, and at times seem to perpetuate stigmatized views. Future researchers could survey a greater number of professionals over a wider geographical expanse to document more clinical wisdom. The current literature base mainly describes intervention ideas typically used with the population. One way to expand the foundational base of knowledge for music therapists would be to explore in more detail the therapeutic foundation that these music therapists have shared, such as, how to recognize communication behaviors, pacing, assessment, and therapeutic function of music. As discussed throughout this thesis, experimental research with this population is inherently challenging. However, these barriers may be addressed through partnerships with clinicians and researchers and leveraging technological advances, such as in the case of research on advanced dementia. For example, researchers may utilize online surveys of family members exploring their perceptions of care provided for loved ones with severe and profound ID, or partnerships

with residential facilities to provide resources for educating staff. Experimental trials may be run with varying education provided to randomized residential facilities with a goal to explore changes in staff's level of comfort and perceived competency for caring for the severe and profound ID population, and how staff education may impact this population's quality of life.

Limitations

The current study was limited by several factors including the demographics of the participants involved, and potentially the recruitment method for participants. This study was purposefully a small, multiple case study that focused on four participants to gain a depth of information concerning the wisdom they have amassed over the years. Although the study design and sample size allowed for a deeper dive into each participant's wisdom, it also limited the transferability of the results. Specifically, although all participants appeared to have an eclectic approach, three were informed by a behavioral approach, therefore limiting exploration of different approaches and potentially limiting the exploration of clinical wisdom.

One of the participants of the study worked with a school population, though many of her clients were young adults. Although the addition of the school-age practice perspective may have been helpful in rounding out experiential wisdom represented in this study, it also influenced the results because all participants were not strictly working with adults past the "cliff" of school services. This limits the number of participants working with only adults to three.

All the participants were white, cisgender women. Therefore, this study is limited in the representation of various cultural and gender perspectives. The "word of mouth"

recruitment method used meant that the participants were somehow all connected or familiar with each other. This led to three of the participants being from the same geographical area, and two of the participants worked together in the same facility. This limited the perspectives from different geographical areas, culture, and work environments. As mentioned in the section on how music therapists determine effectiveness, employers influence practice approach. The results of this study therefore only represented the perspectives of three types of employers. Finally, although I took steps to enhance the trustworthiness of this study, I am a novice researcher. A more experienced qualitative researcher, or one with different lived experiences, may have arrived at different conclusions than I did.

Conclusion

The study explored the clinical wisdom of four music therapists with many years of experience working with the severe and profound ID adult population. The wisdom demonstrated gaps in our societal understanding and treatment of this population, and the need for more research and literature to inform emerging professionals working with this population. The wisdom conveyed also provided a solid foundation of skills to bring to the music therapy practice along with the mindset necessary to be effective with this population. The music therapists in this study have faced their own biases over years of work and honed their ability to communicate with and provide opportunities for meaningful experiences for their clients, which increased both their functional skills and quality of life. It is my hope that documenting this wisdom may assist in passing on an enduring legacy of effective clinical skills that these music therapists shared and offer

others a wider knowledge base for the provision of quality services to adults with severe and profound ID.

APPENDICES

Appendix A: IRB Certificate of Approval

University of Kentucky | Office of Research Integrity
IRB, RDRC

XP Initial Review

Approval Ends:
1/20/2022

IRB Number:
62476

TO: Courtney Catron,
Fine Arts - Music
PI phone #: 8606142698

PI email: courtney.catron@uky.edu

FROM: Chairperson/Vice Chairperson
Nonmedical Institutional Review Board (IRB)

SUBJECT: Approval of Protocol

DATE: 1/21/2021

On 1/21/2021, the Nonmedical Institutional Review Board approved your protocol entitled:

Exploring the clinical wisdom of experienced music therapists working with adults with severe/profound intellectual disability.

Approval is effective from 1/21/2021 until 1/20/2022 and extends to any consent/assent form, cover letter, and/or phone script. In addition to IRB approval, you must also meet the requirements of the VPR Resumption of Research Phased Plan (i.e., waiver for Phase 1, training & individualized plan submission for Phases 2-4) before resuming/beginning your human subjects research. If applicable, the IRB approved consent/assent document(s) to be used when enrolling subjects can be found on the approved application's landing page in E-IRB. [Note, subjects can only be enrolled using consent/assent forms which have a valid "IRB Approval" stamp unless special waiver has been obtained from the IRB.] Prior to the end of this period, you will be sent a Continuation Review (CR)/Annual Administrative Review (AAR) request which must be completed and submitted to the Office of Research Integrity so that the protocol can be reviewed and approved for the next period.

In implementing the research activities, you are responsible for complying with IRB decisions, conditions and requirements. The research procedures should be implemented as approved in the IRB protocol. It is the principal investigator's responsibility to ensure any changes planned for the research are submitted for review and approval by the IRB prior to implementation. Protocol changes made without prior IRB approval to eliminate apparent hazards to the subject(s) should be reported in writing immediately to the IRB. Furthermore, discontinuing a study or completion of a study is considered a change in the protocol's status and therefore the IRB should be promptly notified in writing.

For information describing investigator responsibilities after obtaining IRB approval, download and read the document "PI Guidance to Responsibilities, Qualifications, Records and Documentation of Human Subjects Research" available in the online Office of Research Integrity's IRB Survival Handbook. Additional information regarding IRB review, federal regulations, and institutional policies may be found through ORI's web site. If you have questions, need additional information, or would like a paper copy of the above mentioned document, contact the Office of Research Integrity at 859-257-9428.

seeblue.

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Appendix B: Prescreen Consent Form

IRB Approval
1/21/2021
IRB # 62476
NMED

To XXXXX:

A graduate student researcher, being guided by a faculty advisor, at the University of Kentucky is inviting you to take part in a virtual pre-screening questionnaire, via Qualtrics, for a study about the clinical wisdom of music therapists experienced in working with adults with severe/profound intellectual disability. You are being asked to participate in this research study because you expressed interest through emailing the researcher.

The purpose of this pre-screening questionnaire is to ensure your eligibility to participate in the study, as well as ensure the researcher accepts a diverse group of participants to the best possible extent. No one will be excluded on the basis of a protected class. If you do not want to complete the pre-screening questionnaire, there are no other choices except not to take part in the study. The pre-screening questionnaire should take approximately 15 minutes to complete. You may skip or not answer any question in the interview, as all answers are voluntary. However, if a question is left unanswered you may not be chosen to participate in the study.

Although we have tried to minimize the risks, some questions may make you upset or feel uncomfortable and you may choose not to answer them. We will make every effort to safeguard your data, but as with anything online, we cannot guarantee the security of data obtained via the Internet. Third-party applications used in this study may have Terms of Service and Privacy policies outside of the control of the University of Kentucky. Your answers to the pre-screening questionnaire will be kept confidential to the extent allowed by law. When we write about the study you will not be identified. You will be contacted by the researcher via email after you complete the questionnaire to inform you of your eligibility or ineligibility to participate in the study.

Your information collected for this study will NOT be used or shared for future research studies, even if we remove identifiable information such as your name, age, and disability. If you have questions about the study, please feel free to ask; my contact information is given below. If you have complaints, suggestions, or questions about your rights as a research volunteer, contact the staff in the University of Kentucky Office of Research Integrity at 859-257-9428 or toll-free at 1-866-400-9428. Thank you in advance for your assistance with this important project.

Sincerely,

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Appendix C: Prescreen Questionnaire

This questionnaire is for screening purposes. Based on the qualitative nature of this study, I would like to recruit a diverse sample of music therapists that represents rich experience with nonverbal adults with severe/profound ID. Data recorded in this questionnaire will be retained only if you are selected for the study.

I have read and agree to the prescreen consent form:

Yes

No

Full name:

Short answer text

Phone number:

Short answer text

Email address:

Short answer text

Number of years working as a full time music therapist:

Short answer text

Approximate years of experience working with this population:

Short answer text

Have you worked primarily as a music therapist in the US?

Yes

No

Age:

Short answer text

Gender Identity

Female

Male

Other…

Ethnicity

Short answer text

Level of Education

1.

Undergrad

2.

Masters

3.

Doctorate

Other Credentials

Short answer text

Preferred Language

Short answer text

Music Therapy Approach

Short answer text

Any other demographic information you would like the research to know:

Long answer text

Appendix D: Interview Script

I'm conducting a study on music therapists who work with non-verbal adults with severe and profound intellectual disability. I'm most interested in understanding how music therapists experienced with the population engage with them, communicate with them, and define effective practice and how those elements may or may not change across clients and settings. I've been working with this population mostly in individual sessions in skilled nursing for around 3 years and have found it difficult to determine effective practice or assess how clients are affected by music therapy. My purpose is to gather information on the clinical wisdom of music therapists who are highly experienced in working with this population and then apply it to my own practice.

Prompts:
Prolonged Silence
Take as much time as you'd like to reflect on this question
Could you please further describe what you said about . . .
Please explain what you meant by . . .
Could you give me an(other) example?
It sounds like you're saying . . . is that a fair summary?
What would that look like?

1. What inspired you to work with non-verbal adults with severe/profound intellectual disability?
2. Tell me about the theoretical framework and philosophy that guides your practice. How has your practice changed as you've gained experience?
3. In what ways do you adapt assessments, goals, and interventions across clients with s/p ID, across settings, or over time with the same client?
4. Take a moment to imagine a typical session with a n-verbal adult with s/p ID *(wait a slow count to 10, or until they indicate they are done imagining)*. Please describe this session.
5. Please take a moment to imagine a go-to intervention in your music therapist toolbox that you use with this population *(wait slow count to 10, or until they indicate they are done imagining)*. Please describe this intervention and why you like it.
6. In what ways do you measure or evaluate your therapeutic effectiveness with this population? Please consider factors that indicate music therapy may not be appropriate or is no longer effective for a client.
7. Take a moment to think about different ways you communicate with this population and how you try to objectively interpret their responses (*wait slow count to 10, or until they indicate they are done imagining).* Please describe these communication and interpretation strategies.
8. What is your approach to music selection with this population, and what methods do you use to determine their music preferences? How does age-appropriateness factor into your decision?

9. What readings or other resources do you suggest that could help me understand your approach or the clinical wisdom involved in working with this population?
10. Is there anything else you'd like to add that we haven't covered?

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