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**A PARENT’S EXPERIENCE DURING
THEIR AUTISTIC CHILD’S IN-HOME
MUSIC THERAPY**

A Thesis Submitted to Molloy University
Music Department, Rockville Centre, NY

In Partial Fulfillment
of the Requirements for the Degree

Master of Science
in
Music Therapy

by
Dana Raicaldo
May, 2024

Molloy University

A thesis committee has examined the thesis entitled

A PARENT'S EXPERIENCE DURING THEIR AUTISTIC CHILD'S IN-HOME MUSIC
THERAPY

Presented by Dana Raicaldo

A candidate for the degree of Master of Science in Music Therapy

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ABSTRACT

Little is known about the lived experience of parents who participate in their child's in-home music therapy sessions. This descriptive phenomenological inquiry explored the experience of a parent who participates in her child's in-home music therapy sessions. Through a thematic analysis of the data, five themes emerged: Parental Concern Regarding Jack's Participation Style, Appreciation for Music Therapist, Claire Finds Joy in Jack's Joy, Ambiguity of Mother's Role, and Questioning the "Right Way." An important finding in this research highlights the necessity of a parent understanding their role in music therapy sessions with their children. The study underscored the importance of clear communication and collaborative decision-making between therapists and parents.

Keywords: parent experiences, autistic children, music therapy

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To Cody, thank you for accepting all versions of me and for loving me unconditionally. You make each day better. You have been with me since the start of my music therapy journey, and I have only grown as a person and a musician since we have been together, so thank you for that. I love you.

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Chapter One: Introduction

Parents of autistic children often play a crucial role in their child's therapeutic interventions, yet their experiences during in-home music therapy remain underexplored in the existing literature. Understanding these experiences is essential for optimizing the therapeutic process and supporting the child and parent. This study seeks to address this gap by investigating the lived experience of a parent engaging in their autistic child's in-home music therapy sessions. The research question guiding this inquiry is: What is the lived experience of a parent participating in their autistic child's in-home music therapy sessions? To explore this, I interviewed a parent who participated in their child's music therapy sessions at home. While the importance of amplifying autistic voices and including them in research is acknowledged, this study specifically focuses on understanding the experiences of parents who participate in music therapy with their children.

The motivation to explore this area emerged from firsthand experiences observing parental interactions during the music therapy sessions I facilitated. Moved by the profound empathy I felt for these parents and my admiration for their unwavering dedication to their child, I was deeply inspired to understand the complexities of their experiences in their autistic child's music therapy. The emotions stirred within me—from compassion to a deep sense of purpose—were a response to the vast challenges these parents face, such as navigating societal stigmas, financial burdens, and the constant journey for effective communication methods. These challenges fueled my commitment to this research.

These emotions began to develop when I first started working with autistic children and their parents, gaining a deeper understanding of the difficulties parents of autistic children experience. Witnessing parents' dedication, resilience, and compassion during music therapy

sessions heightened my desire to explore how music therapy may support them as they navigate parenting an autistic child. In my current role as a music therapist, observing a parent express emotion and gratitude as their child achieves musical, social, and developmental milestones brings me tremendous joy. Whether it's a child uttering their first word, purposefully striking specific notes on a xylophone, or exploring a new vocal range, these moments resonate deeply with me.

Researchers have limited knowledge about how these experiences impact the parents. This research aimed to address this gap in the literature. I began exploring available literature to better understand parent experiences and noticed that writing on this topic is limited. There were various articles regarding parents participating in sessions, but there were scarce findings regarding parent experiences during in-home music therapy sessions. This scarcity highlighted the need for a deeper investigation into how parents navigate and perceive their role in their autistic child's therapeutic journey at home. Recognizing this gap, I focused my research on uncovering the nuanced experiences of parents within the context of in-home music therapy with autistic children, aiming to contribute valuable insights that could inform both practice and future research.

Bruscia (2014) defines music therapy as “a reflexive process wherein the therapist helps optimize the client's health using various facets of music experiences and the relationships formed through them as the impetus for change” (p. 36). Music therapists draw from four main methods of music experience: improvisation, re-creative, compositional, and receptive. While the definitions provided here offer a foundational understanding, these methods are comprised of deeper complexities. Improvisation consists of the client and therapist actively participating in spontaneous music-making. Re-creative music therapy is when the client and therapist work

together to reproduce certain aspects of pre-composed songs. The compositional method refers to when clients and therapists compose music together. The receptive method involves music listening.

Music therapists use these four methods to address physical, emotional, cognitive, social, and mental health goals (Gardstrom & Sorel, 2017; Low et al., 2022; Warren & Nugent, 2010).

The nuances of these methods support the multifaceted nature of relationship building.

Additionally, music therapists may incorporate a combination of these methods within any given session to address the needs and preferences of clients. Through the relationships formed in music therapy, children can see themselves in new ways that can be beneficial both in and out of the therapy room (Peralta, 2023).

I currently work in-home with autistic individuals as a part of my employment with Long Island Music Therapy Services, Inc. (LIMT). I employ a humanistic, relationship-based approach centering on music-oriented objectives for my clients. More specifically, I view the music therapy process as allowing clients to use their agency rather than as a technical formula with definitive outcomes (Abrams, 2017). Upon starting a session, some parents join their child and me in a small circle, offering direct support through physical closeness, visual cues, or verbal encouragement. Other parents prefer to listen from an adjacent room, while others leave the therapy area altogether. For example, one mother will put her young child on her lap and begin bouncing them up and down as soon as the music starts. Other parents will stay away from the therapy room or sit within moderate proximity so they can see and hear the session but not engage with me or their child, and some parents may cook dinner or watch a television show in another room. No one way of interacting is better than the other, and circumstances can determine a parent's level of participation.

When working with children, I aim to collaborate with their parents to develop a more informed treatment approach. By communicating with both the parent and the child, I gain a deeper understanding of the child's world. Engaging with parents offers invaluable insights into the child's emotional responses, family dynamics, cultural context, and medical history, enriching my perspective and enhancing my approach to their care. These factors help to inform clinical decisions and guide the therapeutic approach more effectively. For example, my client may be unable to express that they were not feeling well earlier that day, but their mother can tell me that the school nurse called to let her know the child was feeling unwell at school.

In my professional experiences, I have observed diverse responses in music therapy correlating with the presence or absence of the parent. A parent simply being in the room may prompt their child's participation in the music, such as trying a new piano note and immediately looking to their parent for validation. I have seen the parent directly lead the child with prompts such as "Go ahead and try to play the rhythm." Conversely, instances where the parent is absent during music therapy, have occasionally resulted in the client becoming dysregulated, as seen through expressions of sadness or the client physically leaving the therapy space to search for their parent. It is fascinating to me to see these differences. By exploring parents' experiences during music therapy sessions, music therapists may learn what motivates parents to participate and the potential benefits they experience.

Parents have differing experiences in the session versus out of the session. In my experience, parents have vocalized their appreciation for their child's growth in music therapy. Many parents have also described the experience of witnessing progress as providing a sense of pride. At the same time, the child discovers a new path of connecting with themselves, their parent, and the therapist. A parent mentioned seeing their child smiling while playing the drums

brings them joy. When parents do not participate in sessions, they do not witness these experiences firsthand; instead, they receive a verbal report about the progress. Parents may overlook progress in these moments because they did not directly experience the session. In one situation, when I shared the session occurrences with a parent, the parent requested video recordings of memorable moments in music therapy; this suggests the parent values seeing the process.

Parents of autistic children can encounter a myriad of challenges. From navigating complex healthcare systems to seeking appropriate educational support, they grapple with finding specialized resources and therapies tailored to their child's individualized needs (Collins, 2008). Additionally, navigating their child's unique communication and behavioral patterns can be an ongoing struggle (Papadopoulos, 2021). Balancing daily routines while addressing the diverse needs of their autistic child presents emotional and logistical hurdles (Divan et al., 2012). The search for support and understanding within society further compounds these already demanding circumstances, leading to isolation from social networks and community resources (Collins, 2008; National Institute of Health [NIH], 2023).

The NIH (2023) classifies autism as a neurodevelopmental condition characterized by deficits in social communication, restricted interests, and repetitive behaviors. These diverse characteristics classify autism as a spectrum disorder (i.e., autism spectrum disorder [ASD]). A child's symptoms must be present in the early developmental stages and cause clinically significant impairment in social, occupational, or other important areas of functioning to receive a diagnosis of autism (American Psychiatric Association [APA], 2022). As listed in the Diagnostic and Statistical Manual of Mental Disorders (5th ed.; DSM-5; APA, 2013), diagnostic criteria include persistent deficits in social communication and interaction across multiple

contexts and restricted, repetitive patterns of behavior, interests or activities. Moreover, autistic children may have trouble developing meaningful relationships and expressing themselves, show little or no interest in the world around them, and sometimes fixate on specific items, subjects, or interests (NIH, 2023). According to Maenner et al. (2023), the prevalence of autism increased by 20% from 2018 to 2020. The overall prevalence of ASD in 2020 was 27.6 per 1,000 or 1 in 36 children aged eight years. Additionally, autism is 3.8 times more prevalent among boys than girls (Centers for Disease Control and Prevention [CDC], 2023).

There is emotional strain involved with learning about a child's ASD diagnosis (Corcoran et al., 2015). Parents may experience a sense of loss as they come to terms with a life that differs from what they had once imagined. According to Divan et al. (2012), parents of autistic children face significant economic and emotional challenges and frequently encounter situations of discrimination. The emphasis on stigma is widespread among parents, who also contend with issues of stereotyping, rejection, and exclusion in various social contexts (Kinnear, 2015). This stigma can present itself in both subtle ways, such as judgmental glances or dismissive attitudes, and more overtly, through denial of services or opportunities for their child. These environmental stressors lead to social isolation and disrupt parents' ability to maintain a stable and supportive environment for their child. Consequently, the impact on parents' daily lives profoundly affects their mental health, social interactions, and economic stability.

The varied ways parents engage in music therapy with their autistic child have led to my interest in more deeply understanding the nature of this engagement. I have a profound appreciation and a deep sense of fulfillment from experiencing parents interacting with their children during music therapy. Expanded research in this area can significantly benefit future music therapists and the families who receive these vital services.

Epistemology

In this study, I employed constructivism, a learning theory that emphasizes the active role of learners in building their knowledge and understanding of the world (McLeod, 2023).

Constructivism positions knowledge as gained through interpretation and subjective experiences rather than objective facts, but in the context of my reality as socially constructed through language, culture, and shared meaning-making. This epistemological stance allowed me to understand the participants' lived experiences because it directly correlates with this research design.

Chapter Two: Literature Review

This research explored the lived experiences of a parent who participates in their autistic child's music therapy sessions. The literature review below addresses the general characteristics of autistic children, including the raising of autistic children. It explores the perceptions and experiences of parents of autistic children in music therapy.

Reframing Autism Spectrum Disorder

As described earlier, the NIH (2023) designates autism spectrum disorder (ASD) as a neurodevelopmental condition characterized by social, cognitive, communicative, and physical challenges. "Although autism can be diagnosed at any age, it is described as a 'developmental disorder' because symptoms generally appear in the first two years of life" (NIH, 2023, p. 1). The words "Autism Spectrum Disorder" automatically suggest that an autistic person has a disorder.

The stigma often associated with an autism diagnosis can significantly impact autistic individuals and their families, fostering social isolation, limiting opportunities for inclusion, and perpetuating misconceptions that hinder understanding and acceptance (NIH, 2023). Bervoets and Hans (2020) argued that this standard definition of autism conflicts with an autistic person's reported lived experiences. An autistic person discussed their lived experience, stating how autism is a part of their identity, similar to gender (DePape & Lindsay, 2015). Acknowledging diverse and unique lived experiences challenges the conventional definition of autism, highlighting the need for a nuanced understanding that recognizes the individuality within the autistic community (Bervoets & Hans, 2020).

Additionally, Bervoets and Hans (2020) advocated the importance of considering all aspects of an individual and understanding autism from a broad ethical standpoint beyond the

definition given in the DSM-5. Every individual is unique, so it is crucial to consider this and to avoid using blanket generalizations. The contrast between the scientific definition of ASD in the DSM-5 and the real-life experiences of autistic individuals highlights the diversity within the autistic community. Honoring and understanding individual experiences can lessen generalizations and foster a more inclusive and empathetic society, benefiting both children and parents.

Characteristics of autistic children are diverse and unique to each individual. Autism is a spectrum, and the characteristics of autistic children span from little to no noticeable functional differences to vast functional differences. Some autistic children have sensory issues limiting their desire to touch items or eat certain foods (Leader et al., 2020). Additionally, some autistic individuals experience struggles with joint attention, motor skills, expressive and receptive communication, motivation, socialization, anxiety, and cognition (NIH, 2023). These challenges may impact individuals' success in developing meaningful relationships. In line with these varied characteristics, some clinical needs may include behavioral support, educational support, occupational and life skills, and emotional support (NIH, 2023). Parents play a crucial role by facilitating access to essential services that can specifically address their child's unique needs and development.

Music Therapy for Autistic Children

Music therapy provides a dynamic and versatile service for autistic children, offering varied methodologies to meet the individual needs described above. Music therapists have demonstrated a proclivity for a multifaceted approach that employs creative music therapy, sensory integration, and behavioral interventions tailored to this demographic (Eren, 2017). This

showcases the flexibility of music therapy and its capacity to address the wide-ranging needs of autistic individuals effectively.

Integrating preferred music into therapeutic sessions is crucial for enhancing engagement and outcomes in music therapy. Utilizing music that children enjoy has been found to significantly increase their participation and improve therapeutic results (Attar, 2022). Specifically, incorporating singing, which is often associated with preferred music, notably boosts vocal communication and supports social interactions (Attar, 2022). These findings suggest that tailoring music interventions to children's preferences can facilitate better engagement, enhance verbal expression, and foster stronger social connections between children and their parents. This approach contributes to a deeper understanding of how personalized music therapy can effectively support both therapeutic and relational goals.

Joint attention, or the capacity to focus on the same object or activity as another person, is fundamental in developing relationships with autistic children, serving as a bridge to more profound forms of communication and understanding. Research has shown that improvisational music therapy significantly enhances joint attention and non-verbal communication skills in preschool-aged autistic children more effectively than traditional toy play alone (Kim et al., 2008). These findings highlight the benefits of music therapy in improving a child's ability to engage and connect with family members and caregivers. By fostering joint attention, music therapy supports relationship-building by enhancing the autistic child's capacity for meaningful interactions. Strengthened connections lead to increased verbal and non-verbal communication, enriching the child's relationships and contributing to their overall social and emotional development. These enhanced interactions offer new avenues for expression and understanding within relationships.

Consequently, music therapy emerges not just as a therapeutic intervention but as a vital tool for enriching the lives of autistic children and their families. By providing valuable opportunities for improved communication and deeper connections, music therapy serves as a conduit for fostering meaningful interactions and enhancing overall well-being. Thus, it supports therapeutic goals and significantly contributes to the social and emotional development of both children and their families.

Experiences of Autistic Individuals in Music Therapy

Autistic individuals may be motivated to participate in music therapy for various reasons, such as social, emotional, and sensory support (Low et al., 2022). Sensory-rich experiences offered in music therapy are engaging and provide a platform for communication and self-expression (Carpente, 2015). Additionally, through the therapeutic relationship, music therapists can provide structure and emotional support (NIH, 2023). Low et al. (2022) described the experiences of autistic individuals in music therapy.

Delving into the personal experiences of autistic individuals in music therapy, Low et al. (2022) provided a window into the transformative journey of four individuals who underwent at least six months of music therapy. Through four to five interview sessions, these participants shared insights into their journeys within the therapeutic landscape of music. Notably, they reported a multifaceted impact of music therapy on their lives. Participants spoke of developing their musicianship, indicating enhanced musical skills and a deeper connection with music as a medium of expression and self-discovery.

Beyond the musical domain, these individuals reflected significant personal growth. They reported evolving their personal selves, which could encompass a range of experiences from increased self-awareness and confidence to improved communication skills and emotional

regulation. Creating meaningful relationships was another critical aspect highlighted by the participants, illustrating how music therapy facilitated connections with others, possibly through shared musical experiences or the therapeutic alliance with the music therapist.

Interestingly, participants also touched upon the role of music therapy in bringing out their sociocultural identities, suggesting that music therapy does not just function on an individual level but also engages with broader aspects of identity and belonging, offering a space for autistic individuals to explore and express these facets of themselves. The research studied here may reveal similarities in parents' experiences of creating meaningful relationships.

Parents of Autistic Children

The parent-child dyad is a unique and complex relationship. All parents encounter a diverse range of challenges while providing support for their children. New parents are often not expecting an autism diagnosis. Stacy, a mother of two autistic sons in their 20s, said that receiving this diagnosis for her sons felt like her sky was falling. Stacy mentioned having little to no social connections and feeling alone and scared. Although it continued to be hard, Stacy could cope and begin to accept her situation over the years (S. Mason, personal communication, December 7, 2023). Stacy expressed intense gratitude about when her children eventually could communicate with her using Spelling to Communicate (i.e., an augmentative communication device; S2C), which involves pointing to letters on a board as an alternative means of communication (I-ASC, n.d.). Stacy's experience aligns with other parents' experiences (Bilgin & Kucuk, 2010; Papadopoulous, 2021; Rattaz et al., 2023) and demonstrates parents' need for varied opportunities for interaction with their children.

Parents of autistic children may experience added challenges, such as struggling to understand their child's wants and needs, which may lead to stress (Rattaz et al., 2023).

Additionally, parents' concerns about their autistic child's behavior may lead to isolation from family, friends, and society (Papadopoulos, 2021). Rattaz et al. (2023) stated, "Parental feelings of stress are related to the huge amount of information they have to deal with, the lack of support, the stigmatization by members of the community, and the worries about the future" (p. 2). According to the CDC (2023), autistic children sometimes do not respond to their names, do not show shared interest with others, and display blunted facial expressions. Additionally, when a child is non-speaking or has limited language ability, parents may feel hopeless and disconnected from their child (Bilgin & Kucuk, 2010).

Bilgin and Kucuk (2010) explored the experiences of mothers having autistic children. They found that the most critical needs of these mothers included "support from family members, healthcare organizations, and society" (p. 92). Parents bear the responsibility of advocating for their autistic children's immediate needs and securing life-long support. Advocacy for services helps parents feel that their autistic children will be cared for as they age (Akhai et al., 2022; Collins, 2008; Lemboye, 2023; Smith, 2011). The collective insights from these studies highlight the multifaceted challenges faced by parents of autistic children. Participating in music therapy with their child may offer parents opportunities to alleviate stress while strengthening their parent-child bond.

Music Therapy and the Parent-Child Relationship

Parents of autistic children may be stressed, and this stress may adversely affect the parent-child relationship. Music therapists use music experiences that promote harmonious relationships while developing skills in social communication (Carpente, 2016). Music therapy may support and nurture parent-child relationships when parents are involved in treatment (Sorel, 2010). When parents actively participate in the treatment process, music therapy may be a

supportive and nurturing tool for parent-child relationships (Sorel, 2010). Music therapy provides a unique avenue for shared experiences, creating joy and connection during musical activities (Schwartzberg & Silverman, 2016). Parents and children strengthen their emotional bonds through joint engagement in music therapy sessions (Warren & Nuggent, 2010).

The collaborative nature of music-making, as highlighted by Schwartzberg and Silverman (2016), fosters effective communication between a parent and their child. This shared interaction enhances the quality of their relationship. It offers a platform for parents to understand better and respond to their child's emotional cues and learn about their abilities and creativity (Sorel, 2010). Moreover, parents may be able to continue to use many of the strategies used in music therapy outside of music therapy to offer continued support to their child (Schwartzberg & Silverman, 2016; Sorel, 2010; Thompson, 2012, 2019; Warren & Nuggent, 2010; Yang, 2016).

Both Thompson et al. (2019) and Sorel (2010) explored the impact of music engagement on parent-child relationships. Thompson et al. (2019) reveal how making music together enhances social interaction and fosters children's desire for parental involvement compared to block play. Sorel (2010) delves into the transformative effects of music therapy on families with autistic children, emphasizing how active participation in sessions fosters emotional connection, strengthens relationships, and deepens understanding of the child's needs and experiences. Both studies underscore the unique potential of music to enhance parent-child dynamics and promote development within families.

Music Therapy in In-Home Settings

In-home music therapy involves several key components for effectiveness, including the therapist's attunement to the child's mood, adapting to the family's preferences, and employing motivating interventions and positive affect. Observations of the therapist's interactions with the

child often lead to increased parental involvement and responsiveness. Parents may be inspired to incorporate similar strategies into their own daily interactions, thereby enhancing their engagement with music and developing new methods of interaction (Thompson, 2012).

Research further supports the impact of music therapy on parent-child dynamics. Shared music interventions are shown to improve emotional attunement, mutual engagement, behavioral reciprocity, and turn-taking. These interactions help foster emotional connections, strengthening the parent-child relationship and improving overall relational dynamics (Yang, 2016). Such findings illustrate how music therapy can create meaningful interactions and enhance the quality of relationships between parents and their children.

Conclusions From the Literature, Rationale, and Research Question

Parenting autistic children presents unique challenges. As the literature review has shown, music therapy can be a valuable treatment option for autistic youth. Parents who choose music therapy as a service for their children value the experiences provided. Additionally, when parents participate in music therapy, either actively or through observation, they may experience strengthened relationships and learn new ways of connecting with their children. This literature highlights compelling aspects of parent experiences in music therapy that warrant greater attention. The active participation of parents in their child's music therapy may provide a platform for fostering connections, strengthening the parent-child bond, and deepening the parents' understanding of their child's potential. Literature detailing parent perceptions on enhancing the parent-child relationship through music therapy exists (Schwartzberg & Silverman, 2016; Sorel, 2010; Thompson, 2019; Warren & Nugent, 2010; Yang, 2016). However, literature explicitly addressing parents' experiences in music therapy remains limited. Therefore, to better understand these experiences, I will address the following research question:

What is the lived experience of a parent engaging in their autistic child's in-home music therapy sessions?

Chapter Three: Methodology

Research Design

This research study utilized a descriptive phenomenological design (Wheeler & Murphy, 2016). Descriptive phenomenological research aims to discover and describe “how a person perceives, feels, thinks, and derives meaning from a *lived* phenomenon, that is, something that a person has experienced” (Wheeler & Murphy, 2016, p. 60). The phenomenological research design is consistent with a constructivist perspective, which proposes that we continually create our reality in the moment based on our lived experiences. By adopting a phenomenological perspective, this research sought to gain a deeper understanding of the subjective experiences of parents of autistic children who participate in music therapy with their children.

Epoche

An epoche is an approach employed in qualitative research aimed at setting aside preconceived notions or personal beliefs to strive for a more objective interpretation of data. In utilizing this method, researchers can bracket out their assumptions, allowing a more comprehensive and unbiased analysis of the information obtained (Wheeler & Murphy, 2016). I utilized epoche during data analysis to acknowledge and temporarily set aside my preconceived notions about the positive impacts of music therapy for autistic children and the enhanced benefits linked to parental involvement. I share the following story to overtly demonstrate my experience and beliefs about including parents in music therapy.

When I entered the client’s home, Charlie (pseudonym) immediately approached me and looked into my instrument bag. Then, Charlie quickly ran over to the couch and sat on his mother’s lap, anticipating the “Hello” song. With a lollipop drum in hand, Charlie played along to the music while I played guitar, and his mother and I both sang. I sporadically left spaces in

the music for Charlie to fill in vocally. Charlie often remained silent or filled the space on an open vowel “ah.” On this day, Charlie softly approximated the word “hello” in the appropriate place where I left space in the music. Charlie continued playing the drum for the remainder of the song. At this point, intense emotion overcame his mom; her palpable joy gave me goosebumps. Mom was pleased that Charlie had sung the word “hello.”

After the session, I shared with Mom that it may take a little longer for Charlie to engage because his brain processes information differently. Mom shared that she hadn’t considered his processing time, and it was helpful to understand Charlie in a new way. During this experience, the mother’s participation in the session directly influenced Charlie and contributed to a positive outcome. The mother also provided Charlie with regulation through physical support and sensory input by bouncing him up and down on her lap. The sessions afterward continued to maintain and elevate the positivity and exceed that goal.

I enter the research process with the following beliefs. Music therapy benefits the child, the mother, and their relationship. The mother's active involvement fosters the child's participation and enhances her understanding of the child, thereby nurturing their relationship. Parents may benefit from an improved relationship and bonding with their child, which they may not have experienced without music therapy.

Participants and Recruitment

I recruited one participant through purposive sampling after Institutional Review Board (IRB) approval (Wheeler & Murphy, 2016). Purposive sampling requires the researcher to purposefully identify potential participants who have experience with the phenomenon of study. Recruitment procedures included: 1) Reaching out to board-certified music therapists via email, through Lauren Klimek (owner of Long Island Music Therapy, Inc.) to inquire about their

clients' families' interest in the study, and posting the recruitment invitation to Facebook groups, Music Therapists Unite!, The Mid-Atlantic Region of the American Music Therapy Association and Licensed Creative Arts Therapist of NY, 2) Contacting and connecting with a potential participant, 3) Verifying potential participants met inclusion criteria, and 4) Receiving signed informed consent forms.

The inclusion criteria for participation in this program were as follows: individuals must be parents to autistic children aged between 4 and 21 and receiving in-home music therapy services. Active participation was an essential requirement. I described active engagement as being present in the same room as their child during music therapy sessions; participating in making music; and providing visual, verbal, and physical support to their child throughout the sessions. Proficiency in English was necessary for interview participation. Additionally, participants were required to have access to a phone, computer, or tablet to take part in the virtual interview. The recruitment email (see Appendix A) included a description of desired participants and requisite inclusion criteria, a brief description of the research, and contact information for the researcher.

Informed Consent

The informed consent process facilitates a transparent decision process for potential participants (Wheeler, 2015). I wrote the informed consent document in plain English (see Appendix B). It detailed all aspects of the research process, such as potential risks and benefits, what I asked of participants, and assurance that they may choose to leave the research at any time without consequence. I was available to discuss the informed document with potential participants as necessary.

Materials

I used an iMac to record the Zoom meeting and recorded audio on two other Apple devices for backup (i.e., iPhone 15 Pro Max and 12.9-inch 3rd generation iPad). Materials used for audio collection during the interviews included voice recording applications on Apple devices, such as *Voice Memos*. After completing the interviews, I transferred the recordings to an external hard drive and stored them in a secure and protected location. I stored the data on safe and protected devices in case something happened to the hard drive.

Data Collection

Interviews

The primary data for this research included transcribed interviews. After completing the informed consent process, I invited the participant to a virtual interview scheduled at their convenience. The interview was forty minutes and guided by a set of open-ended questions. The questions created were to gather information about their experience participating in their child's music therapy sessions. The interview questions were designed to explore various aspects of parent participation in music therapy sessions. These questions included: (1) "What was your experience like participating in the music therapy sessions with your child?" (2) "Have you observed any specific changes in your child as a result of the music therapy sessions?" (3) "How do you perceive your role during the music therapy sessions?" (4) "In what ways has music therapy influenced the relationship between you and your child?" (5) "What strategies or techniques used in the sessions did you find particularly useful?" and (6) "Can you share any special memories or moments from the music therapy sessions that stand out to you?" The interviews conducted over Zoom took place no more than two weeks after their child's most

recent session. I included client names when interviewing each parent and later changed them for confidentiality purposes in the final narrative of this research.

Data Protection

I used Apple devices (i.e., iMac, iPhone 15 Pro Max, and 12.9-inch 3rd generation iPad) for audio and video recording. Data protection included uploading all audio files from Apple devices immediately onto a password-protected computer. They were then transported to a password-protected Google folder and uploaded onto an encrypted hard drive for backup. I stored the hard drive in a locked storage unit that only I could access. I will delete all data entirely after one year.

Data Analysis

Data analysis aimed to uncover similar patterns or emergent themes from the interviews to understand the participant's experiences. The data was analyzed using an inductive thematic analysis (Braun & Clarke, 2006). After transcribing the interviews, I sent the verbatim transcript to the participant for member-checking. This process allowed the participant to verify information or provide necessary clarifications (Wheeler & Murphy, 2016). After the participant verified and returned the transcript, I incorporated Braun and Clarke's (2006) six phases of data analysis:

1. Familiarizing yourself with the data: This initial step involved immersing oneself in the qualitative data, which included reading and re-reading the data. The goal was to become intimately familiar with the content to understand the information comprehensively.
2. Generating initial codes: I started the coding process once I was acquainted with the data. I created initial codes by identifying and labeling data segments that

captured specific meanings or concepts. These codes were short words or phrases summarizing portions of the data.

3. Searching for themes: I began identifying potential themes after generating initial codes. I grouped related codes and searched for patterns, similarities, or recurrent ideas across the dataset. I looked for connections that signify more significant concepts or overarching themes.
4. Reviewing themes: As themes emerged, I critically reviewed and examined them in relation to the coded extracts and the entire dataset. It was essential to ensure that the identified themes accurately reflected and covered the relevant aspects of the data. This stage involved refining, revising, and potentially merging or splitting themes to ensure they accurately represented the dataset.
5. Defining and naming themes: Once verified and defined, I provided clear definitions and labels for each theme. These definitions encapsulated the essence of the theme and effectively represented the effectively grouped codes. Naming themes helped to capture the essence conveyed by the collected data.
6. Producing the report: The final step involved synthesizing the analysis into a cohesive report. I presented the identified themes along with supporting excerpts from the data. I also constructed a narrative that explained and elucidated each theme, demonstrating its relevance and significance within the context of the qualitative dataset. This narrative offers a clear and comprehensive understanding of the data.

Each step contributed to a thorough and systematic qualitative analysis, ensuring a comprehensive exploration and presentation of the information collected.

Trustworthiness

To promote trust in the research process, qualitative researchers strive to meet four general areas of trustworthiness: credibility, transferability, dependability, and confirmability (Lincoln & Guba, 1985). According to Lincoln and Guba (1985), *credibility* refers to the extent to which the findings are believable, *transferability* refers to how the data may apply or be generalizable to other settings, *dependability* refers to the consistency of the research process, and *confirmability* refers to the researcher's process of bracketing out potential bias.

Credibility was addressed through member checking (i.e., returning the transcript to the participant to check for accuracy) and peer debriefing (i.e., discussing possible findings with the research advisor). I upheld transferability by providing a detailed description of the participant's experience. I addressed dependability by thoroughly detailing the research process throughout the data analysis process. Finally, confirmability was addressed through a reflexive research process, maintaining a detailed log of the research process, and bracketing out my viewpoints through the epoche process.

Ethical Considerations

I submitted a thesis proposal to Molloy University's Institutional Review Board, which was approved (see Appendix C). Upon approval, I recruited participants and asked them to review and sign an informed consent document. I maintained participant privacy and confidentiality, and all data was kept on password-protected locked devices.

Data Presentation

The data presentation involved showcasing the identified themes, subthemes, and their corresponding data extracts in the form of a master's thesis. This presentation included narrative descriptions and data excerpts (i.e., quotes) that support and illustrate each theme.

Chapter Four: Results

Analysis of the data revealed five themes. Participant quotes support the themes that are presented and defined. This section delves into a mother's experiences and insights during in-home music therapy sessions. The themes encapsulate her initial expectations, evolving perspectives, adaptive techniques, and unwavering commitment.

Participant

I recruited one participant, Claire (pseudonym). Claire lives on Long Island and is a mom to a 12-year-old autistic child, Jack (pseudonym). Claire is a dedicated mother who prioritizes Jack's well-being, especially in the context of music therapy. Jack is diagnosed with autism and his primary diagnosis is a rare chromosomal disorder that comes with a severe intellectual disability and severe to profound hearing loss. His Individualized Education Plan (IEP) outlines the services he receives at school. Jack's interdisciplinary team at school introduced Claire to music therapy. Before the team's suggestion, Claire was unfamiliar with in-home music therapy.

Theme One: Parental Concern Regarding Jack's Participation Style

This theme reflects Claire's concern regarding Jack's participation and involvement in music therapy. Early on, she shared, "Jack tends not to like new things, and he tends to have fixated interests of which music is not one of them." She also mentioned that during their first session, "Jack was kind of pulling on his hair a little bit, which to me is a calming technique. So I think he might have been a little stressed out ... think it was curiosity." Claire's concern about Jack's participation in music therapy stems from his resistance to new experiences and his fixation on specific interests that do not include music. During their initial sessions, she noticed his calming technique of pulling on his hair and interpreted it as a sign of stress or curiosity.

Jack is severely hard of hearing and communicates primarily through an assistive device. Claire was concerned about how his communication style would affect his participation in music therapy. Claire stated,

Even just to get Jack to ... sit there and [pay] attention, sometimes he'll reach out to touch the instrument. Whether or not he's indicating he wants more because he is nonverbal, I should mention that. So, between the deafness and the nonverbal communication is the challenge. So I don't know what to expect; I think it's going great.

She also mentioned that Jack sometimes reaches out to touch instruments, possibly indicating a desire for more engagement within music.

Theme Two: Appreciation For Music Therapist

This theme encapsulates how Claire's experience in music therapy with her child has led her to appreciate the music therapist's person-centered approach and respect for her son's voice. During one session, Claire noticed how Jack began vocalizing while spinning on a chair. These vocalizations only happened when the therapist was present. She stated, "The music therapist is great ... he kind of just rolls with whatever my son is bringing that day to the session ... if he's not interested in those instruments, let's try something else", and "He'll follow him around the house sometimes just to kind of keep him engaged." She appreciates the therapist's approach and the potential of music, as they create a supportive environment where her son feels at ease to explore new experiences.

Claire talked about her appreciation for the music therapist's person-centered approach. Claire said the music therapist had an ability to "meet [Jack] where he is at." She also stated, "[My son] doesn't want the therapist to leave at the end of the session." Claire pointed this out

mainly because most of Jack's therapists are females, so she was surprised by how he responded to a male therapist. She also said,

But I think just [Jack] being exposed to more things and [experiencing] challenges, you know, it's challenging, right, having somebody come in your house and have an expectation for you like music therapy. He's just doing better with that. So ... music therapy is a part of that, you know, kind of building his resilience.

Claire noticed her son forming a bond with the music therapist.

Subtheme Two A: Music Therapy Builds Strength

Claire spoke about the potential of music therapy to build Jack's resilience. She articulated, "So I definitely think music therapy is a part of ... building his resilience." Furthermore, Claire said, "I think it's building his resilience, and just some of the negative behaviors are decreasing. So definitely noticeable." These statements from Claire illuminate her belief in music therapy as a tool for enhancing her child's resilience, showcasing its potential to address challenges and facilitate behavioral changes.

Theme Three: Claire Finds Joy in Jack's Joy

This theme represents Claire's moments of happiness during Jack's music therapy experiences. Regarding the first session, Claire stated, "I was stunned that he sat almost the whole time." She noticed that it didn't seem to be an adverse experience to him, much like other new experiences, and that made it feel like a win. She expressed joy by saying, "The first week was memorable because he sat through almost the whole thing, which was just amazing. I was like, this is incredible...It was really nice to see he doesn't get upset when the music therapist is here," and "he's not pushing him out the door, which he will do if he doesn't like something."

Claire offered other thoughtful reflections, such as, "If he enjoys the session, that's wonderful, right to see him just be happy by something that, you know, could have been a stressful situation for him." She also stated, "So yeah, I usually have a big smile on my face. Well, I guess I just get to watch him as opposed to ... [being] in that caretaker mode." Claire appreciated the opportunity to be in the moment with her son and enjoyed seeing Jack have fun. This insight highlights how Claire is uplifted when witnessing and being with her son while he experiences music therapy.

Subtheme Three A: Claire's Observation: Jack's Response to Music Therapy

Claire recognized a difference in Jack's behavior that might be attributed to music therapy. Regarding the spinning on the chair, she remarked, "It was interesting to see kind of how the movement helped to bring that out. But when he spins, and it's not music therapy, he is not vocalizing. So that was very interesting." Further,

So I'm really curious to see how he's going to do today with it if that's going to be something where, when he's sitting in that chair with the movement, you know, does he have increased vocalizations? Because then that's something we're learning from him, right?

This sensory connection, experienced and understood by Claire, added depth to her understanding of Jack's unique responses within the music therapy environment and her appreciation for learning new things about him.

Theme Four: Ambiguity of Mother's Role

When discussing her role, Claire mentioned that her participation is "kind of like a gray area." She stated, "I don't want to interject myself in between him and the therapist." She is in

the room with her son and the music therapist but allows them the autonomy to proceed independently:

I never really asked the music therapist, and I probably should, how involved he wants me to be, does he want me to be doing hand over hand? Does he want me to ... show first by modeling? [I] never really did that. So after this, I'm going to, because I tried to sit back more and not, I don't want to say not participate, because obviously I said I participate. But just try to kind of point him in the right direction.

Claire sought the best care and highest benefit from the services that her son was receiving.

Claire felt supporting and encouraging Jack's participation by incorporating innovative engagement strategies was essential. For example, Claire said,

Maybe I'll try to find a toy that he can use as an intermediary to ... push the drum with that toy. He's very fixated on chewelry. And he likes to swing them, so maybe swinging so it hits the drum. So I'll try to give him something that I know he's interested in that maybe can be incorporated into what I think the music therapist is trying to pull out.

This adaptive approach, born from her deep understanding of her child's preferences, allowed her to participate actively.

Claire highlighted, "[I] try to remove distractions, for I'm trying to maybe come up with an intermediary way he might interact with the instruments. Definitely encouraging sitting, definitely removing access to other areas of the house." Claire also stated, "I think my participation is definitely just trying to keep him from fixating on leaving the session to go do other things," and "I'll kind of participate then kind of get to step back a little bit and kind of see what he's able to do on his own." Claire's actions demonstrate her interest in nurturing Jack's independence.

Claire wants experiences for her child to be fun; she stated that she doesn't want to be "making him do it; it should be fun." Her role in the session is often one of encouragement; she stated, "Generally, a lot of what I am doing in this session is trying to get him to sit, maybe pay attention if a drum is put out and he doesn't want to put his hand on the drum...I might model." Claire expressed that the goal wasn't necessarily to have her son hit the drum at specific times, but rather to observe how he explored the instruments and engaged with the music. She acknowledged her role in keeping him on track during the sessions, while also being mindful not to overstep. Claire emphasized that the focus was on her son's therapy, not on her own involvement, stating, "It's not music therapy for Mom. It's music therapy." Ultimately, she mentioned her intention to discuss with the therapist whether her involvement should increase or decrease. Claire wasn't sure, what the therapist expected from her. One might consider Claire's role one of an *attentive observer*.

Subtheme Four A: Insight on Individualized Education Program (IEP) and Goals

During our discussion about the Individualized Education Program (IEP), Claire realized the importance of her role of communicating with the IEP team. She remarked,

There's a point to putting this on his IEP, and it's to, you know, help him, you know, in theory, with his IEP goals, and what we've also learned from this is his IEP goals might not be as appropriate as they should be.

Through participating in Jack's music therapy, she realized that Jack's current IEP goals might not align with his strengths and needs. She further emphasized,

So really, between the music therapy and the parent training, the ABA, like it's forced us to kind of look at those goals. Are they the appropriate goals? So it's going to be really helpful for his next IEP meeting to maybe revisit those,

Through music therapy, Claire gained firsthand insights into Jack's abilities, preferences, and more through her direct involvement, providing a front-row perspective. She compared this to other therapies that see Jack one-on-one and then provide feedback after the sessions.

Theme Five: Questioning the “Right Way”

Claire's experience in her son's music therapy sessions is marked by a sense of uncertainty and introspection regarding her level of involvement. She admits, “I don’t know what to expect, I think it’s going great,” reflecting her initial ambiguity and positive outlook. Her concern was evident as she questioned, “Am I participating the appropriate way?” and “I tend to be a worrier anyway, so like, am I participating too much? Or am I not participating enough? Will the music therapist tell me?” These statements highlight her anxiety about striking the right balance between being supportive and overbearing.

Claire acknowledged the potential benefits of the therapist initiating a proactive discussion with the parent, as she said, “So that might be a good conversation for a music therapist to have with the parent, like kind of upfront,” to clarify expectations and roles. Her belief in the importance of regularly checking in to ensure her involvement is appropriate without becoming a “helicopter” or “snowplow” parent reinforces this idea. Despite her concerns, Claire remains in the room, hyper-aware of her presence and its impact, as she navigates the delicate balance of her participation in the therapeutic process.

Chapter Five: Discussion

This research study explored one parent's experience participating in their autistic child's in-home music therapy session. The research question guiding this inquiry was as follows:

What is the lived experience of a parent engaging in their autistic child's in-home music therapy sessions?

Data were analyzed using Braun and Clark's (2006) six phases of thematic analysis. Analysis revealed five themes that capture the essence of what it's like for a parent to participate in their autistic child's in-home music therapy sessions.

The Essence of Claire's Lived Experience

Claire initially had reservations about enrolling Jack in music therapy due to his communication differences, particularly his severe hearing impairment and reliance on an adaptive communication style. These comorbidities added layers of complexity to her experience with the therapy, influencing how she perceived and responded to Jack's participation. While her experiences were shaped by his autism, it is important to recognize that his hearing and communication challenges also played a significant role. This intersection of conditions provides a unique context for understanding her lived experiences during the in-home music therapy sessions. However, active involvement in Jack's in-home sessions offered invaluable insights into Jack's preferences and strengths. Claire enjoyed seeing Jack have fun and trying new things in music therapy, and she was pleased to see Jack's level of comfort and engagement with the music therapist. Claire also enjoyed having opportunities to sit back and watch as Jack developed independence. Claire appreciated the music therapist's person-centered approach, yet Claire yearned for guidance from the music therapist as to how she should participate in sessions.

Though Claire was invested in Jack's music therapy experience, she felt uncertain about the music therapist's expectations of her.

Concern, Appreciation, and Joy

Claire's concerns regarding Jack's participation and involvement in music therapy resonate with the challenges many parents of autistic children face. Research by Leader et al. (2020) and the NIH (2023) outlines the diverse characteristics and challenges experienced by autistic children, such as sensory issues and communication barriers. These challenges can impact their ability to engage in therapy sessions fully.

Concerns were articulated by Claire, regarding Jack's communication style and how it might impede potential participation. Additionally, Claire's observations of Jack's initial behaviors, such as pulling on his hair during the music therapy session, reflect her sensitivity to his emotional state and her desire to understand and support him. This mirrors findings from Rattaz et al. (2023) and Bilgin and Kucuk (2010), which discuss the stress and concerns parents often experience when trying to understand their autistic child's wants and needs.

The experience Claire has in music therapy with her child highlights the significance of the therapist's approach and the impact it has had on Claire's experience of Jack's participation and engagement. The music therapist's respect for Jack's voice and his ability to adapt to Jack's preferences and needs reflect the principles of person-centered care and individualized interventions advocated in the literature (Bervoets & Hans, 2020). This approach is crucial, especially for autistic individuals, as it promotes a sense of agency and autonomy in therapy sessions, leading to increased motivation and active participation (Low et al., 2022).

Claire's observations of Jack vocalizing during sessions and expressing a desire for the therapist to support the potential for positive outcomes of music therapy. This aligns with

research by Attar (2022) and Kim et al. (2008), which emphasize the role of preferred music and enjoyable experiences in enhancing engagement and communication in therapy settings.

However, the music therapist's methods are unclear.

Furthermore, Claire's appreciation for Jack forming a bond with the therapist reflects the therapeutic alliance and the importance of building trusting relationships between therapists and clients, as discussed by Schwartzberg and Silverman (2016). This bond fosters a positive therapeutic environment and contributes to Jack's emotional well-being and resilience, as Claire mentions in her observations of Jack's improved response to challenges.

Connecting Claire's experiences with the literature provides a deeper understanding of a parent's involvement in music therapy. Claire's recognition of Jack's increased vocalizations during sensory movements aligns with studies highlighting the sensory support provided by music therapy, as discussed by Low et al. (2022). This connection suggests that music therapy interventions can enhance sensory experiences, leading to positive outcomes and improved communication for children with developmental challenges. Claire's witnessing of Jack's increased vocalizations during sessions not only gave her a better understanding of her child's preferences but also gave her joy and happiness. Research by Attar (2022) and Kim et al. (2008) supports the importance of utilizing preferred music and joyful experiences to enhance sessions.

Claire's joy in witnessing Jack's engagement and happiness during music therapy sessions resonates with research emphasizing the role of music therapy in promoting emotional well-being and reducing stress in children, as noted by Sorel (2010) and Warren and Nugent (2010). These studies underscore how music therapy supports children's emotional needs and fosters meaningful connections between parents and their children, contributing to a supportive and nurturing environment. For example, in Sorel's (2010) study, Carly and Elliot's journey

illustrates how a parent found joy in playing music with her child, sharing music-making moments that brought a smile to her face. Carly and Elliot's story exemplifies the transformative potential of music therapy in addressing fostering connections and creating a positive therapeutic environment for families, echoing the findings and benefits outlined in this research.

Adaptive strategies that Claire employs during music therapy sessions, such as finding intermediary tools like toys or removing distractions, demonstrate her deep understanding of Jack's preferences and her proactive efforts to support his engagement. These strategies align with research literature emphasizing the benefits of parental involvement in therapy sessions, particularly in the potential to foster positive parent-child relationships (Sorel, 2010).

Furthermore, Claire's emphasis on creating a fun and enjoyable experience for Jack resonates with research highlighting the importance of incorporating playfulness and enjoyment into therapeutic interventions (Schwartzberg & Silverman, 2016). Her role as an attentive observer, encouraging Jack's exploration without imposing specific expectations, reflects a nuanced understanding of the therapeutic process.

Benefits of Parent Participation in In-Home Services

The literature on music therapy for autistic children, as discussed by Eren (2017), Attar (2022), Kim et al. (2008), and Low et al. (2022), highlights the effectiveness of music therapy in addressing various challenges faced by autistic individuals, including sensory issues, communication barriers, and social interaction difficulties. Active participation of parents in music therapy sessions can significantly enhance the therapeutic outcomes and strengthen the parent-child bond (Sorel, 2010; Thompson et al., 2019; Warren and Nugent, 2010; Yang, 2016). While Claire could not specifically correlate Jack's more relaxed way of being and enjoyment in activities to music therapy, she did acknowledge that in-home services seemed to make a

difference. Further, participating in the in-home services helped her recognize the importance of goal setting and helped her feel more prepared to attend IEP meetings to advocate for Jack's future.

Claire's observations during Jack's music therapy sessions have unveiled a connection between sensory input and music therapy outcomes. The spinning chair, for instance, emerged as a focal point for Claire's observations. She noted that when Jack engaged in the spinning motion during music therapy, there was a notable increase in vocalizations, a phenomenon absent during non-music therapy-related spinning episodes. This observation sparked Claire's curiosity, prompting her to ponder the correlation between movement, sensory input, and Jack's expressive responses. This aligns with Carpenet's (2015) research, in which he discusses how sensory-rich experiences in music therapy are engaging and provide a platform for communication and self-expression. Claire may use this new information in daily life with Jack, which may enhance both their lives.

Claire's role as an attentive observer adds a layer of richness to Jack's therapy sessions. Her ability to recognize subtle shifts in Jack's behavior during music therapy sessions speaks volumes about the therapeutic potential embedded in sensory-enriched musical experiences. Through this process of observation and reflection, Claire not only gains insights into Jack's therapeutic process but also has the potential to deepen her connection with her son, fostering a deeper understanding of his needs and preferences within the therapeutic setting, which may transfer beyond the therapeutic setting.

Claire's active engagement in in-home services, including music therapy, revealed the crucial role of effective communication and meaningful goal setting within the Individualized Education Program (IEP) framework. Although she didn't center her discussion on music therapy

participation, her insights gained through first-hand involvement, which became an option during in-home service provision, informed it. Claire's direct involvement gave her a front-row view of Jack's abilities, preferences, and responses, unlike other therapies where professionals work independently. This highlighted the need for goals aligned with Jack's experiences, prompting a call for ongoing communication and collaboration within the IEP team. By incorporating parental insights from active participation, the IEP team can ensure that goals are meaningful, relevant, and conducive to the child's holistic development. Claire's experience underscores the value of holistic assessments and interventions, emphasizing the importance of individualized, purposeful goals that resonate with the child's lived experiences and abilities within the IEP process.

Implications for Music Therapy Practice

The study's focus on the parent's perspective on music therapy for autistic children underscores crucial implications for practice. Tailoring interventions to align with individual sensory and communication profiles incorporating preferred music and non-coercive methods is paramount for enhancing parent engagement and promoting positive outcomes. Active parental involvement is a cornerstone, fostering a stronger parent-child bond and extending therapeutic benefits beyond sessions. Moreover, prioritizing safety considerations and maintaining a nurturing environment are essential for building trust and ensuring continued progress. These insights highlight the need for personalized, collaborative, and parent-centered approaches in music therapy practice, ultimately supporting the well-being and development of autistic children and their families.

Implications for Music Therapy Education

The findings of this study highlight the importance of incorporating training on working with parents and families into music therapy education. Given the central role that parents play in their autistic child's therapeutic process, it is crucial for music therapists to be equipped with the skills necessary to engage parents effectively and supportively. Universities and training programs should emphasize the development of these competencies, ensuring that future music therapists are prepared to navigate the complex dynamics of family involvement in therapy.

Incorporating modules that focus on family-centered approaches, communication strategies, and techniques for involving parents in sessions could greatly enhance the efficacy of music therapy interventions. By understanding the unique challenges and experiences of parents, music therapists can create more inclusive and supportive therapeutic environments, ultimately leading to better outcomes for both the child and the family as a whole.

Prioritizing Communication Between Music Therapist and Parent

An important unexpected finding in this research was Claire's role ambiguity. Understanding how to participate effectively in music therapy sessions was a prominent concern for Claire as she sought clarity on her role within her son Jack's therapy. In unpacking Claire's role and perspective, it's evident that she navigates a delicate balance between actively participating in Jack's music therapy sessions and allowing the therapist and Jack space for independent interaction. Claire describes her participation as a "gray area," indicating her awareness of not wanting to disrupt the therapeutic process while still wishing to contribute positively but also suggesting uncertainty. Claire was more of an attentive observer than an active participant.

Claire articulated her desire for clarity regarding the level of involvement expected from her. Her intention to discuss this with the music therapist shows her commitment to understanding, optimizing, and respecting Jack's therapy experience. Claire is thoughtful, considering Jack's needs and the therapist's expertise. However, music therapists might consider taking on this responsibility at the outset of music therapy. Claire also expressed interest in consulting the music therapist about integrating Jack's communication devices with music therapy. For instance, she suggested adding a button on his AAC device labeled with a picture of a guitar or a music therapist to facilitate easier access during sessions. Claire's desire to engage properly underscores the necessity of having upfront conversations with parents. This helps them understand their part and aligns with literature emphasizing the benefits of parental involvement. Engaging parents can significantly boost therapeutic outcomes by enhancing the parent-child relationship. According to Sorel (2010), music therapy can be a powerful tool to strengthen emotional bonds, foster moments of joy and connection, and create a shared therapeutic space. Similarly, Schwartzberg and Silverman (2016) and Warren and Nugent (2010) discuss how music therapy offers parents and children opportunities to engage in joint activities that are emotionally enriching and supportive. The literature advocates parent inclusion in music therapy.

Moreover, concerns like those of Claire are common among parents of autistic children, who often worry about meeting their children's emotional and communication needs effectively. Rattaz et al. (2023) and Bilgin & Kucuk (2010) shed light on parents' stress and uncertainties, emphasizing the importance of supportive therapies that address child and parental needs. Addressing these concerns through clear communication and supportive strategies can alleviate parental anxiety, making music therapy a more effective and fulfilling experience for both parent and child.

Recommendations for Future Research

Future research endeavors in music therapy could further explore the long-term effects of in-home music therapy sessions on family dynamics, parental stress levels, and the overall well-being of the child and their caregivers. Additionally, investigating the specific mechanisms through which music therapy promotes positive outcomes for autistic children and identifying optimal strategies for enhancing parental engagement and participation would be valuable areas of inquiry. Future ideas may include longitudinal studies on parental expectations and child outcomes in music therapy or comparative studies between therapeutic approaches. In future studies, it is imperative to amplify autistic voices to ensure their perspectives and experiences are central to developing inclusive practices like music therapy.

Claire noted a tangible decrease in negative behaviors, attributing this progress to the therapeutic intervention. This reflection aligns with studies indicating that engaging therapies, such as music therapy, can positively influence behavior and resilience in children (Low et al., 2022). Though Claire clearly stated a decrease in Jack's negative behaviors and an increase in resilience, these concepts were not further explored. Therefore, it is unclear what types of behaviors were addressed and what resilience means for Jack. Moreover, the types of music therapy experiences that were included in sessions to address these areas is unclear. Further inquiry is warranted.

Finally, though this study aimed to explore parents' experiences in music therapy, little emerged about the role of music in the music therapy process. The findings predominantly centered around interpersonal and logistical aspects, so future researchers might consider duplicating this research with a heavier emphasis on music in the therapeutic process.

Future Considerations: Centering Autistic Voices in Music Therapy Research and Practice

Moving forward, it's vital to prioritize the inclusion of autistic voices, including those who are non-speaking, in music therapy research and practice. Incorporating direct input from autistic individuals is essential for developing more effective, person-centered interventions that meet their diverse needs and preferences.

The Autistic Self Advocacy Network (ASAN; 2024, para. 1) follows the motto “nothing about us without us.” Autistic people believe that “When non-autistic people make decisions about autism without Autistic input, those decisions are usually bad” (ASAN, 2024, para. 1). Further, Autistic people believe that all research addressing autism should include Autistic voices. While this research aimed to illuminate parents' experiences participating in their autistic child's music therapy sessions, future researchers may consider exploring in-home music therapy from shared parent-child voices.

Future researchers may consider including autistic people in planning studies and creating therapy programs. Additionally, efforts could focus on creating accessible platforms for autistic individuals to share their perspectives and experiences with music therapy. This involves using methods that allow for different communication methods, ensuring that all autistic individuals have a say and their input is respected. This inclusion may involve using alternative communication methods, such as augmentative and alternative communication (AAC) systems or S2C, to facilitate meaningful engagement and feedback from non-speaking autistic individuals. By including autistic voices, music therapists can be sure to create respectful practices.

By centering autistic voices in research and practice, we can gain deeper insights into what aspects of music therapy are most beneficial, meaningful, and enjoyable for autistic

individuals. This knowledge will inform the development of more tailored and inclusive interventions that promote greater engagement, empowerment, and overall well-being within the autistic community. Embracing the diversity of autistic experiences and amplifying autistic voices in music therapy will lead to more impactful and responsive interventions that honor the agency, autonomy, and unique perspectives of all autistic individuals.

Limitations

While this study provides valuable insights into parents' experiences participating in their autistic child's in-home music therapy sessions, several limitations should be acknowledged. These include potential biases inherent in self-reported data and the possibility of social desirability bias influencing participant responses. Although I aimed to incorporate a thorough data analysis process, time constraints may have restricted the depth of exploration and data immersion. Additionally, as a new researcher, there may be a higher potential for researcher bias.

This study was specifically designed to explore the lived experiences of parents involved in their child's music therapy. The focus on individual experiences is central to the phenomenological approach, which seeks to capture the essence of these experiences rather than produce generalizable outcomes. However, the findings did not extensively address the role of music itself in the therapeutic process. While the results may offer some guidance for music therapists in refining their practices, they provided limited new understanding of how music specifically contributes to therapeutic outcomes.

In future research, exploring the generalizability of these findings and the specific impact of music within the therapy process could further enhance our understanding of these complex dynamics.

Chapter Six: Conclusion

In conclusion, this study stresses the importance of considering parental perspectives and active involvement in designing and implementing music therapy experiences for autistic children. By recognizing parents as crucial participants in the therapeutic process, music therapists can optimize treatment outcomes and foster holistic, family-centered care that addresses the child's diverse needs and the family unit. While this research acknowledges its limitations, such as focusing solely on parental perspectives and gaining minimal new knowledge about the role of music, it nonetheless contributes valuable insights to music therapy. Music therapists can ease parental concerns about participation by maintaining clear communication and providing guidance on how parents can actively support their child's progress. This collaborative approach may foster trust and empower parents to participate actively in their child's therapeutic journey. As we continue to advance our understanding and practices in music therapy, this study serves as a stepping stone, paving the way for future practitioners to maximize the potential of music therapy as a transformative tool for autistic individuals and their families.

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Appendix A: Recruitment Email

Subject: Invitation to Participate in Research Study on Parent Experiences in In-Home Music Therapy Sessions for Autistic Children

Dear Music Therapists,

I hope this message finds you well. My name is Dana Raicaldo, and I am a graduate music therapy student at Molloy University currently undertaking my master's thesis. I am reaching out to inquire if you work with any parents who might be interested in participating in a research study focused on understanding parents' experiences of participating in their autistic child's in-home music therapy sessions. This proposed research has been approved by the Molloy University Institutional Review Board.

For this research, I am seeking parents with autistic children between the ages of 4 and 21 who are actively engaged in in-home music therapy sessions. If a parent you know meets this criteria and would be interested in participating, please have them contact me at draicaldo@lions.molloy.edu. There is no cost associated with participation in this research, and participants will not be compensated.

Parents will be asked to participate in a confidential 40-60-minute interview conducted over Zoom at a mutually agreeable time. The focus of the interview will be parents' experiences of participating in their autistic child's music therapy sessions. Parents may choose to leave the research at any time without consequence.

The inclusion criteria are as follows:

- Must be a parent to an autistic child between the ages of 4 and 21 who receives in-home music therapy services
- Must actively participate in music therapy sessions with their autistic child. Active participation means that parents must be in the same room as their child during music therapy, and they must engage musically in some way.
- Must be able to speak English well enough to participate in the interview
- You must have a phone, computer, or tablet to participate in a virtual interview

Please let potential participants know that their involvement in this research will be completely confidential. Additionally, insights gained from their participation may contribute to advancing music therapists' understanding of parent experiences within in-home music therapy sessions for autistic children.

Thank you for your time and potential assistance in connecting with suitable participants.

Should you have concerns about this research, please contact me at the email address below or Dr. Amanda MacRae at amacrae@molloy.edu.

Warm regards,

Dana Raicaldo

Graduate Music Therapy Student

Email: draicaldo@lions.molloy.edu

Appendix B: Informed Consent Document

Graduate Music Therapy
1000 Hempstead Ave
Rockville Centre, NY 11570
(516) 323-4000

Title of Study: PARENTS' EXPERIENCES DURING THEIR AUTISTIC CHILD'S IN-HOME MUSIC THERAPY

This study is being conducted by: Graduate student: Dana Raicaldo
draicaldo@lions.molloy.edu

Academic Advisor: Amanda MacRae amacrae@molloy.edu

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 brief summary about the study; however you can find more detailed information later on in the form.

- The main purpose of this research study is to gain a better understanding of the experiences of parents with their autistic children in music therapy. This will be done by interviewing parents who participate in their autistic child's music therapy sessions.
- Inclusion criteria for the participants includes:
- Must be a parent to an autistic child between the ages 4 and 21 who receives in-home music therapy services
- Must actively participate in music therapy sessions with their autistic child. Active participation means that parents must be in the same room as their child during music therapy and they must engage musically in some way.
- Must be able to speak English well enough to participate in the interview
- Must have a phone, computer, or tablet to participate in virtual interview

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

You are being invited to join this study because I want to learn from your lived experiences. Your stories and what you have been through can help me to understand what it's like for a parent to participate in music therapy with their child.

What will I be asked to do?

For this study, you will be asked to participate in forty-sixty minute interview with me, to discuss your experiences in your child's music therapy sessions.

Where is the study going to take place, and how long will it take?

The interview will take place over Zoom and should take no longer than sixty minutes.

What are the risks and discomforts?

You will be asked to share your experiences of participating in music therapy with your child. Potential risks and discomforts are unknown, but they are believed to be minimal. Additionally, data protection measures will be in place to protect your shared information.

What are the expected benefits of this research?

Individual Benefits: There may be no direct benefits from participating in this research.

Do I have to take part in this study?

Your participation in this research is your choice. 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?

Instead of being in this research, you may choose not to participate.

Who will have access to my information?

Your name and other personal information will be kept privately on my computer. Your name will be changed to a pseudonym. No identifiable information will be shared in the final write-up.

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?

You may drop out of the study at any time with no consequence.

What if I have questions?

Before you decide whether you'd like to participate in this study, please ask any questions that come to mind now. Later, if you have questions about the study, you can contact Dana Raicaldo at (516) 606-8482 or draicaldo@lions.molloy.edu, or Amanda MacRae at amacrae@molloy.edu.

What are my rights as a research participant?

You have rights as a research participant. All research with human participants is reviewed by a committee called the *Institutional Review Board (IRB)* which works to protect your rights and welfare.

If you have questions about your rights, an unresolved question, a concern or complaint about this research you may contact the IRB contact the Molloy IRB office at irb@molloy.edu or the IRB CHAIR :Dr. Patricia A. Eckardt peckardt@molloy.edu call 516 323 3000.

Documentation of Informed Consent:

You are freely making a decision 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 your questions answered, and**
- 3. After sufficient time to make your choice, you have decided to be in the study.**

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

Certificate of Confidentiality

The Department of Health and Human Services (HHS) has issued a Certificate of Confidentiality to further protect your privacy. With this Certificate, the investigators may not disclose research information that may identify you in any Federal, State, or local civil, criminal, administrative, legislative, or other proceedings, unless you have consented for this use. Research information protected by this Certificate cannot be disclosed to anyone else who is not connected with the research unless:

1. there is a law that requires disclosure (such as to report child abuse or communicable diseases but not for legal proceedings);
2. you have consented to the disclosure, including for your medical treatment; or
3. the research information is used for other scientific research, as allowed by federal regulations protecting research subjects.

Disclosure is required, however, for audit or program evaluation requested by the agency that is funding this project or for information that is required by the Food and Drug Administration (FDA).

You should understand that a Confidentiality Certificate does not prevent you or a member of your family from voluntarily releasing information about yourself or your involvement in this research. If you want your research information released to an insurer, medical care provider, or any other person not connected with the research, you must provide consent to allow the researchers to release it. This means that you and your family must also actively protect your own privacy.

Finally, you should understand that the investigator is not prevented from taking steps, including reporting to authorities, to prevent serious harm to yourself or others.

How will my [information/biospecimens] be used?

Your name and other personal information will be kept privately on my computer. Your name will be changed to a pseudonym. No identifiable information will be shared in the final write-up.

If biospecimens (even after they are de-identified) will be used for commercial profit, this must be disclosed to participants, including whether or not that profit will be shared. (*NEW Additional Element*).

A statement regarding whether clinically relevant research results, including individual research results, will be disclosed to subjects, and if so, under what conditions; and

For research involving bio specimens, whether the research will (if known) or might include whole genome sequencing (i.e., sequencing of a human germline or somatic specimen with the intent to generate the genome or exome sequence of that specimen).

(*NEW Additional Element*).

For protocols that must meet the NIH Genomic Data Sharing (GDS) Policy, see <https://www.nih.gov/news-events/news-releases/nih-issues-finalized-policy-genomic-data-sharing> for more information on GDS. NIH expects investigators to obtain participants' consent for their genomic and phenotypic data to be used for future research purposes and to be shared broadly. The consent form should include an explanation about whether participants' individual-level data will be shared through unrestricted- or controlled-access repositories.

The following paragraph is an example of the language that may be used:

Genetic and other relevant study data, such as health information, may be shared broadly in a coded form for future research or analysis. We may give this data about you to other researchers or companies not at UAB, including to a [specify public or controlled access] government health research database. We will not give them your name, address, phone number, or any other identifiable information. Research results from these studies will not be returned to you [if applicable, describe any rare instances where research results would be returned].

If the data will be shared with unrestricted-access databases, include the following paragraph:

Public (Unrestricted-Access) Databases: Your information may be put in unrestricted-access databases. This means the information is publicly available and anyone can use the database. The public database could include information of hundreds of thousands of genetic variations in your DNA code, as well as your ethnic group and sex. The only health information included will be whether you had [specify disease] or not. This public information will not be labeled with your name or other information that could be used to easily identify you.

If the data will be shared with controlled-access databases, include the following paragraph:

Controlled-Access Databases: Your information may be put in controlled-access databases. This means only researchers who apply for and get permission to use the information for a specific

research project will be able to access the information. Your information stored in these databases will not include any identifying information. We will replace identifying information with a code number. We will keep a master list that links your code number to your identifying information here at the UAB. Only certain study personnel for this study at UAB will have access to this master list. Researchers approved to access information in the controlled-access database will agree not to attempt to identify you.

Include the following paragraphs for all GDS:

Risks: The risk of sharing your genomic data is that someone could link the information stored in the databases back to you. If your information suggested something serious about your health, it could be misused. For example, it could be used to make it harder for you to get or keep a job or insurance or be used to discriminate against you or your family. There may also be other unknown risks.

Benefits: There is no direct benefit to you from sharing your genomic data. Allowing researchers to use your data may lead to a better understanding of how genes affect health. This may help other people in the future.

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?

Yes, you are able to opt out of the study at any point

What if I have questions?

Before you decide whether you'd like to participate in this study, please ask any questions that come to mind now. Later, if you have questions about the study, you can contact Dana Raicaldo at 516-606-8482 or draicaldo@gmail.com, or Amanda MacRae at amacrae@molloy.edu.

What are my rights as a research participant?

You have rights as a research participant. All research with human participants is reviewed by a committee called the *Institutional Review Board (IRB)* which works to protect your rights and welfare.

If you have questions about your rights, an unresolved question, a concern or complaint about this research you may contact the IRB contact the Molloy IRB office at irb@molloy.edu or the IRB CHAIR :Dr. Patricia A. Eckardt peckardt@molloy.edu call 516 323 3000.

Documentation of Informed Consent:

You are freely making a decision 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 your questions answered, and**
- 3. After sufficient time to make your choice, you have decided to be in the study.**

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

Your signature

Date

Your printed name

Date

Electronic Signature Agreement:

I agree to provide an electronic signature to document my consent.

Consent for Audio Zoom

Your signature

Date

Your printed name

Date

Consent for Video Zoom

Your signature

Date

Your printed name

Date

*** If a waiver of DOCUMENTATION of informed consent has been requested, remove the words: Documentation of AND you will be given a copy of this consent form to keep from above section.**

Dana Raicaldo

1/28/2024

Signature of researcher explaining study

Date

Dana Raicaldo

Printed name of researcher explaining study

Appendix C: IRB Approval Letter



**MOLLOY
UNIVERSITY**

1000 Hempstead Ave., PO Box 5002, Rockville Center, NY 11571-5002
www.molloy.edu

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: February 15, 2024

TO: Dana Raicaldo
FROM: Molloy University IRB

PROJECT TITLE: [2149586-1] PARENTS' EXPERIENCES DURING THEIR AUTISTIC CHILD'S IN-HOME MUSIC THERAPY

REFERENCE #:
SUBMISSION TYPE: New Project

ACTION: APPROVED
APPROVAL DATE: February 14, 2024
EXPIRATION DATE: February 13, 2025
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.

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 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. If your project will continue beyond expiration date your documentation for continuing review

must be received with sufficient time for review and continued approval 45 days before the expiration date of February 13, 2025.

Please file Final Report when project finished. Use same form for both :MOLLOY UNIVERSITY APPLICATION FOR ONGOING CONTINUING REVIEW OR FINAL REPORT, and upload to IRBNet as an Amendment to this project. Instructions for uploading an amendment are also on IRBNet Forms and Templates for Researchers.

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.