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The Experience of Home-Based Music Therapists Working with Individuals with Intellectual and Developmental Disabilities: A Thematic Analysis

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THE EXPERIENCE OF HOME-BASED MUSIC THERAPISTS WORKING WITH INDIVIDUALS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES: A THEMATIC ANALYSIS

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THE EXPERIENCE OF HOME-BASED MUSIC THERAPISTS WORKING WITH INDIVIDUALS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES: A THEMATIC ANALYSIS

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ABSTRACT

According to the Administration for Community Living (ACL), an estimated 7.38 million people in the United States live with an intellectual and/or developmental disability (2021). Many individuals with intellectual and developmental disabilities (I/DDs) reside in community-based settings, such as private residences, family members' homes, or group homes (ACL, 2021). However, little research exists exploring home-based music therapy (HBMT) for people with I/DD, especially from the clinician's perspective. Thus, this study examines the experiences of home-based music therapists working with individuals with I/DD to provide a foundational overview. Three music therapists working in home-based settings participated in semi-structured guided interviews, which were then analyzed using inductive thematic analysis (Braun & Clark, 2006). Results indicate four themes representing the experiences of home-based music therapists working with individuals with I/DD, including: 1) the pragmatics of successful HBMT practice, 2) the home as a unique therapeutic setting, 3) the therapeutic process of the home-based music therapist, and 4) the personal experience of being a home-based music therapist. Findings suggest the need for comprehensive academic and clinical training specifically addressing HBMT. The development of formal standards of clinical HBMT practice could also increase the recognition of HBMT within the profession and unify current home-based clinicians who pose a greater risk for professional isolation.

Keywords: music therapy, home-based music therapy, in-home music therapy, home-based care, intellectual and developmental disability

Table of Contents

LIST OF TABLES

CHAPTER 1: INTRODUCTION

Of the estimated 7.38 million people in the United States living with intellectual and developmental disabilities, most live in community settings (ACL, 2021). Community settings may include one's private residence, family member's homes, or group homes (ACL, 2021). Therefore, music therapists working with this population often provide services in community-based settings. This is where the home-based clinician becomes relevant. Current literature exploring music therapists' experiences as home-based clinicians is sparse (Schmid & Ostermann, 2010). Further, existing studies in the music therapy field predominantly focus on client and caregiver perspectives in palliative and end-of-life homecare populations (Schmid & Ostermann, 2010). Thus, research is needed to explore the firsthand perspectives of home-based music therapists working with individuals with I/DDs.

This study explored the experience of home-based music therapists working with individuals with I/DDs. For example, while guidelines for working in settings with specific populations, such as intellectual and developmental disabilities or private practice, can be found on the American Music Therapy Association (AMTA) website, home-based work is not explicitly addressed (2015). Results from this study indicate experiences unique to working in this type of setting, which could help develop guidelines specific to HBMT with individuals with I/DD. Further, these findings provide a foundation for future research to explore more deeply.

Researcher's Position

My interest in home-based care developed early on during my undergraduate music therapy internship as a home hospice music therapy intern. I remember feeling initially overwhelmed and uncomfortable with entering the private setting of the client's home. These feelings quickly subsided as I became accustomed to this way of working. Nearly three years

have elapsed since then, and I now work as a home-based music therapist serving individuals with I/DDs. As a home-based care provider, I engage in the community more than when employed by an individual healthcare facility. As a home-based music therapist, I enjoy flexibility in creating my schedule, the independence of traveling from session to session, and the insight that working in the client's immediate environment provides. While this way of working suits me, some challenges are unique to this setting. For example, I rarely converse with other clinicians outside of weekly supervision. While I am with clients all day, I am isolated in terms of daily contact with other professionals. While the present guidelines for professional practice for individuals with intellectual and developmental disabilities and music therapists working in private practice have been helpful for my practice, I have had to navigate home-based and community-based settings as a therapeutic milieu, mainly through trial and error. Curious about the experiences of other clinicians practicing in this unique setting, I began looking more into this topic.

My research epistemology aligns with non-positivistic interpretivism. This theory of knowledge posits the existence of multiple realities subjective to the individual's lived experience (Hiller, 2016). My own experience navigating Western healthcare has informed this worldview. As a neurodiverse female, finding adequate healthcare is not always easy, and I often feel reduced to a number or statistic being passed along through the system. I continuously find myself in positions of self-advocacy, fighting to be taken seriously by medical providers to receive comprehensive care that appropriately addresses my needs. This life experience has spilled over into my clinical work and now informs my approach as a music therapist.

CHAPTER 2: LITERATURE REVIEW

Introduction

This section examines relevant literature covering three general topics: (a) home-based care, (b) I/DD, and (c) music therapy. Reference materials include articles from peer-reviewed journals, published books, and seminal works in music therapy and other relevant fields. Most of the literature reviewed was from 2010 onward, although earlier sources were referenced to provide historical context.

Home-Based Care

Defining Home-Based Care

Home care refers to any "health service provided in the patient's home to promote, maintain, or restore health or lessen the effects of illness and disability" (NYSDOH, 2017, para.1). Home care extends to nearly all facets of Western healthcare including but not limited to, skilled nursing, therapies, dietary management, pharmacy, case management, and personal care (U.S. Dept. of Health and Human Services, 2020). According to the Centers for Medicare and Medicaid Services, federally funded home- and community-based services function to "enable people to stay in their homes, rather than moving to a facility for care" (U.S. Dept. of Health and Human Services, 2020, para. 1). Types of home-care funding providers vary. For example, in New York State, some home-based programs are funded by Medicaid or other public entities, such as the Office for People with Developmental Disabilities (NYSDOH, 2017 & OPWDD, n.d.). These funding agencies often have strict guidelines for what types of programs are eligible. For example, the OPWDD will fund community music classes, not music therapy. Navigating these nuances can be challenging and confusing for clients and music therapy providers. Individuals may also pay out of pocket or use personal insurance to receive home

health services from various private agencies (NYSDOH, 2017). What constitutes the home setting is nuanced, especially when considering congregate housing settings such as group homes and assisted living facilities (Cienkus, 2022). While these congregate settings are considered the patient's "home," there can still be the feeling of institutionalization. This idea will be explored further in later paragraphs. For this study, home-based care is limited to private residences, not congregate housing settings. How did home-based care come about as a setting for delivering health services?

Origins of Home-Based Care

To better contextualize the origins of home-based care, we turn to the social services field. Home-based care has roots in the family preservation model of counseling (Woodford et al., 2006; Beder, 1998). This model ascertains the values of "(a) having children grow up with their parents, (b) helping families to develop self-sufficiency, (c) providing community-based services in the least restrictive environments, and (d) using permanency planning for families" (Woodford et al., 2006, p. 241). Early home visits, originally called friendly visits, were carried out by charity organizations and women volunteers in response to the economic depression of the 1870s (Beder, 1998). Eventually, these visits were taken over by professional caseworkers as a precursor to modern medical social work (Woodford et al., 2006; Beder, 1998). In the late 1890s, the first medical social work programs were developed at Massachusetts General Hospital and Johns Hopkins Hospital (Beder, 1998). At this time, physicians believed they could "better understand their patients' medical problems if they knew something about their social environment" (Beder, 1998, p. 516). Thus, social workers were deployed to homes as a way of reporting "domestic and social conditions of the patient, to help the patient fulfill the physician's orders, and to provide linkage between the hospital and community (Cabot, 1915 as cited by

Beder, 1998, p. 516). In these ways, medical professionals began considering their patients from a broader context of systemic factors such as social, financial, and cultural influences (Beder, 1998).

Within the counseling discipline, the theoretical rationale behind home-based visits includes the beliefs that "family functioning is the vehicle through which individual problems and needs should be addressed" and "working in the home, or the family's natural environment, will increase the chance for change to take place" (Woodford et al., 2006, p. 241). For example, Bandura (1971) posits that humans learn through observing and modeling others' behaviors. Bandura's social learning theory suggests that "psychological functioning is best understood in terms of a continuous reciprocal interaction between behavior and its controlling conditions" (1971, p. 2). From an early age, the home environment becomes the primary place for learned behaviors based on observation of family members' and caretakers' actions, emotional responses, and reactions.

From this social development perspective, working in and experiencing the home environment may give clinicians greater context about the individual receiving services. Bronfenbrenner's (1979) ecological systems theory provides a framework for clinicians to understand the individuals they work with related to their more comprehensive sociocultural network. According to Bronfenbrenner, the essence of an ecological orientation is "the progressive accommodation between a growing human organism and its immediate environment, and how this relation is mediated by forces emanating from more remote regions in the larger physical and social milieu" (1979, p. 13). As humans, our surrounding sociocultural contexts shape who we are and our own experience of health and wellness (Bronfenbrenner, 1979). While Bronfenbrenner's ecological systems theory expands beyond the influence of the immediate

home, it encourages one to consider how different ecological levels interact and their effects on the individual (Bronfenbrenner, 1979). These theoretical perspectives on social development help contextualize and necessitate the relevance of the home as a therapeutic setting.

Benefits and Challenges of Home-Based Care

Home-based care benefits both the providers and individuals receiving services. For example, home-based care allows the clinician to work with the client, their family members, and caregivers within the home setting (Pasiali, 2004; Holden et al., 2019; Thompson, 2012). This has multiple benefits as it allows the therapist greater insight into the client's ecological systems and social environment, which influence individual development, functioning, and health (Bronfenbrenner, 1979; Bandura, 1971; Richmond, 1907, as cited in Beder, 1998). However, these benefits of the home environment could, at times, also serve as challenges. For example, Forrest (2014) found that the presence of family members, pets, and familial or cultural rituals occurring in the home can sometimes distract from or prevent the music therapy process. Home-based care may also help the individual receiving services continue to enjoy the familiarity and comfort of their home or community residential facility (US Department of Health and Human Services, 2020). Receiving services in the home may alleviate the stress of arranging transportation and traveling long distances for care, thereby increasing accessibility (Holden et al., 2019). Further, home-based care offers an alternative to institutionalized settings so that individuals ideally remain active members of their communities (Cienkus, 2022). The relevance of home-based care within the deinstitutionalization movement will be explored in later paragraphs.

Home-Based Care for Individuals with I/DD

Defining I/DD

According to the National Institute of Child Health and Human Development (NICHD), intellectual and developmental disabilities (I/DDs) "are differences that are usually present at birth and that uniquely affect the trajectory of the individual's physical, intellectual, and emotional development" (2021, para. 1). Some diagnoses that fall under the category of I/DD include cerebral palsy, Down syndrome, Fragile X syndrome, and autism spectrum disorders (NICHD, 2021). It is essential first to understand the distinction between intellectual and developmental disabilities as they deal with different areas of human functioning. Intellectual disability "is characterized by differences with both intellectual functioning or intelligence, which include the ability to learn, reason, problem solve, and other skills; and adaptive behavior, which includes everyday social and life skills" (NICHD, 2021, para. 2). The term developmental disability is used as "a broader category of often lifelong challenges that can be intellectual, physical, or both" (NICHD, 2021, para. 3). Not all individuals with intellectual disability have a developmental disability and vice versa. However, this proposal uses *individuals with I/DD* as a general umbrella term encompassing any intellectual and developmental disability.

A Brief History of I/DD in the United States

To contextualize home-based care, we must first acknowledge the history of institutionalization, detention, and segregation of individuals with disabilities (Cienkus, 2022). In the early 1900s, it was commonplace for individuals with disabilities to be segregated in asylums, effectively cut off from their families and communities (Cienkus, 2022; Chapman et al., 2014). This out-of-sight, out-of-mind mentality pushed individuals with I/DD to the periphery of society. Friedman (2019) argues that institutionalization is closely linked to disability prejudice,

which directly results from pathologizing individuals with I/DD. During the 1960s, attitudes toward individuals with disabilities shifted with the help of various government policies (Cienkus, 2022). For example, legislation such as the 1963 Community Mental Health Act reframed I/DD as a health condition that could be assisted medically (Cienkus, 2022). While this policy continued to pathologize individuals with I/DD, it did contribute to the deinstitutionalization movement, which sought to reduce the number of disabled individuals being funneled into institutionalized settings. In 1972, a news report aired on ABC exposing the unethical and inhumane treatment of residents living at The Willowbrook State Developmental Center in Staten Island, New York (Disability Justice, n.d.). The class action lawsuit that followed gave way to greater public awareness, advocacy, and guidelines for the ethical and humane treatment of individuals with disabilities. Further legislation followed, such as the Protection and Advocacy (P&A) System in the Developmental Disabilities Assistance and Bill of Rights Act of 1975, The Education for All Handicapped Children Act of 1975, and The Civil Rights of Institutionalized Persons Act of 1980 and helped set a precedent for the treatment of individuals with disabilities living in institutional settings (Disability Justice, n.d.).

Since the deinstitutionalization efforts of the '60s and ‘70s, individuals with I/DD have lived in various settings, including independent living centers and congregate housing options such as group homes, assisted living facilities, and supportive housing (Cienkus, 2022; Fleischer & Zames, 2011). Friedman acknowledges that disability prejudice persists and “although deinstitutionalization of people with I/DD is at an all-time high, institutionalization continues” (2019, p. 271). From an equity and inclusivity perspective, it is essential to note that many of these options still do not address the challenges faced by individuals with I/DD who seek independent living and home ownership (Cienkus, 2022). While this is a step in the right

direction and necessary for some, the debate continues whether congregate housing is truly deinstitutionalized (Cienkus, 2022). Other housing types include non-congregated options such as private residences and living with family members or host/foster families. As of 2022, approximately 77% of individuals with I/DD who receive long-term care reside in non-congregate settings (Landes et al., 2021, cited by Cienkus, 2022). While this provides a brief overview of the transition from institutionalization to home-based care, it is essential to note that the history of disability rights is a complex and nuanced fight that continues today. For this study, home-based care includes non-congregate settings such as private residences and family homes.

Benefits of Home-Based Care for Individuals with I/DD

There are noted benefits for individuals with I/DD receiving home-based care. For example, home-based medical care reduces hospitalizations in individuals with I/DD (Mills et al., 2022). Extended hospital stays can be costly while isolating the individual from their familiar surroundings and family network. Home-based primary care (HBPC) is described as a "more intensive community-based medical model" in which providers can "partner with the staff serving the individual with I/DD, using their shared knowledge of the patient's home setting to provide a more comprehensive assessment and more effective treatment plan" (2022, p. 1653.e18). In these ways, HBPC is a promising model of care for individuals with I/DD.

Music Therapy

Music therapy is "a systematic process of intervention wherein the therapist helps the client to promote health, using music experiences and the relationships that develop through them as dynamic forces of change" (Bruscia, 1998, p. 20). Music therapy in the United States was developed in response to the needs of veterans following World War II. It was found that

hospitalized veterans benefited from live music played in Veterans Administration (VA) hospitals (Wheeler, 2015). In 1944, Michigan State became the first university to offer a formal music therapy curriculum (Wheeler, 2015). Today, music therapists work in various settings, such as nursing homes, schools, hospitals, rehabilitation centers, forensics, psychiatric units, and group homes (Wheeler, 2015). As of May 2023, the number of board-certified music therapists in the United States surpassed 10,000 (CBMT, 2023). Music therapists serve diverse populations encompassing a range of ages, diagnoses, and abilities (Wheeler, 2015). Music therapists also employ a variety of theoretical approaches, such as psychodynamic, humanistic, cognitive-behavioral, developmental, and neurologic (Wheeler, 2015). Regardless of the theoretical orientation, setting, and population served, all music therapy follows the same treatment process: (1) referral, (2) assessment, (3) treatment planning, (4) documentation of progress, and (5) evaluation and termination of treatment (Wheeler, 2015). This treatment process holds true for home-based settings.

Music Therapy for Individuals with I/DD

The National Institute of Child Health Development (NICHD) states that potential areas of need for individuals with I/DD may include learning, communication, cognition, memory, social interactions, behavior, and emotions (n.d., para. 2). Music therapy is an individualized practice, meaning that goal areas will vary based on the participant's strengths, interests, and needs (Wheeler, 2015). Specific applications of music therapy with this population vary and can occur throughout the individual's life. For example, in early childhood intervention, music therapy can assist children with developmental delays in achieving milestones of development related to physical, communicative, psychosocial, cognitive, and sensory domains (Humpal, 2015). Music therapy may also assist children with intellectual disabilities in developing

communicative, social, conceptual, and practical skills for daily living (MacLaughlin & Figlure Adler, 2015). When working with individuals with autism spectrum disorder (ASD), musical experiences may address "relating, communicating, socializing, sensory integration, motor functioning, and cognitive functioning" (Carpente & LaGasse, 2015, p. 292). In these ways, music therapy can address various domains of human functioning.

Home-Based Music Therapy

Relevant Theoretical Orientations

To understand home-based music therapy (HBMT) within the greater music therapy discipline, it may be helpful to understand HBMT from a community music therapy (CoMT) perspective. CoMT centers on music as a sociocultural phenomenon, whereas making music inherently necessitates social action (Stige et al., 2010). CoMT "addresses mechanisms of exclusion and inclusion in broader contexts and requires a more socially engaged practice" (p. 9). This orientation of music therapy practice aligns with HBMT in that therapy takes place outside the traditional boundaries of professional and institutional care, thereby increasing the accessibility of services by extending them into the participant's immediate social sphere. Family-centered music therapy (FCMT) is another approach to therapy that often coincides with home-based care (Toumi et al., 2021). FCMT focuses on interpersonal relationships within the family to make positive changes to the client's immediate home environment as a means of therapeutic change (Toumi et al., 2021). This concept will be explored further in an overview of HBMT research.

Current HBMT Practices

In 2010, Schmid and Ostermann put forth a systematic overview of settings and conditions for home-based music therapy. The results indicate that HBMT occurs across various

populations, with research predominately focusing on elderly patients and those receiving hospice and palliative care (Schmid & Ostermann, 2010). Of the 20 publications reviewed, not one centers on the experiences of home-based music therapists, suggesting a need for literature exploring clinician perspectives (Schmid & Ostermann, 2010). To further the future efficacy of HBMT, the authors suggest a deeper exploration of specific approaches used with various populations in home-based settings (Schmid & Ostermann, 2010).

Existing research helps us understand the unique aspects and challenges of HBMT, such as the presence of family members and caregivers (Horne-Thompson, 2003, as cited in Schmid & Ostermann, 2010). Some music therapists practicing family-centered and relation-oriented approaches do so in the client's immediate home. In these settings, the music therapist will likely include the family members in the therapeutic process, thereby treating the patient and their caregivers (Horne-Thompson, 2003). This systems-based approach to music therapy is increasingly prevalent, as evidenced by a systematic review of the growing literature and research on family-centered and relation-oriented approaches (Tuomi et al., 2017). While these approaches to music therapy are not exclusive to home-based music therapy, they are conducive to the naturalistic setting provided by home-based work (Tuomi et al., 2021).

Populations and Needs

Presently, multiple populations receive HBMT. HBMT is used in stroke rehabilitation (Street et al., 2015), pediatric palliative care (Forrest, 2014), parents of young children with disabilities (Yang, 2016), dementia (Otera et al., 2020 & Holden et al., 2019), survivors of breast cancer, (Hsieh et al., 2019), amyotrophic lateral sclerosis (Apreleva Kolomeytseva et al., 2022) and autistic children (Thompson, 2012; 2017 & Thompson, McFerran & Gold, 2014). As this study aims to understand the experiences of home-based music therapists working with

individuals with I/DDs, it is vital to understand how HBMT currently functions within this setting. HBMT often occurs within the family-centered music therapy (FCMT) approach to address social skills and interpersonal engagement between children with autism and their caregivers (Thompson, 2012; 2017; Thompson et al., 2013). HBMT provides the benefit of working directly within a child's everyday social environment, described in other therapeutic disciplines as advantageous for addressing psychosocial and interpersonal skills (Beder, 1998 & Woodford et al., 2006). Parent-child interactions are a frequent topic of exploration in HBMT literature (Thompson, 2012; 2017; Thompson et al., 2013; Yang, 2016; Pasiali, 2004). One such concept describes music therapists teaching music protocol to parents to use with their children outside of the music therapy session (Pasiali, 2004 & Yang, 2016). While this technique is exciting and, as the findings suggest, outcome-effective, this application of music therapy differs from the home-based music therapy addressed in this study.

Home-Based Music Therapy for Individuals with I/DD

While research directly exploring home-based music therapy for individuals with I/DD is limited, existing literature does suggest that naturalistic settings are conducive to working with this population. For example, music therapy services delivered in natural settings, such as the client's home, are preferred when working with developmental issues in early childhood (Humpal, 2015). Working in home-based settings allows the music therapist to collaborate with families (Humpal, 2015). This collaboration is vital because family values, choices, and culture can inform the therapeutic partnership and treatment process (Humpal, 2015). In family-centered, home-based settings, music therapists have addressed social skills and interpersonal engagement (Thompson, 2012; Thompson, 2017; Thompson et al., 2013). In the case of home-based care with children with I/DD and their family members, "the active involvement of parents

in music therapy sessions opens the possibility for positive family outcomes as well as meaningful child development outcomes" (Thompson, 2012, p. 114). Further, home-based music therapy increased confidence in mothers seeking new ways of socially engaging with their autistic children (Thompson, 2017). This study will take a different exploratory angle by illuminating the music therapist's unique perspective as a home-based clinician.

Summary

Home-based care exists throughout many facets of American healthcare. Music therapists work with various populations, including individuals with I/DD. Many individuals with I/DD live in community, home-based settings. Despite this, limited research exists exploring the experiences of home-based music therapists working with individuals with I/DD in home-based settings. Therefore, the experience of music therapists working with individuals with I/DD in home-based settings was investigated.

CHAPTER 3: METHODOLOGY

Research Objectives and Purpose

This study explored the experience of home-based music therapists working with individuals with I/DDs. Verbal data from three semi-structured interviews were analyzed using inductive thematic analysis. This study sought to fill the gap in the literature on music therapists' experiences as home-based clinicians. The outcomes of this study speak to the future of music therapy clinical training and standards of professional practice.

Research Design

The guiding research question in this study is the experience of home-based music therapists. This research question evokes a phenomenological lens as it studies a first-person point of view to understand a particular phenomenon (Phenomenology, 2013). When conducting qualitative thematic analysis based on descriptive phenomenology, researcher openness, questioning of pre-understandings, and adopting a reflective attitude are three methodological principles (Sundler et al., 2018). Participants were recruited through purposive sampling to participate in semi-structured interviews. An inductive thematic analysis was then conducted utilizing the verbal data to understand better the experiences of home-based music therapists working with individuals with I/DD. An inductive approach to thematic analysis is essentially a "bottom-up" process whereby themes are "data-driven" (Braun & Clark, 2006, p. 84). The inductive analysis method requires "coding the data without trying to fit it into a preexisting coding frame, or the researcher's analytic preconception" (Braun & Clark, 2006, p. 84). Thus, inductive thematic analysis was used to analyze data to derive meaning from the participant's lived experiences as home-based music therapists.

Participants

Three participants were interviewed for this study. Participant inclusion criteria were developed based on the American Music Therapy Association's (AMTA) Scope of Music Therapy Practice (2015). This scope of practice defines the requisite education and clinical training for board certification in music therapy. Therefore, inclusion criteria considered clinical training, certification, and professional experience. Participants met the following inclusion criteria:

1. Graduated with a bachelor's degree, its equivalent, or higher from a music therapy degree program approved by the AMTA
2. Has held the Music Therapist – Board Certified (MT-BC) credential for at least three years
3. Currently in and has worked in a home-based setting for at least three years.
4. Can read, understand, and speak English

Participants were excluded according to the following criteria:

1. Works primarily in settings other than private residences and clients' family members' homes, such as congregate housing settings
2. Works primarily with populations other than individuals with I/DD

Recruitment

Following approval from the Molloy Institutional Review Board (IRB), see Appendix A for approval letter, I recruited participants via email using an email list purchased from the Certification Board for Music Therapists (CBMT). This list included professional music therapists certified by the CBMT who have been practicing for at least three years in the United States. According to Keith (2016), purposive sampling allows the researcher to "choose

participants that they believe will provide useful data" (p. 142). A formal invitation to participate in the study was sent to potential participants. This invitation included information on the purpose and methodology of the study, possible benefits and risks, and a statement on confidentiality. Potential participants were asked to reply to the email invitation if they expressed interest in participating in the study. Before beginning the data collection procedures, I gathered participants' informed consent per Federal Common Rule guidelines outlined by the Molloy University IRB manual (2022). The informed consent document can be found in Appendix B. I also obtained permission to audio record all interviews. Participants were advised that they maintained the right to withdraw from the study at any time.

Data Collection Procedures

One individual interview per participant was conducted through Zoom at the participants' convenience. All interviews occurred in a quiet, private home office and took approximately 45 minutes. All interviews were audio recorded using Zoom's recording feature on a password-protected computer. An additional audio recording was collected on a separate password-protected iPhone as a backup to the Zoom recording. All data was transferred to an encrypted, password-protected flash drive and deleted from the original recording devices (computer and phone). The original recordings on the computer and phone were then deleted from the devices.

Open-ended semi-structured questions were utilized for each interview and can be found in Appendix C. Following each interview, I transcribed the audio recording in Word. Each completed transcript was member-checked with the respective participant. The member-checking process took approximately 15 minutes, where participants read over the transcript and replied via email with any comments or clarifications.

Data Protection Procedures

Audio files were securely stored on a flash drive protected by password protection and encryption. As the primary investigator, only I have access to this data. The data will be retained on the device for three years following the conclusion of this study, after which all information will be permanently deleted. No further data collection would have occurred in the event of a participation withdrawal, but any previously gathered information would be retained. Participants were assigned pseudonyms (*A*, *B*, and *C*) to safeguard their identities and ensure anonymity. Any potentially identifying details in the interview transcripts were modified to preserve confidentiality. I transcribed each recorded interview, and the transcription was member-checked. The member-checking process consisted of the transcript being returned to the respective interviewee for email review and agreement on the content.

Materials

Zoom software on my laptop was used to audio record each interview. The Voice Memo feature on my password-protected iPhone was a secondary audio collection backup. After each interview, all audio files were transferred to an encrypted, password-protected flash drive stored in a lock box in my home office. The original audio recordings on the computer and iPhone were deleted.

Data Analysis

Data were analyzed using Braun & Clark's guidelines for thematic analysis in psychology (2006). Thematic analysis interprets different aspects of the research topic by "identifying, analyzing, and reporting patterns (themes) within data" (Braun & Clark, 2006, p. 79). To conduct the thematic analysis, I first transcribed and familiarized myself with the verbal data from the semi-structured interview (Braun & Clark, 2006). Next, I produced initial codes

from the data. Once codes were generated, I searched for themes by examining the codes and contemplating how various codes came together to create broader themes (Braun & Clark, 2006). A list of "candidate themes" was then compiled, reviewed, and refined to ensure all themes effectively encapsulated the nuances of the coded data to develop a thematic map (Braun & Clark, 2006, p. 91). After developing a suitable thematic map, the themes were defined and refined to uncover their fundamental essence and determine which facets of data each encompasses (Braun & Clark, 2006). A report was then produced detailing a final analysis of the themes. I referred to the "15-point checklist of criteria for good thematic analysis" developed by Braun and Clark for quality assurance (2006, p. 96).

Confidentiality and Ethical Considerations

Participants were assigned a pseudonym to protect their identity and uphold anonymity. Any additional potentially identifying features within the interview transcript were adjusted to maintain anonymity. Pseudonyms were maintained throughout the study and data collection procedures. Printed copies of the data (transcripts) identified the participants only by their anonymous pseudonyms. Audio-recorded interviews and identifying information were not shared with the thesis advisor or committee members. However, de-identified interview data was discussed with the thesis advisor to analyze emerging themes for thematic analysis.

CHAPTER 4: RESULTS

This study aimed to explore the experiences of home-based music therapists working with individuals with I/DD. Three participants (A, B, and C) who met the above inclusion criteria were interviewed. While this study's inclusion criteria required at least three years of home-based music therapy experience to participate, Participant C fell just under three years. Having fit all other criteria, an exception was made to include their experiences in this study. It is important to note that while meeting the inclusion criteria as HBMT providers, all participants also engaged in other forms of non-HBMT work, such as contract work in group homes, community centers, early childhood programs, and facility-based employment in institutions such as hospitals. Two out of three participants worked in the Mid-Atlantic region but in differing states. Hours worked per week as home-based music therapists varied greatly, as did the number of years of practicing; see Table 1 for more details. All three participants were passionate about their HBMT work and eager to share their experiences.

Table 1

Participant Demographic Information

Participant	Geographic Location	Years Practicing	Employment Status	Source of Employment
A	Great Lakes	20	Full-time	Self-employed
B	Mid-Atlantic	26	Part-time	Self-employed
C	Mid-Atlantic	2	Full-time	Agency

Thematic analysis was used to analyze the verbal data from the three interviews (Braun & Clark, 2006). Participants have practiced for different lengths in different parts of the country. However, four themes were identified: 1) the pragmatics of successful HBMT practice, 2) the home as a unique therapeutic setting, 3) the therapeutic process of the home-based music

therapist, and 4) the personal experience of being a home-based music therapist. Ten categories were then derived from these four themes, as exemplified in Table 2.

Table 2

Thematic Findings: Experiences of Three Home-Based Music Therapists Working with Individuals with I/DD

Theme and Description	Category and Descriptions	Example Statements
Theme 1: The pragmatics of successful HBMT practice. Related to the business structure of HBMT and organization necessary for engaging in this work	Category 1a. Session preparation: What needs to happen before even showing up for the session	…Unlike when you're at the music therapy lab, or clinic, you can't just walk over to the instrument closet and grab something…so I feel like there's a lot more prepping and planning.
	Category 1b. Session Execution: How does the therapist, as an outsider coming in, enter and be within the family home	You're a guest in that space, and it sounds so simple, but it requires so much reflexivity in everything that you do…
	Category 1c. Working with Established Guidelines: External factors that impact the provision of HBMT services	Being a waiver provider, they give us the guidelines by which we must maintain certain things. You know, the rights and responsibilities of the provider and the rights of the consumers themselves.
Theme 2: The home as a unique therapeutic setting. The specific ways in which the home influences and functions as the therapeutic setting	Category 2a. Benefits of the home as a therapeutic setting: How can the home be an advantage to the therapeutic process	I really get to see the client interact in their environment in a very authentic way.
	Category 2b. Challenges of the home as a therapeutic setting: How does the home negate or limit the therapeutic process	I think one of the biggest hurdles was learning how to tune out the other things that were happening in the house

Theme 3: Therapeutic process of the home-based music therapist. How the therapist facilitates therapeutic experiences and relationships within the home	Category 3a. Therapeutic approach of the home-based music therapist: Through what lens does the music therapist practice and how do they facilitate therapy?	The patient is first, their needs are centered.
	Category 3b. Working with the whole family: The therapeutic relationship comprises not just the therapist and client, but all family present in the home at that time	I get to see the natural flow of the family, and not help the flow, not help with the actual doing of the things for the family but know how music therapy can be an influence in the family home.
Theme 4: The Personal experience of being a home-based music therapist. The individual choices home-based music therapists have made for their own practices and personal implications for this work style	Category 4a. Personal decisions: The freedom and autonomy to make individual choices related to work	I have stopped taking people unless they are geographically desirable.
	Category 4b. Advantages to this work style: What about HBMT best serves the therapists' preferred work style	I have my own business so making my own hours, I love.
	Category 4c. Challenges of this work style: Challenges encountered in HBMT not encountered in other settings	I think it can have some isolating and fatiguing challenges, the cost of gas, the cost of wear and tear on your car, those kinds of things.

Theme 1: Pragmatics of Successful HBMT Practice

This theme addresses the structure, organization, and practicalities necessary for home-based music therapy practice. These are the metaphorical nuts and bolts of the HBMT business that someone looking to work in this setting needs to be aware of. The pragmatics of successful

HBMT practice can be further broken down into three categories: 1a) session preparation, 1b) session execution, and 1c) working within established guidelines.

Category 1A: Session Preparation

The first category addressed is session preparation. Session preparation includes time management and scheduling, session planning, resource utilization, and cultural considerations. Data for this theme describe the clinician's preparatory steps for a successful HBMT session. For example, participants spoke about how the mobile nature of their work requires a degree of planning ahead, especially when scheduling sessions. Grouping clients by proximity and trying to see people in the same area on the same day helps maximize the therapist's time. One participant stated, "I am in your [the client's] town on this day. If you are not within a 15-minute radius of this location at this open slot, I am not the person [therapist] for you." Scheduling in this way helps limit unnecessary travel and makes the most of the therapist's time.

Preparatory steps are also taken when packing the day's resources, such as instruments. One participant stated: "Unlike when you are at the music therapy lab or clinic, we cannot just walk over to the instrument closet and grab something." While planning a session, it is essential to know what materials are needed for that session so that the client has these materials "at their disposal." While the preferred instruments of each participant varied, there was an emphasis placed on portable speakers and instruments because they are convenient for travel.

Further, participants discussed the importance of familiarizing themselves with the client's cultural background. This includes an awareness of the client's dominant language and cultural etiquette, such as dressing modestly or taking shoes off before entering the home. One participant described these actions as helpful when trying to "facilitate the relationship" upon first meeting a family. Another participant spoke about the importance of educating herself on

others' cultures while maintaining self-awareness to not "topple over" the client's identities. This requires a degree of self-education outside of sessions.

Category 1B: Session Execution

Session execution includes the pragmatics of entering a stranger's home, personal/professional identity boundaries, and setting boundaries and expectations with families. Session execution is different from session facilitation in that execution deals with the practicalities of entering and being in the family home instead of the therapist's actual therapeutic process. One participant noted that going into people's homes can be "really nerve-wracking," especially earlier in their career. Practical information such as whether pets are present could impact "some [clinicians]…because that may limit who they see." When facilitating sessions within the home, the topic of boundaries also arose. Boundaries can be further categorized in two ways: the clinician's balance of personal and professional identity and setting boundaries and expectations with the family. One participant stated:

> You have to be a chameleon. I have my own personal beliefs, politics, religion…and it all comes out when you are in someone's home, especially when you have been with the family for many years. You get to know what they believe in, and you have to keep the peace, especially during [the] political turmoil in recent times…

Boundaries also came up about setting expectations with families. For example, one participant explained how "… there is a level setting that needs to happen. Sometimes, I have found that I have needed to set expectations for families." Since families have invited you into their home, there is sometimes a "bias toward having you there," and sometimes "their bias is this [the music therapy] is going to be gorgeous and amazing and wonderful." Setting expectations can also take the form of locating yourself as a therapist. For example, one participant shared,

> I have a hard time working with people with strong ABA [applied behavioral analysis] experience. I have said [to families] that this may not work out. I may not be the right therapist for you because this is not how I work. If you want compliance and more ABA-like things, that will not happen here.

Setting these expectations upon initially meeting and working with families seems vital for developing positive therapeutic relationships in the long term.

Category 1C: Working within Established Guidelines

Working within established guidelines includes implications of outside funding on sessions and state guidelines. One participant explained how the waiver-based system in their state dictates what settings they can provide services in… "because we have such a strong waiver program, we are actually not allowed to go into any schools…" Another participant also worked in a state with a waiver-based system and described how "it is frustrating because we are so limited to the type of care that we can deliver, even from a billing perspective…" While the waiver system is "a great opportunity for them [clients] to get services," there are drawbacks to having to abide by specific reimbursement criteria that dictate the frequency and duration of sessions, which may not always be "therapeutic" for the individual receiving services. In one participant's experience, the waiver systems have created a consumer-based approach: "There is consumer choice…but I feel like everything should be consumer-based anyways, you know, what the consumer wants." As a result of outside funding and state guidelines, one participant has found that "sometimes we have to word things differently to make sure that clients get the care that they actually need versus what the state thinks they need." One participant only takes private pay and notes that this has less to do with the home-based setting and more with the

specific state they are practicing in and the limited funding and reimbursement options for music therapy services.

Theme 2: The Home as a Unique Therapeutic Setting

Participants recognized the home as a unique therapeutic setting that differs from clinic- or facility-based work. They noted that the home setting presents benefits and challenges to the therapeutic process. Unlike in a facility-based setting, family members and pets are often present within the therapeutic space, making for a different working dynamic. One participant stated: "I am in the family home, sometimes with the family dog, often in the family living room." This setting is undoubtedly different from more traditional clinic-based settings.

Category 2A: Benefits of the Home as a Therapeutic Setting

The benefits of the home as a therapeutic setting include physical space/setting, client's authenticity afforded by a naturalistic setting, family systems approach, ease of generalization, and convenience for the family. One participant stated: "I find that with my families, they are close should I need something or should the client need something, but far enough away to give them [the client] the independence to be their own person within our session." The same participant brought up how the home as a therapeutic setting can be a resource within itself: "Anytime that they [the client] feel activated or overwhelmed, they can go into their room…having that safe space that they can take a minute if they need to, and then, come back out once they feel comfortable…". In this way, the home is a "preferred environment" where the client can "feel comfortable…be very much themselves and have more freedom." The naturalistic environment that fosters client authenticity also appears to lend itself to ease of generalization of skills learned in therapy. For example, two participants addressed the ease of generalization that comes from holding music therapy in the home: "… I am doing it [music

therapy] in the home and showing the people that are important to that client what I am doing, how I am doing it, and why so that they can immediately replicate it" and "the siblings seeing that, the parents seeing that, [being] on the same page in the same environment with the family helps everyone."

In terms of convenience for the family, providing services in the family home means the family has one less place to travel to during the day. Regarding families traveling elsewhere in the community for services, one participant observed: "It is a lot of time toxicity that you take away from the family. It is a financial burden. You are taking away from the family by adding more stuff to their life." When coming into the home, "the family has that sort of breather, of I do not have to go to one more place, so they are less stressed." Home-based music therapy provides an alternative to traveling into the community to receive services. The family then gains back time and money that would have been spent traveling elsewhere.

Category 2B: Challenges to the Home as a Therapeutic Setting

The challenges to the home as a therapeutic setting include distractions within the home, residual family dynamics, and limited access to an interdisciplinary treatment team. All participants brought up distractions in the home; for example, if it is dinner time, there may be the distraction of someone making dinner in the kitchen. Other times, there are residual family dynamics, such as "if (the client) and mom have been snippy with each other earlier in the day, it can spill over into therapy…". While having family present during sessions has advantages, it can trend the other way when family is too involved and oversteps during sessions. One participant compares navigating this dynamic to being in a "battle." While the family member is coming from a "good place," this type of dynamic can limit opportunities for growth for the client by inhibiting the therapist's ability to "push boundaries." Another participant stated: "It

can be a challenge to know your place" because "it is their [the client's] home first and foremost." In these ways, participants navigated the role of a music therapist in confluence with being an outsider entering someone's private space.

All participants mentioned limited access to a broader treatment team as a difference between home-based care and facility-based work. Because of the solitary nature of HBMT, the ability to collaborate with other healthcare professionals working with that client is limited. One participant stated: you have a bird's eye view, or somebody [a colleague] comes to you, and you have this ongoing [ability to] touch base," but in home-based settings, you "show up from week to week and not have a clue about what has gone on." One participant stated that limited access to a treatment team "truncated" their effectiveness because of an inability to "push in properly."

Theme 3: Therapeutic Process of the Home-Based Music Therapist

Participants spoke about their therapeutic processes as HBMT providers working with individuals with I/DD. This data is further divided into two categories: the therapeutic approach of the home-based music therapist and working with the whole family.

Category 3A: Therapeutic Approach of the Home-Based Music Therapist

The therapeutic approach of the home-based music therapist includes the clinician's therapeutic presence, client-led theoretical approaches, client-centered interventions, and cultural considerations. The therapist being a guest in the client's home is a concept unique to home-based care. This factor seems to influence how participants carry themselves within the therapeutic space. One participant stated, "I am an outsider coming into this environment." Another participant acknowledged, "That is something you have to be cognizant of; you are a guest in that space; without that awareness, the rapport would look very different." This participant also spoke about the importance of not coming into the client's home "large and in

charge" because this attitude can "take away autonomy from the client," thereby limiting the therapeutic process. Part of this therapeutic presence also relates to cultural identity: "I feel like it is ethically irresponsible not to have that presence and awareness of my identities that I am bringing into their space."

The specific theoretical approaches and interventions varied by the participant, but all were described as client-centered to meet the needs of the individual they are working with. For example, one participant stated, "I pick-n-pull…whatever the person needs. It is so hard to stay with one theoretical approach." Specific approaches utilized included music-centered, humanistic, cognitive behavioral, systems-based, and intersectional feminism. Specific interventions were also varied, yet client-centered based on the individualized goals for each client. The interventions described encompassed recreative, improvisational, compositional, and receptive music therapy methods. Examples of specific interventions and domains addressed included drumming, playlist curation, instrumental improvisation, and orchestrating boomwhacker choirs. Participants described addressing various areas of need, including communicative, musical, physical/motor, psychological, sensory, and social skills.

Category 3B: Working with the Whole Family

Working with the whole family relates to a family systems approach, the music therapists' integration into the family, and the development of long-term client relationships. Two participants spoke about working with the whole family, not just the individual client they were there to see: "…We did group playtime [the client and their siblings] altogether, and I think that helped build community within their family…strengthen their relationship and work together." Another participant explained how siblings and parents especially "reap the benefits" of the in-home session. Working with the whole family lends itself to the therapist's integration

into the family, something distinctive to home-based work. Participants named this integration directly. For example: “I have enjoyed the opportunity to get to know families and fit myself in with them as opposed to them just coming to me once a week…This truly integrates into their lives, and I think it is special.” One participant compared HBMT to facility-based settings and stated, “I feel that when I worked in a hospital, it had a different vibe…I may only see your family once,” but in home-based settings, “I feel more invested, and they [the family] feel more invested in me.” Integration into the family system brings a heightened awareness of the interpersonal dynamics between family members and how these dynamics may spill over into the therapeutic space. Two participants also spoke about the opportunity to work with families in the long term. One participant stated, “I still have the same clients I started with 20 years ago…It is a blessing to be able to work with one family for so long.” Another participant spoke about the impacts of long-term client relationships. The relationship between clinician and family has sometimes “trended towards friendship” over time and can sometimes be “more relaxed.”

Theme 4: The Personal Experience of Being a Home-Based Music Therapist

Theme 4 explores the personal decisions faced by home-based music therapists. This theme also unpacks attitudes towards home-based work, including perceived advantages and challenges.

Category 4A: Personal Decisions

Personal decisions include the individual music therapist's choices related to their home-based practice. These decisions include whether to be a business owner, professional support, safety considerations, and payment. Participants A and B were business owners, providing home-based music therapy as part of their private practice. Participant C was an employee of an agency that provided home-based services and other music therapy contracts in the community.

The different ways each participant practiced home-based music therapy contributed to their perspective on the work.

Participants also engaged in various degrees of professional support. For example, two participants had no co-workers because they were in private practice. One of these participants sought out professional support on online forums for other music therapists engaging in the same type of practice in their state. The other participant said they spoke regularly with a peer who "has owned a successful practice for a long time but does not do much home-based care." Despite this difference, conversations with this peer proved beneficial when seeking professional support. Another participant, having worked for a medium-sized company with multiple employees, utilized built-in supervision as a space for professional support. This participant also spoke about the importance of utilizing university-based supervision provided by their academic institution.

Another personal choice faced by participants was safety precautions. Two participants acknowledged the medical fragility of the individuals they worked with and how this foresight impacted the infection control precautions they took inside and outside the client's home. In the wake of the COVID-19 pandemic, one participant described being "protective" of their clients by engaging in safety precautions such as masking, staying up to date on vaccinations, and testing frequently during increased outbreaks. Another participant limited their socialization outside work hours to avoid large groups and crowds because many clients are "fragile and suspectable to everything." This awareness also carried into cancellations related to illness. One participant spoke about canceling sessions when their child was sick out of precaution for their clients. In other cases, the client's family would wish to cancel as a precaution when the therapist's child was sick, in case the therapist was contagious even while asymptomatic.

Category 4B: Advantages of this Work Style

Advantages of this work style include versatile work opportunities, an active and dynamic work pace, and flexibility of hours. Self-employed participants described the freedom to create their schedules, and all participants described engaging in various work opportunities while maintaining a home-based caseload. Two participants discussed this flexibility as supporting their family life and parental responsibilities: "I get to create my schedule…and if I have to cancel because I am a mom with young kids, then I try to reschedule…but you do not owe me for something that I do not provide." Another participant described working in HBMT as a parallel process to their own family life: "…You kind of fall into a family schedule… it has been nice with the flow of my life. It is like parallel play. This family is doing this thing, and I am doing my thing with my family, and it all jives well." Participants also spoke about enjoying the active and dynamic work pace: "If I were in a facility all day long just at a desk or something…I do not think that is the life for me anymore, to be in one place. I have to move and do different things." In speaking to each participant, it became clear that home-based work in the individual family home is not the entirety of their professional practice. For example, one participant stated, "Going into this job provided a little of everything. Even though my caseload primarily consists of clients with I/DD and homecare, I still do other types of contracts, which I like. I still have some variety." All participants discussed simultaneously engaging in non-HBMT work. While the degrees to which participants engaged in other work varied, the diversity of work settings included contracts with community organizations, early education programs, private music lessons, working for institutions of higher learning, and even holding separate full-time jobs in other music therapy settings such as hospitals. One participant described their engagement in versatile work opportunities as having "my hand in all the different cookie jars, so

the variety keeps me sane." These facets of HBMT were viewed positively and advantageously for each participant's preferred work style.

Category 4C: Challenges of this Work Style

Challenges of this work style include navigating the learning curve from student to professional, fatigue, and financial considerations. All three participants experienced a learning curve when transitioning from student to professional. For example, one participant stated, "Nothing prepared me for the dynamics that come with doing in-home care, and it is so different from having somebody come to your facility…". Another participant ran into the question: "How do you actually work with a whole family, even if the family is not the identified patient? How do you establish relationships with the family that make them see the value of what you are doing?" More pragmatic areas of this learning curve included skills such as "how to set up a private practice and keep it running" and navigating state-specific billing.

Another area addressed was personal financial considerations. This includes supporting oneself financially as a home-based music therapist. For example, one participant stated: "Home-based music therapy has never been my primary wage earning" because "it would be hard for me to make a living doing only home-based care." Another participant explained how, early in their career, they were making "poverty line" wages and relied on their spouse's secondary income to help "float" and support the household. Wages in this participant's state have since increased, and they acknowledge that "this definitely helps." Another financial consideration was having to purchase instruments and materials upfront to use for sessions. While these purchases were "tax write-offs and deductions," these were costs that still had to be budgeted for by participants, especially those running their private practice.

Participants also spoke about the experience of fatigue resulting from various factors. These factors included physical fatigue from driving long distances and mental fatigue due to professional isolation. One participant stated, “The travel is a bear," creating “wear and tear on your vehicle and body.” This participant also spoke to resentment when traveling long distances: “When I hate driving, I resent going, and I do not like feeling that.” The “isolating and fatiguing challenges” also arise from participants alone in the field. As mentioned earlier in challenges to the home as a therapeutic setting, not having an interdisciplinary team to check in with can create additional “mental fatigue.” Another participant stated that this work “takes its toll because there are a lot of different challenges and barriers” distinctive to “providing in-home care.” This participant named burnout directly and explained that while they are a new professional, they know of other HBMT clinicians who have since left the field due to burnout.

CHAPTER 5: DISCUSSION

This study aimed to explore the experience of home-based music therapists working with individuals with I/DD. Three music therapists participated in individual semi-structured interviews. Thematic analysis (Braun & Clarke, 2006) was used to analyze data. Although each participant shared their unique experience, there were commonalities among all three home-based clinicians identified by four main themes. The four themes encompassing participant's experiences as home-based music therapists include 1) the pragmatics of successful HBMT practice, 2) the home as a unique therapeutic setting, 3) the therapeutic process of the home-based music therapist, and 4) the personal experience of being a home-based music therapist.

Home-based music therapy offers an active and dynamic work style supporting clinician independence and flexibility. This independence seems partly due to the solitary nature of this work; clinicians are out in the field by themselves, traveling from client to client. A potential consequence of this independence is professional isolation, limiting the therapist's access to professional supervision, support, and interdisciplinary collaboration opportunities, which may be more readily accessible in larger organizations or facility-based settings. As seen in this study, some home-based music therapists are the sole employees of their private practice, meaning they have no co-workers with whom to readily check-in. However, participants working in private practice described greater flexibility in setting hours, creating schedules, and developing business policies such as cancellations and payments. All participants discussed the ability to work with diverse populations and settings while still being able to maintain a home-based caseload, suggesting a level of flexibility and diversity in work settings. This was exemplified by participants simultaneously providing music therapy services to community centers, early

childhood programs, and healthcare facilities. Participants described how maintaining a diverse caseload helps keep the work fresh and engaging.

While all music therapy sessions require planning, the home-based setting requires thorough preparation and forethought. Materials, such as instruments, speakers, and personal protection equipment (PPE), had to be gathered and packed in advance. Participants described how they considered the portability and organization of materials in preparation for sessions, including what bags they used and how they organized their cars. This organization extended into planning daily schedules and coordinating routes to maximize the therapist's time and minimize unnecessary driving. Consideration was also given to the client's cultural background and its impact on family dynamics, values, and norms. Participants spoke about the importance of educating themselves on less familiar cultures and maintaining an awareness of their own cultural identity. In preparation for sessions, participants also discussed consideration for how they physically presented themselves to avoid hindering the facilitation of the therapeutic relationship. This was exemplified by participants' decisions to wear more conservative clothes or avoid accessories that may be giveaway personal beliefs that the therapist wishes to keep private.

Walking into a stranger's home to provide music therapy services was described as initially nerve-wracking. This clinical experience is one that not all music therapy students have had the opportunity to practice during their training. All three participants discussed navigating a learning curve as they transitioned from student to professional practice in home-based settings. This finding suggests the need for greater clinical training specific to home-based settings to prepare students who may eventually engage in this type of work. Specific topics related to this learning curve include working with the whole family, understanding state-specific funding and

reimbursement guidelines, and setting up and running a private practice. One participant stated that having home-based clinical practicums during their academic training would have been beneficial for easing this transition from student to professional. This participant also expressed how greater transparency on the realities of everyday home-based practice from professionals currently engaged in this type of work could have been beneficial. Bringing home-based music therapists into academic and clinical training programs to speak on their experiences could be one practical way to help lessen this learning curve.

Home-based music therapists engage directly with established family dynamics, values, and customs in a way that may not be present in clinic-based settings. Horne-Thompson (2003) published a comparative exploration of the role of music therapy with palliative care patients in contrasting home and hospital settings based on direct clinical experience and existing literature. Similar to Horne-Thompson's article, participants in this study discussed how their roles as home-based therapists differ from that of facility-based clinicians. Further, the home as a therapeutic setting can benefit and challenge the therapeutic process and relationship. As a naturalistic setting, the home lends itself well to developing client authenticity, comfort, and generalization of skills. At the same time, the home is the client's private space, and participants discussed an awareness of being outsiders in this space. Participants emphasized respecting client autonomy while present in these private spaces. This perception was also discussed regarding home-based palliative care music therapy (Horne-Thompson, 2003). Participants described how the presence of family members in the session extends the therapeutic process to the whole family, thereby incorporating a family-centered systems-based approach. This can sometimes result in the therapist needing to navigate tense family dynamics and distractions within the home. Another challenge of working in a home setting can result in limited access to

a treatment team. The music therapist must then rely on family members and caregivers for vital communication and relaying client information. Horne-Thompson (2003) also found this true of family members involved in palliative care patients' music therapy sessions. While receiving information from the family does not replace interdisciplinary collaboration, this insight still benefits the clinician.

HBMT is not a one-size-fits-all approach. The therapeutic process of three home-based music therapists working with individuals with I/DD reveals an emphasis on client-centered interventions situated within theoretical approaches selected to best meet the needs of the individual. Participants discussed a variety of music therapy interventions and methods, emphasizing portability and accessibility of instruments and materials, which is congruent with findings from Schmid and Ostermann's systematic overview of home-based music therapy literature (2010). When considering their therapeutic approach, participants took special care to acknowledge that they were guests in the client's home. This therapeutic presence honored the client, family, and their space while promoting client autonomy and independence.

Participants described how their role in the home differs from facility-based settings due to the private and personal nature of being in the family home. The therapeutic process does not exist in a vacuum but is contextualized by the home and its occupants, including caregivers and family members. As a result, participants described a level of integration into the family which may not happen in other non-home-based settings. Participants discussed how home-based settings allow music therapy to be more comfortable and relaxed for their clients. Although working with a different population, Horne-Thompson (2003) similarly notes that home-based music therapy can be more relaxed due to the session occurring in the client's familiar environment. The therapist's integration into the family also seems to result in a more relaxed

boundary for some clinicians' professional versus personal identity. Participants spoke about developing close relationships after working alongside a family for many years. This seems to be exacerbated when the therapist also lives in the community where they work, which can naturally lead to an intermingling of the personal/professional identity within a community context. The development of long-term client relationships also impacts treatment planning in that the therapist updates goals and objectives that grow with the client, sometimes over many years. While this situation is not unique to home-based care and can occur in facility-based long-term care settings as well, it perhaps suggests the importance of having skills to create relevant treatment plans throughout the lifespan of human development.

All participants discussed personal decisions that shaped their individual HBMT practice and experience. Participants described the HBMT workstyle as active, dynamic, and being on-the-go. These attributes allow for greater flexibility and the opportunity to work with diverse populations and settings if clinicians choose. At the same time, this work style brings forth unique considerations for burnout, including the physical fatigue from constant travel. Logistics such as needing reliable transportation, wear-and-tear on the car, and upfront costs such as providing your instruments are practicalities the therapist needs to consider. Two participants had been practicing home-based music therapy for over 20 years; such long years of experience reflect success against burnout and indicate motivation to continue working in this setting despite the challenges.

Implications for the Field of Music Therapy

There were commonalities among all three participants' experiences as home-based providers. Participants spoke to the complexities of home-based settings and how they differ from facility- or clinic-based music therapy. Participants also discussed navigating the learning

curve from student to professional in home-based practice. The AMTA (2013) developed ten standards of clinical practice delineated by setting, area of focus, or population served. While I/DD and private practice are both given individual categories, home-based music therapy is not addressed. These professional documents guide the clinical training and practice of music therapists. Including HBMT as an area of focus could inform more consistent formation of music therapists and better prepare them for work in these settings. Including home-based music therapy as a standard of clinical practice could help unify music therapists and standardize their procedures for working in this setting. Since home-based clinicians are at greater risk for professional isolation, this standardization and unification could be a protective factor.

Other implications of this study relate to music therapy education and training. Health care and services for individuals with I/DD continue to shift towards more community-based models of care. It makes sense for home-based music therapy to also move in this direction. Providing student music therapists opportunities to engage in home-based fieldwork placements could strengthen professional skills for this setting. In cases where this is not feasible, creating opportunities for students to speak with current home-based music therapists could provide a better understanding of the realities of this work. Participants discussed navigating learning curves, such as working with the entire family and effectively using the home as a therapeutic space. Family-centered and relation-oriented approaches could assist clinicians working with this population. Further, HBMT presents unique benefits and challenges that can differ from traditional facility-based settings. These differences are not always explicitly addressed in training programs and may surprise or challenge the new home-based music therapist.

Another implication for the field of music therapy is therapist burnout. Clinicians engaged in HBMT described experiencing mental and physical fatigue due to frequent travel and

professional isolation. Gooding's 2019 integrative review synthesizing the literature on music therapist burnout from 1981-2017 suggests five factors contributing to burnout: 1) compensation, 2) job opportunities/advancement issues/personal factors, 3) work environment, 4) training, and 5) workload issues. Participants described direct experience with some of these factors, including compensation, personal factors, work environment, and training. Although these factors were not always explicitly linked to burnout, they were present in home-based work and could influence clinician burnout in this setting. HBMT's isolating and fatiguing features could be mitigated by teaching practical skills, such as seeking professional support and community while working alone in the field. Other practical skills include maximizing time when planning out routes and scheduling sessions to limit excessive driving and make the most of the day. Developing skills in navigating personal and professional boundaries can help maintain a balanced work environment. While therapist compensation varied based on participants' locations, providing students with information on compensation and payment methods could help familiarize them with the existing options. These insights could ease new therapists' transition from student to professional practice.

Recommendations for Future Research

The guiding research question for this study was: What are the experiences of home-based music therapists working with individuals with I/DD? The findings of this initial study on understanding the experiences of home-based music therapists may provide a foundation for future research to build upon since little was known about this topic. Future research could explore specific areas of HBMT in greater depth. For example, focusing on themes in this study, such as the home as a unique therapeutic setting or the specific therapeutic processes utilized by home-based music therapists, could inform clinical training of music therapists looking to pursue

this type of work. Quantitative studies could address the prevalence of home-based music therapists working in the country. Statistical analysis of present HBMT could bolster the importance and relevance of addressing HBMT during academic and clinical training.

Another topic brought forth by participants was the phenomena of burnout and how, if at all, this way of working may contribute to experiences of professional burnout. No literature currently addresses home-based music therapy and burnout. This would be a relevant area of future study as participants addressed factors contributing to burnout, as suggested by Gooding (2019). The factors addressed in this study include compensation, personal factors, work environment, and training, all addressed by home-based music therapists. Future research could address how these home-based experiences could relate to burnout, if at all.

Limitations

This study had limitations regarding inclusion criteria, demographics, and practical time constraints. Inclusion criteria did not specify hours worked per week in home-based settings. Working full-time as a home-based music therapist could result in different experiences and insights than working part-time in this setting. Further, when asked how many hours per week participants worked, they expressed discrepancies between what they considered full-time versus part-time. Two out of three participants were from the Mid-Atlantic region. Including participants from three different regions of the country could provide a richer understanding of the experiences across a diverse range of music therapists. A practical limitation of this study was the time constraints as part of my degree program. This greatly limited the number of participants who could be interviewed. Although small samples are appropriate to qualitative methodologies, a larger sample may have provided data richer in detail and depth, leading to more robust conclusions.

CHAPTER 6: CONCLUSION

This study aimed to explore the experiences of home-based music therapists working with individuals with I/DD. Three home-based music therapists participated in a semi-structured interview. From this data, four themes were identified: 1) the pragmatics of successful HBMT practice, 2) the home as a unique therapeutic setting, 3) the therapeutic process of the home-based music therapist, and 4) the personal experience of being a home-based music therapist. Participants discussed the structure, organization, and preparation necessary for this clinical work. They also addressed how the home as a therapeutic setting influences the therapeutic experience. Participants described their therapeutic process, including the lens they practice from, and emphasized client-centered care. Within their therapeutic process, participants also spoke about working with the whole family and how this influences the therapeutic relationship. Finally, participants shared the personal decisions they had to make as they navigated home-based work and perceived advantages and challenges to this work style.

Overall, HBMT offers a dynamic work environment that allows the therapist to be independent and flexible. The mobile nature of this work requires advanced planning and preparation to set both the therapist and client up for success. However, clinicians engaged in HBMT may also find themselves experiencing mental and physical fatigue due to the frequent travel and professional isolation. Clinicians described how the home offers a unique therapeutic setting. Learning how to work with the whole family and maneuvering family dynamics are skills clinicians described learning to navigate as they engaged in this work. The therapeutic process while working with individuals with I/DD in home-based settings was individualized and client-centered. This client-centered approach extended into the therapist's theoretical approaches, methods, and interventions. There are different ways of working as a home-based

clinician, stemming from personal choices, such as opening a private practice or working for an established agency.

This research question was intentionally broad to provide a foundational overview of the experiences of home-based music therapists working with individuals with I/DD. Future research can explore, in greater detail, the nuanced aspects of this experience. One research topic that could be fruitful is the potential connection between burnout and working in home-based settings. Addressing HBMT during academic and clinical training would lessen the learning curve on the job and prepare future music therapists for success in this setting. Developing more formal standards for clinical HBMT practice could increase its recognition within the profession and unify current home-based clinicians who are at greater risk for professional isolation. As the field of music therapy grows and society shifts to more community-based models of care, home-based music therapy plays an increasingly important role in the lives of music therapists and the individuals they serve.

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APPENDIX A: IRB Approval Letter

MOLLOY UNIVERSITY

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Patricia A. Eckardt, PhD, RN, FAAN
Chair, Molloy University Institutional Review Board
Professor, Barbara H. Hagan School of Nursing and Health Sciences
E: peckardt@molloy.edu
T: 516.323.3711

DATE:	December 13, 2023
TO:	Sarah Mayr
FROM:	Molloy University IRB
PROJECT TITLE:	[2121420-1] The Experience of Home-based Music Therapists Working with Individuals with Intellectual and Developmental Disabilities: A Thematic Analysis
REFERENCE #:	
SUBMISSION TYPE:	New Project
ACTION:	APPROVED
APPROVAL DATE:	December 12, 2023
EXPIRATION DATE:	December 11, 2024
REVIEW TYPE:	Expedited Review
REVIEW CATEGORY:	Expedited review category # 7

Thank you for your submission of New Project materials for this project. The Molloy University IRB has APPROVED your submission. This approval is based on an appropriate risk/benefit ratio and a project design wherein the risks have been minimized. All research must be conducted in accordance with this approved submission.

You may proceed with your project.

This submission has received Expedited Review based on applicable federal regulations.

Please remember that informed consent is a process beginning with a description of the project and insurance of participant understanding followed by a signed consent form. Informed consent must continue throughout the project via a dialogue between the researcher and research participant. Federal regulations require that each participant receives a copy of the consent document.

Please note that any revision to previously approved materials must be approved by this committee prior to initiation. Please use the appropriate revision forms for this procedure.

All UNANTICIPATED PROBLEMS involving risks to subjects or others (UPIRSOs) and SERIOUS and UNEXPECTED adverse events must be reported promptly to this office. Please use the appropriate reporting forms for this procedure. All FDA and sponsor reporting requirements should also be followed.

All NON-COMPLIANCE issues or COMPLAINTS regarding this project must be reported promptly to this office.

This project has been determined to be a MORE THAN MINIMAL RISK project. Based on the risks, this project requires continuing review by this committee on an annual basis. Please use the appropriate forms for this procedure. Your documentation for continuing review must be received with sufficient time for review and continued approval (45days) before the expiration date of December 11, 2024.

Please note that all research records must be retained for a minimum of three years after the completion of the project.

If you have any questions, please contact Patricia Eckardt at 516-323-3711 or peckardt@molloy.edu. Please include your project title and reference number in all correspondence with this committee.

Sincerely,

Patricia Eckardt, Ph.D., RN, FAAN
Chair, Molloy University Institutional Review Board

This letter has been issued in accordance with all applicable regulations, and a copy is retained within Molloy University IRB's records.

APPENDIX B: Informed Consent

Molloy University IRB
Approval Date: December 12, 2023
Expiration Date: December 11, 2024

Music Therapy Department
1000 Hempstead Avenue, Public Square 220
Rockville Centre, NY 11570
516-323-3320

Title of Study:
The Experience of Home-based Music Therapists Working with Individuals with Intellectual and Developmental Disabilities

This study is being conducted by:
Sarah Mayr, MT-BC
Brigette Schneible, PhD, MT-BC

Key Information About this Study:
This consent form is designed to inform you about the study you are being asked to participate in. Here, you will find a summary of the study; however, you can find more detailed information later in this form.

This study will explore the subjective experiences of home-based music therapists working with individuals with various intellectual and/or developmental disabilities. Data will be collected through individual semi-structured interviews lasting approximately 45 minutes. Participants will be asked about their clinical experiences working as home-based clinicians with individuals with intellectual and/or developmental disabilities. Interviews will be conducted via Zoom. A Zoom audio recording will be collected in addition to a second audio recording on the primary investigator's iPhone. The primary investigator will transcribe all interviews. All transcripts will be de-identified. Once the primary investigator transcribes interviews, participants will be invited to read over their respective transcripts to ensure accuracy. The data will be analyzed using thematic analysis from a phenomenological lens.

Why am I being asked to take part in this Study?

You are invited to participate in this research study because you have been identified as someone who meets the following inclusion criteria:

1) Graduated with a bachelor's degree, its equivalent, or higher from a music therapy degree program approved by the AMTA
2) Has held the Music Therapist – Board Certified (MT-BC) credential for at least three years

Molloy University IRB
Approval Date: December 12, 2023
Expiration Date: December 11, 2024

3) Currently in and has worked in a home-based setting* for at least three years.
4) Can read, understand, and speak English
5) Works primarily with individuals with I/DD

*Eligible home-based settings include private residences and clients' family members' homes. Music therapists serving individuals in congregate housing settings are ineligible to participate in this study.

What will I be asked to do?
You will be asked to participate in one interview lasting approximately 45 minutes via Zoom. The interview will include questions regarding your educational background, theoretical orientation, and experiences as a home-based music therapy provider with individuals with intellectual and/or developmental disabilities. The interview will be audio recorded via Zoom, and an additional backup audio recording will be created on the primary investigator's iPhone. These audio recordings will be transferred to a password-protected, encrypted flash drive and deleted from the primary investigator's computer and iPhone. You will also receive a written interview transcription via email and can revise/add/edit your responses to send back to the primary investigator.

Where will the study take place, and how long will it take?
The interview will be conducted over Zoom. You are free to participate in the interview from the setting of your choice. The interview will take approximately 45 minutes.

What are the risks and discomforts?
There are no anticipated risks or discomforts for participating in this study. You can choose what questions you want to answer or skip. You are also free to provide as much music or as little detail as you would like when responding to interview questions.

What are the expected benefits of this research?
There are no individual benefits to participating in this research study.

Do I have to take part in this study?
Your participation in this research is voluntary. If you decide to participate in the study, you may change your mind and stop participating at any time without penalty or loss of benefits to which you are already entitled.

What are the alternatives to being in this study?
There are no alternatives to participating in this study. You can decide not to participate in this research study.

Who will have access to my information?
Only the primary investigator (Sarah Mayr) and thesis advisor (Dr. Brigette Schneible) will have access to your information.

How will my information be used?

Molloy University IRB
Approval Date: December 12, 2023
Expiration Date: December 11, 2024

The primary investigator will analyze the information collected through semi-structured interviews via thematic analysis. To ensure accuracy, the primary investigator will audio record the interview via Zoom and iPhone, transcribe the interview verbatim, and send the transcription to the respective participant to confirm the correct information. Upon receipt of accuracy confirmation, the primary investigator will analyze the data. The data will then be categorized into themes. The participant's information collected in this research will not be used or distributed for future research studies. To ensure that this research activity is being conducted properly, Molloy University's Institutional Review Board (IRB), whose members are responsible for the protection of human subjects' rights for all Molloy-approved research protocols, have the right to review study records but confidentiality will be maintained as allowed by law.

Can my participation in the study end early?
Your participation in this study is voluntary. Participants may choose to withdraw from the study at any time. Any data that has been collected will be destroyed upon the participant's withdrawal.

Will I receive any compensation for participating in this study?
There is no compensation for participating in this study.

What if I have questions?
Please get in touch with the primary investigator, Sarah Mayr, with any questions related to participation in this study at smayr@lions.molloy.edu. Participants may contact the primary investigator (Sarah Mayr) with questions at any time throughout the study.

What are my rights as a research participant?
You have rights as a research participant. The Molloy University Institutional Review Board (IRB) reviews all research involving human participants. The IRB protects your rights and welfare as a research participant. If you have any questions, concerns, or complaints about your rights as a participant or this research study, you can contact the Molloy University IRB office at irb@molloy.edu or 516-323-3000.

Documentation of Informed Consent:
You are freely deciding whether to be in this research study.

Signing this form means that:
1. You have read and understood this consent form
2. You have had all your questions answered
3. Having been provided sufficient time to decide, you have chosen to be in this study.

You will be provided a copy of this consent form to keep.

_____ _____
Participant Signature Date

Molloy University IRB
Approval Date: December 12, 2023
Expiration Date: December 11, 2024

_____ _____
Participant Printed Name Date

I understand and consent to my interview being audio-recorded on both Zoom and the primary investigator's iPhone:

_____ _____
Participant Signature Date

_____ _____
Participant Printed Name Date

_____ _____
Signature of Researcher Explaining Study Date

_____ _____
Printed Name of Researcher Explaining Study Date

APPENDIX C: Interview Questions

Molloy University IRB
Approval Date: December 12, 2023
Expiration Date: December 11, 2024

Interview Questions

1. How long have you worked as a music therapist in a home-based setting?
2. Briefly describe the home-based setting(s) you most frequently work in.
3. What led you to work in this setting with this population?
4. Have you received any academic or clinical training specifically geared towards your work as a home-based clinician? If yes, please explain.
    a. Is there any training you wished you had received, would like to receive, or think might be helpful for home-based work?
5. Do you encounter any benefits to working in a home-based setting?
6. Have you encountered any challenges to working in a home-based setting?
7. Are there any resources needed that are unique to this setting?
    a. Are there resources that you utilize regularly?
8. Describe the professional support you receive from your employer, coworkers, or colleagues.
9. Are there any guidelines you follow for practicing in this setting? This could include employer guidelines, music therapy professional competencies, guidelines from related fields, etc.
    a. Has this impacted your work? How so?
10. Is there anything else you would like other music therapists or student music therapists to know about working in a home-based setting with individuals with intellectual and/or developmental disabilities?
    a. If yes, please explain.

Molloy University IRB
Approval Date: December 12, 2023
Expiration Date: December 11, 2024

Participant Information Questions to be asked at the end

1. What region are you currently practicing in?
    a. (Great Lakes, Mid-Atlantic, Midwestern, New England, Southeastern, Southwestern or Western)
2. Are you working full-time or part-time in home-based settings? Roughly how many hours per week?
3. Do you hold any advanced training certifications? (I.e., Nordoff-Robbins, Analytical Music Therapy, Guided Imagery, Neurologic MT)
4. Do you practice from a particular theoretical orientation? (I.e., humanistic, psychodynamic, family systems, etc.)

*Interview questions will **not** collect personal information about the participant's clients, the specific company or facility the participant works for, or names of prior music therapy programs the participant may have attended.