PROMOTING SELF-DETERMINATION IN MUSIC THERAPY WITH INDIVIDUALS WITH I/DD WHO COMMUNICATE EXTRAVERBALLY: REFLECTIONS AND IMPLICATIONS FOR PRACTICE

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by
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Abstract

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Self-advocacy is important for all individuals with intellectual or developmental disabilities. In order to work on self-advocacy, skills in self-determination must be established first. Self-determination involves decision-making, choice-making, self-awareness, and acting intentionally. Music therapy may be useful in the promotion of these skills, especially when approached from the perspective of social and affirmative models of disability. In this study, the researcher utilized an action research approach as well as a set of therapeutic guidelines in order to explore the relationship between music therapy and self-determination in individuals with intellectual and/or developmental disabilities who communicate extraverbally. Results from this study show the need to address self-determination in music therapy and be reflexive as music therapists on the how power, choices, and engagement shows up in sessions.

Keywords: self-advocacy, intellectual and developmental disabilities, self-determination, extraverbal communication, action research

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CHAPTER 1

Introduction

Personal Significance

Since childhood, music has played an important role in my life: from soothing me to sleep to creating moments of fellowship with friends and family. As I grew up and started learning how to play instruments, I began forming relationships with people revolving around music, where we would share common interests and teach each other new musical skills, such as learning how to play guitar, learning to reach chord changes, and challenging each other to discover new music. Music acted not only as a social connector but as a communicator. As a person who struggles with anxiety, social communications and situations were not always easy. Music provided me with a medium to make friendships without ever worrying about choosing the right words. My friends and I could laugh, play, and convey our emotions without ever saying a word. I felt the power of music as a communicator and connector many times as I played in ensembles throughout high school and college.

After I graduated with my bachelor's degree, I worked at a summer camp for children with medical needs. The children at the camp had diagnoses such as diabetes, cancer, cerebral palsy, heart diseases, and physical disabilities. Many of the kids spent an extraordinary amount of time in hospitals, being told what to do and what not to do. At the camp we had the opportunity to give children the autonomy to do what they wanted to do, not what they had to do, should do, could not do, or were not good at doing. As the music

counselor, the music therapist and I would provide opportunities for children to play almost any musical instrument they chose. There were some weeks where kids were just excited to bang on a drum set, and it was marvelous to see the joy on their faces as they hit the drums as loud as they could. It was during my experiences at camp that I began to realize the importance of autonomy for these children. Many never had the chance to play an instrument and were afraid to even choose one to play. While focusing on autonomy was an exciting concept at camp, it was sometimes hampered by other counselors, parents, and people in charge. I remember many instances of being frustrated by people trying to teach kids the "correct way" to play or judging the way some kids would play an instrument. There were times that I saw counselors fail to give campers an instrument because they believed it was something the child could not do. My time at the camp taught me the value of autonomy but also the reality of how people perceive individuals with disabilities, especially when those individuals communicate beyond verbal communication.

Throughout my music therapy journey, I remember learning the value of individuality and validation at some of my practicum sites, particularly when it came to individuals with intellectual and developmental disabilities (I/DD). I initially had a hard time understanding how to communicate and understand individuals who did not communicate verbally or with an augmentative and alternative communication (AAC) device, but in my practicum experiences I began to learn to listen and observe any movement, facial expression, and vocalization from the people with whom I interacted. As I continued my training for the internship, I noticed autonomy and self-advocacy were important themes in my sessions,

especially in the individuals I worked with who communicated extraverbally[1]. Through developing rapport with individuals, I was able to ask them questions, provide them with choices, and joke around with them. I also started to notice that while there were differences in the ways we approached making choices and autonomy, depending on the diverse abilities of each individual. Regardless of these differences, the individuals were all working on self-advocacy and self-determination in some form or capacity.

As I started to research these terms and dive deeper into the research of self-determination, self-advocacy, and music therapy, I started asking myself questions about my own self-determination. Do I feel like I am a good self-advocate? Do I often act in self-determined ways? What is advocacy? Do I express my own desires and boundaries in a way that advocates for my needs? Do I allow other people to do this? How do I advocate and act in a self-determined way through music/extraverbally? How do I cause barriers for other people to be their own self-advocate? I also began to reflect on my own experiences with music and how it impacted my own self-advocacy. As an anxious person[2], music was the medium with which I could communicate my desires, make friends, and make choices in a safe and comfortable environment.

The question of my own identity has also been critical throughout my personal journey and has been influenced through researching this topic. As a music therapist, I want to support the individuals I work with and validate their position on their identity with their disability. In the same vein of thinking, I have questions about how I identify with my own

[1] In following with an affirmative model of disability, this paper will describe communicating primarily using a method of communication that is not verbal as *extraverbal communication*, affirming the communication style (Cameron, 2011).
[2] In following with the social and affirmative models of disability, this paper will use identity-first language when referring to disabled people (Andrews et al., 2019; Sinclair, 2013).

mental health issues of anxiety and depression. I have dealt with anxiety and depression for the majority of my life, but I have never considered it a serious hindrance to my functioning or a disability. I have never received a formal diagnosis and consider myself "high-functioning". While my anxiety has led to difficulties in my life, relationships, and academics, I do not personally feel as though it has been a societal hindrance or has led to many levels of oppression. I see this as my own privilege within the disability community: to struggle with a mental illness but to not experience the same oppression that others with disabilities experience. Throughout this research process, I will continue to reflect on my own experiences and privileges and how they may influence my practice with individuals with I/DD.

Definition of Terms

Individuals with Intellectual/Developmental Disabilities

The American Association of Intellectual and Developmental Disabilities defines I/DD as a disability characterized by significant limitations in both intellectual functioning and in adaptive behavior, originating before the age of 22 (AAIDD, n.d.). Intellectual functioning involves learning, reasoning, and problem solving, as well as other general cognitive skills. Intelligence quotient (IQ) tests are often used to measure a person's level of intelligence, however, there are many issues that arise from using an IQ test to accurately measure a person's cognitive skills and complex reasoning while also taking into consideration cultural, social, and adaptive differences (Richardson, 2002). Adaptive behaviors involve conceptual, social, and practical skills that are utilized in everyday situations, such as language and literacy skills, social rules/laws, and activities of daily living (AAIDD, n.d.)

Self-Advocacy

Self-advocacy is defined in several different ways, and its definition continues to evolve as cultural and social understanding of the term expands and progresses. Wehmeyer et al. (1998) defined self-advocacy as a set of skills which allows individuals to speak up and say what they need (as cited in Test et al., 2005). Van Reusen et al. (1994) broke down these skills, explaining that self-advocacy involves the individual's ability to communicate, convey, negotiate, or assert a person's own interests, desires, needs, and rights. Schreiner (2007) succinctly summed up these definitions by stating that self-advocacy is "the ability to speak up for what we want and need" (p. 300). While there are many variations of the definition of self-advocacy, they all agree that self-advocacy is about representing one's own views or interests.

Self-Determination

Self-determination is a sub-skill and foundational element of self-advocacy (Ryan & Griffiths, 2015; Test et al., 2005). Wehmeyer (2005) stated that self-determination, or self-determinism, involves the idea that one causes oneself to act in certain ways. As opposed to determinism, which attributes behaviors to being caused by one's environment, self-determinism attributes behaviors as the result of oneself deciding to make them happen (Hoefer, 2016). Perspectives within self-determination, like causal agency theory and the social-ecological theory also acknowledge how much of a role individuals or environmental factors play in being self-determined (Ryan & Griffiths, 2015; Wehmeyer, 2005; Wehmeyer & Garner, 2003). Self-determination also involves an understanding of one's rights, deciding on goals, solving problems, making decisions, and acknowledging that their behavior leads to a desired outcome (Friedman, 2017; Ryan & Griffiths, 2015; Wehmeyer & Garner, 2003).

Decision-making, active participation in one's environment, choice making, self-observation, and self-awareness are also ways that can help a person be more self-determined (Ryan & Griffiths, 2015; Wehmeyer, 2005).

Music Therapy

Bruscia (2014) defines music therapy as a process by which a music therapist helps individuals receiving music therapy optimize their health by using facets of music experiences and the relationships formed through them. Credentialed music therapists and individuals receiving therapy use music in order to form relationships and thus promote growth by focusing on competencies and areas of personal growth. Music experiences within music therapy are based on theory and research and are continually developing with new findings. Music interventions commonly used with individuals with intellectual and developmental disabilities include focusing on communication skills, social skills, self-awareness, and community involvement (Adler & Samsonova-Jellison, 2017; Curtis & Mercado, 2004; Graham, 2004; Lee & McFerran, 2012).

Humanism/Critical Humanism

Humanism is centered around the ideas of freedom, agency, autonomy, choice, responsibility, and self-actualization (Hadley & Thomas, 2018). Mainly associated with Rogerian person-centeredness and Maslow's hierarchy of needs, traditional humanism is primarily focused on the individual and sometimes can run the risk of encouraging self-centered individualism (Bunt & Stige, 2015; Maslow, 1943; Rogers, 1951). According to a Rogerian person-centered practice, there are three core conditions that contribute to therapeutic change: an unconditional positive regard, congruence, and empathy (Corey, 2005). A more modern and contextual approach to humanism is referred to as critical

humanism, which acknowledges politics, race, gender, socio-economic factors, sexuality, and disability within the therapeutic relationship (Hadley & Thomas, 2018). Critical humanism expands the individuality embraced within traditional humanism and applies a critical, socio-political and -cultural lens and encourages the therapist to be self-reflexive.

Resource-Oriented Music Therapy

Resource-oriented music therapy is a perspective of music that focuses on health from a recovery perspective (Rolvsjord, 2010). The practice is founded on four basic principles: involving the nurturing of strengths, resources, and potentials, involving collaboration rather than intervention, viewing the individual within their context, and seeing music as a resource. Resource-oriented music therapy is primarily focused within the mental health population and works to enhance team collaboration, self-determination, togetherness, and emotional awareness, as well as other areas of potential growth (Rolvsjord, 2010; Solli et al., 2013).

Purpose of Study

In current music therapy literature, there is little research directly focusing on self-determination (Gadberry & Harrison, 2016). Much of music therapy practice, especially in the United States, is focused on a goal-oriented approach to music therapy, such as working on communication, social, or emotional skills (Choi, 2008; Kern & Tague, 2017). While enhancing communication or emotional regulation skills may benefit the components that lead to self-determination, it seems that focusing only on a goal-oriented approach misses much of the nuances within the therapeutic relationship that could be used to enhance self-determination: competence, relatedness, and autonomy (Gadberry & Harrison, 2016; Ryan & Deci, 2004). While much of music therapy literature is focused on goals, there is literature that calls for a change in perspective to a process-oriented approach and considers more

complex aspects within the music therapy relationship (Beebe, 2020; Metell, 2019; Murphy & McFerran, 2017; Stige, 2009). By focusing on factors such as participation, theoretical understanding of disability, and collaboration within these spaces, music therapists can provide more complex and unique opportunities to create spaces that promote self-determination.

Research Questions

Due to the need for a more process-oriented approach to music therapy to support the growth and desires of individuals with I/DD, the purpose of this study is to identify ways in which music therapy might promote self-determination within music therapy sessions with individuals with I/DD who communicate extraverbally. As the aim of action research is to be reflexive, flexible, and evolving, the initial research questions to be addressed include (Stige & McFerran, 2016):

1. In what ways can a music therapist promote self-determination for individuals with I/DD who communicate extraverbally?
2. How do individuals experience self-determination outside of the music therapy session?
3. What social change needs to occur as a part of or product of these sessions?

CHAPTER 2

Review of Literature

Viewing disability from a social or affirmative model acknowledges the cognitive, physical, societal barriers, and environmental barriers that come with having a disability while also recognizing a person's ability to grow and lead a life towards independence (Gross, 2018; Rickson, 2014). As music therapists, it is our goal to help individuals with I/DD to work towards this goal. Often in music therapy we focus on giving people choices and sometimes allowing them to choose their own areas of growth in sessions. Being able to realize goals, express them to others, and discover ways to work towards these goals requires skills in self-advocacy and self-determination. To practice self-advocacy and self-determination, people must be aware of their strengths and weaknesses and must be able communicate those to others in order to advocate their own desires (Test et al., 2005).

Individuals with intellectual and developmental disabilities may be able to advocate their own needs on varying levels, regardless of age or IQ (Ryan & Griffiths, 2015; Wehmeyer & Garner, 2003). Music therapy may be beneficial in promoting self-advocacy and self-determination in individuals with I/DD in both individual and group settings by promoting independence, self-awareness, and other skills that assist with advocacy through incorporating decision-making, problem-solving, and self-awareness in sessions (Wehmeyer, 2005). The purpose of this paper is to define and distinguish self-advocacy and self-determination and explore ways to include these focus areas into music therapy sessions.

Disability Perspectives

Medical Model

The medical model of disability focuses on an individual's disability or deficits and how those differences keep people from participating in their communities and social spheres (Pickard et al., 2020; Rickson, 2014). Because disability is viewed as a hindrance for people to participate in society, the medical model places an importance on fixing, minding, or rehabilitating individuals' differences (Swain & French, 2000). The belief is that by fixing or working on the individual's disability, they may be able to assimilate or "normalize" within society and their disability will not be seen as a way to separate them from the rest of society. The medical model can be useful for some people; for example, when people have difficulty seeing, they fix that deficit by getting glasses, contacts, or Lasik eye surgery. However, the medical model also has an oppressive side (Pickard et al., 2020). Believing that all differences, disabilities, or deficits must be fixed or eliminated can be damaging to the disabled person as well as society. Additionally, separating people through a "normal" versus "abnormal" lens propagates a dichotomous and divided mentality, lending to a variety of social and civil rights injustices.

Social Model

Considered an opposition to the medical model, the social model of disability relates to the barriers and systemic oppression that society creates in order to keep disabled people from accessing their true potential (See footnote one; Barnes, 2012). According to Thomas (2008, p.15), "the social model asserts that 'disability' is not caused by impairment but by the social barriers (structural and attitudinal) that people with impairments (physical, intellectual and sensory) come up against in every arena." Where the medical model states that disabled

people are oppressed by their disability, the social model states that disabled people are oppressed by society. Since disability is not viewed as an impairment, individuals can focus on working toward social change and valuing diversity (Rickson, 2014). Individuals who ascribe to the social model work on creating a more inclusive society by protesting and calling for social and political changes.

While the social model is more inclusive and celebratory of disability, it also has some criticisms for where it lacks. Some arguments state that the model over-emphasizes socio-structural barriers and ignores an individual's personal and experiential aspects of disability (Cameron, 2011). Shakespeare (2010) argues that impairment is still an important component of a disabled person's identity. While focusing on social changes can be helpful, only emphasizing society's oppression neglects that a disability may also cause barriers to an individual's quality of life. Additionally, not all individuals with disabilities may agree with the social model's oppressive description of society's pressure on disabled people. Individuals may have their own experiences with oppression, society, and disability that gives them a different perspective of where the oppressive factors lay.

Affirmative Model

The affirmative model of disability is similar to the social model, with some specific nuances. The basis of the affirmative model is the rejection of tragedy, dependency, and abnormality (Swain & French, 2000). The model does not emphasize placing the blame of oppression on society or a disability, but instead affirms the disabled person and challenges the notion that the problem lies within the individual. Individuals' experiences with disability are a valid and primary aspect of the model, emphasizing the importance of determining one's own lifestyle, culture, and identity. Disability and impairment are also associated with

a positive identity, fighting the emphasis toward normalization and rehabilitation within the medical perspective. While there might be negative aspects to impairment or disability, having a disability is not always undesirable. The affirmative model emphasizes the power and value of having a disability, and how differences can be positive and intrinsically satisfying (Cameron, 2008; Rickson, 2014). Essentially, the basis of this model is about the affirmation of unique ways of being situated in society (Cameron, 2011).

While the affirmative model does not focus entirely on the oppressive society, social justice and inclusion are still critical aspects of individual's experiences with disability. The disability arts movement aligns closely with the sentiments of the affirmative model, where individuals can express their opinion, preferences, experiences, differences, and call for social and political change (Cameron, 2008; Cameron, 2011; Whitehurst, 2007;). The movement provides a space for individuals to explore their personal experiences in a variety of mediums and expressions: visual arts, literary arts, and music. Initially driven by the social model of disability in the 1980s, the conversations and art works being created by disability arts spurred the conversation for an affirmative model (Cameron, 2011). Individuals within the community demonstrated and expressed their experiences as people with impairments in a disabling society, expressing the need for a model that validated the diversity of individuals' experiences with disability while affirming their role in society.

Review of Literature

Figure 1

Self-Advocacy Framework

Note. Adapted from Test et al. (2005).

Self-advocacy

Test et al. (2005) laid out a conceptual framework for self-advocacy, including self-awareness, knowledge of rights, communication, and leadership. Each level focuses on a different component of self-advocacy at an increasing level. The knowledge of self, or self-awareness, is a critical component and in a way acts as a foundation for the rest of the development of self-advocacy. Self-awareness is a fundamental skill in self-advocacy because "it is necessary for individuals to understand and know themselves before they can tell others what they want" (Test et al., 2005, p. 45). Within this level, individuals are aware of their own interests, preferences, strengths, needs, learning styles, and attributes of their disability. The second component, knowledge of rights, involves people being aware of their

rights as a citizen, a disabled individual, and as a student receiving services under the law. This level deals with interactions and rights of the services and treatment an individual may receive as well as their general human rights.

Communication is the next level of self-advocacy (Test et al., 2005). The communication level involves negotiation, assertiveness (appropriately communicating feelings, needs, and desires), problem solving, and compromising. Clear and effective communication in terms of these components can lead to more effective self-advocacy. Test et al. (2005) also mentioned that there is no implication that this communication level only refers to individuals who communicate verbally; therefore, people who communicate using means beyond words may also be at this level of self-advocacy. Finally, there is the level of leadership. Within this level, the perspective of advocacy shifts from advocacy for an individual to a group with common concerns. At this level, individuals learn about group roles, dynamics, and the skills required to function in a group.

While Test et al. (2005) ranked these levels in increasing order, from self-awareness to leadership, they mentioned that self-advocacy can occur at any of these levels: an individual need not be a master in the leadership level of self-advocacy in order to be a self-advocate. Some individuals may be able to successfully advocate for their own wants and needs while others may be able to advocate for their own rights at a political level. Individuals may also become self-advocates at various moments in their life and it may also fluctuate as people learn, adapt and experience new things. Overall, this conceptual framework validates that self-advocacy may look different but can still be effective at any of these levels.

Self-Determination

Self-determination is another term that is closely tied to self-advocacy, but researchers and clinicians do not always agree on how they are related. Some perspectives state that they are interchangeable terms, essentially meaning the same thing, while others argue that self-determination is a sub skill of self-advocacy (Test et al., 2005). Ryan and Griffiths (2015) mentioned that self-determination is an important component of self-advocacy due to the need for informed decision-making in advocacy work. They also see 5 as a foundation of self-advocacy, in which skills such self-regulation, self-awareness, and decision-making are formed. This differs somewhat to the framework previously mentioned by Test et al. (2005), that focuses on self-awareness as a foundational element but implies that self-regulation and decision-making belong to higher levels of advocacy. Wehmeyer and Garner (2003) also stated a person's capacity to be self-determined directly impacts the effectiveness of their own advocacy, implying that self-determination is a crucial component rather than synonymous with self-advocacy. This study will follow take the stand of presenting self-determination as a component of self-advocacy (Ryan & Griffiths, 2015; Wehmeyer & Garner, 2003).

Looking more closely, there are key differences about self-determination that separate it from self-advocacy. Self-determination involves the process of acting in a determined or volitional way (Wehmeyer, 2005). Environmental factors, such as teachers, guardians, or social systems, can influence how self-determined a person may act (Ryan & Griffiths, 2015; Wehmeyer, 2005; Wehmeyer & Garner, 2003). These social-ecological perspectives acknowledge that a person may be in charge of behaviors and outcomes, but also consider that the environment may strongly influence a person's development into being self-

deterministic. An understanding of rights, choosing goals, making decisions, solving problems, and acknowledging one's volition are other aspects of self-determination (Friedman, 2017; Ryan & Griffiths, 2015; Wehmeyer & Garner, 2003). While decision-making is an important component of self-determination, it is not the only way to be self-determined (Wehmeyer, 2005). Active participation in one's environment, choice making, self-observation, and self-awareness are also ways that can help a person be more self-determined (Ryan & Griffiths, 2015; Wehmeyer, 2005).

Wehmeyer (2005) continued to define self-determinism by breaking down common misinterpretations. He stated that self-determination should not be seen as a behavior or even a set of skills, but more as a way of choosing to behave or act. Instead, acting in a self-determined way refers to the intentional act of causing something to happen. Additionally, being self-determined is more a characteristic of a person that enables them to act volitionally, to make decisions, and behave in such a way to cause things to happen. Self-determination is also not synonymous with self-reliance or independence, but it can lead towards self-reliance, implying that there may still be a need for adaptations or supports in order assist in making choices. The characteristic of being self-determined can help a person advocate for their own needs, move towards goals, and can help them become more independent. It is for these reasons that self-determination is different from self-advocacy: self-determination is more a characteristic rather than it is a set of skills that make it an important aspect of self-advocacy.

Self-Determination Theory. Self-determination theory operates on the belief that all individuals have the natural and innate ability to develop a more elaborate and unified sense of self that creates connections to their own inner world and the social interactions they have

around them (Ryan & Deci, 2004). While this ability exists in all humans, there are also social-contextual factors that may hinder or support this innate tendency. Ryan and Deci (2000, 2004) outlined three contextual criteria that can aid allow an individual to thrive in a self-determined way: competence, relatedness, and autonomy.

Competence relates not to a skill set but it involves a “felt sense of confidence” within a person’s social environment (Ryan & Deci, 2004, p. 7). It encourages people to seek challenges in order to enhance a skill or to work toward a goal. Relatedness has to do with interactions with others. Being cared for and caring for others can lead to a sense of connectedness as well as relatedness. Further, relatedness deals with a sense of belonging and community, not an intended outcome. Within the role of self-determination, relatedness is important because it emphasizes the importance of the innate desire to be included and belong without the contingency of an outcome. Finally, autonomy is described as the origin or source of one’s own behavior. Individuals who behave in a way of expressing their own self-initiative is a way of acting autonomously. Ryan and Deci acknowledged that these conditions are relatively simple in scope, but they can provide an important basis acknowledging the needs as it pertains to self-determination. If an individual is interacting in an environment that encourages competence, relatedness, and autonomy, then self-determination is being encouraged.

Intrinsic and extrinsic motivators also play a role in self-determination (Ryan & Deci, 2000). Intrinsic motivation most commonly demonstrates self-determination, as the person is acting in a volitional way due to their own desires. Extrinsic motivation typically stems from social-contextual factors which cause a person to act, while not typically of their own volition. However, Ryan and Deci (2000) stated that extrinsic motivation can vary in

autonomy. Much like providing grades in school, some students see the personal gain in working hard for a grade while others feel the pressure put on them by their parents, teachers, or society: one is motivated internally for an external outcome while the other is motivated externally. While we are most often motivated by external factors in our adult life, we need also internal motivators for our own well-being and mental health. Sheldon et al. (2020) found that individuals who were working towards intrinsic goals self-reported a higher, more positive well-being than individuals who were working towards extrinsic goals. Both intrinsically motivated activities and autonomous extrinsically motivated activities are essential to well-being and mental health, as they both encourage interest, adaptability, vitality, and enjoyment (Ryan & Deci, 2000).

Ryan and Deci (2000) described that using the three conditions can assist in promoting autonomous regulation for extrinsically motivated behaviors. Modeling, prompting, or valuing behaviors help to form an initial interest in specific behaviors and help form connections between people. This relatedness, as mentioned earlier, is an important step in internalizing the behavior for intrinsic motivation. Additionally, when people are completing tasks that are valued by social groups, they can feel a sense of accomplishment which can lend itself to competence in the task. This then can motivate the individual to continue doing the task because of the felt sense of confidence. Finally, autonomy acts sort of as the culmination of both of these within a non-directive environment. Ryan and Deci (2000) mentioned that autonomy can be facilitated by choice-making, volition, and freedom from external pressures or motivators. Providing the context for autonomy can help an individual explore and transform values into their own.

Self-determination theory not only establishes the potential growth for people to act in self-determined ways but to exercise that volition in a way that contributes to their own well-being. While environmental and social-contextual factors can hinder the growth of self-determination in individuals, there is still potential to create contexts that provide opportunities for relatedness, competence, and autonomy. Focusing on immediate social contexts to encourage these basic needs for self-determination can encourage internal motivation, but it is also important to note that this change extends beyond immediate social contexts or the therapy session (Ryan & Deci, 2000). In order to meet these needs at a larger and more in-depth scale, it is important to examine these broader reaching environmental and find ways to advocate and make these changes.

Self-Advocacy, Self-Determination, and I/DD

Self-advocacy and self-determination are common areas of focus for research and clinical work with individuals with I/DD. Especially for clinicians, teachers, and therapists who work from a social or affirmative perspective of disability, these areas are critical for helping the people they support work towards their life goals. While a medical model of disability may focus on the impairment of individuals with I/DD or other disabilities, both social and affirmative models focus on the ability of the individual, while acknowledging the social, physical, or cognitive barriers that may exist (Gross, 2018; Rickson, 2014). Clinicians who work with individuals with disabilities should aim to work with individuals as though they are actively working towards self-determination. Wehmeyer (2005) explained that it is the role of all teachers or clinicians to help individuals with I/DD become more self-determined through encouraging people to express their preferences, encourage problem solving, promoting self-advocacy, and focusing on individually directed learning. The hope

here is not to promote control in individual's lives but to encourage people to act volitionally, to become causal agents in their lives, and to cause intentional outcomes.

Along with these perspectives of disability comes the belief that self-advocacy and self-determination is possible for all individuals, regardless of IQ or ability. A study by Wehmeyer and Garner (2003) found that there was no correlation between self-determination and autonomous functioning, regardless of the severity of a person's disability, implying that self-determination is independent of their IQ. The question then is whether the attributes of self-determination could be considered one of the adaptive skills evaluated outside of the IQ when assessing people with I/DD.

Ascribing to the affirmative model of disability also acknowledges that a person can be an advocate regardless of how they communicate. Bascom (2012) mentioned that agency is just as crucial in individuals who communicate extraverbally as those who communicate verbally. Agency can be found in everyday activities when people are given the respect and understanding of their own voice and opinion. The focus is not on a person's disability keeping them from verbally communicating their needs but respecting that the person may communicate in a different way and that we should take their behaviors and actions seriously, regardless of whether it is verbal or extraverbal (Ryan & Griffiths, 2015). There are challenges that make supporting communication difficult: lack of financial support, access to technology or devices, inadequate training, or technological issues. Regardless of these barriers, the individual should be respected and treated with the understanding that they are capable of communicating their needs through their actions, behaviors, vocalizations, or using an AAC device.

By working towards self-advocacy and self-determination, individuals with I/DD can enhance many other aspects of their lives, including social inclusion and self-identification. A common way for individuals to work on these skills is through self-advocacy groups, which teach, train, and practice self-advocacy (Anderson & Bigby, 2017; Friedman, 2017). Anderson and Bigby (2017) found that advocacy groups helped individuals who were long-term members form a sense of community. In an inclusion and advocacy study with students with disabilities, having the opportunity to share a space with student without disabilities helped encourage social interaction and inclusion between the students in the standard and resource classrooms (Pearl, 2004). Advocacy groups also allow for individuals with I/DD to have a space to explore their identity. Anderson and Bigby (2017) stated that forming these groups allowed individuals to explore new roles and see themselves in different contexts and new lights. This fresh new space is due to both being surrounded by peers but also having self-authored spaces, or spaces to learn and grow on their own. Individuals with I/DD may be constantly observed by support staff but being in these advocacy groups may allow for them to be in a space where the staff either was not physically present, or their presence was less imposing. Anderson and Bigby noted that this could be significant as it could be the "first time [that] freed people to be heard and taken seriously by their peers" (p. 113).

Self-Determination, Self-Advocacy, and Music Therapy for Individuals with Intellectual/Developmental Disabilities

Music therapy may provide many opportunities to foster advocacy and self-determination in individuals with I/DD by providing a safe and creative environment to explore and express themselves in a variety of ways. While there is little research focusing explicitly on self-advocacy or self-determination in music therapy groups, and even fewer

regarding individual sessions, the work that music therapists do is not far from this aim. As mentioned previously, self-determination is not a goal to be reached but involves the process of acting intentionally and volitionally (Wehmeyer, 2005). Many music therapists in the United States practice under the behavioral perspective working towards specific goals, and a behavioral approach is the second most common theoretical practice for music therapists internationally (Choi, 2008; Kern & Tague, 2017). Therefore, there is a disconnect between enhancing self-determination and viewing it as a goal within music therapy.

Music therapy can still be used to promote self-determination even though it may not be an explicit objective or goal through the process within the music therapy session. A shift in focus from goal-directed therapy to incorporating process-orientation can help ease this disconnect. However, this shift need not be a drastic one, and instead can be seen as a scaffolding of skills and evolution within the music therapy session to accommodate the individual based on the potential area of growth. This shift in focus is also seen in recent music therapy literature, calling for a change in how we frame sessions and interact with clients (Beebe, 2020; Metell, 2019; Murphy & McFerran, 2017; Stige, 2009). Beebe (2020), surveyed music therapists and results indicated a need for more education on self-determination and inclusion of clients in the discussion of their self-determination. There is also a need for more collaboration within music therapy sessions to exercise choice and control (Murphy & McFerran, 2017), a need to reframe how we view participation within sessions (Stige, 2009), and a need to co-create and restructure how we view our disabled clients and their sessions (Metell, 2019).

Goal-Oriented Approach. Some articles focusing on music therapy and self-determination have placed an emphasis on the skills within self-determination as an area of

focus. Gadberry and Harrison (2016) made a case for using music therapy to work on self-determination by focusing on the skills related to self-determination, as outlined by Wehmeyer et al. (2010): choice-making, goal setting, self-management, self-awareness, and self-knowledge. By working toward these goal areas, the hope was that the individual will start to develop the initial skills within self-determination. The authors also addressed that supporting awareness, attention, and interaction through improvisation and musical attunement can encourage a positive change in the individual's determination skills. Lee and McFerran (2012) conducted a study on communicating song choice in sessions, with the aim to promote communication skills. By promoting communication skills, a component of self-determination, the study found that individuals were better able to exercise choice-making within a session; however, the authors noted that there should be distinction that the individuals were communicating a song choice and not a song preference. While both of these articles provide a framework for working towards self-determination, there seems to be a missing component of preference and the individual's own volition within sessions. While working towards communication, self-awareness, and choice-making can provide an initial framework of developing self-determination, a deeper focus of promoting self-determination requires a less goal-directed approach.

Music therapy groups may also help promote self-determination and self-advocacy on a social and community level. Music therapy groups can provide opportunities to advocate to the community through public music performances (Ansdell, 2005; Curtis & Mercado, 2004). Ansdell (2005) wrote about the benefits of performing within music therapy and community music therapy. While the article focused more on the relevance of performance to music therapy, Ansdell (2005) stated that these public performances are important because of

how they advocate the skills of the performers. For individuals with I/DD, community performances provide opportunities for the performers to learn how to prepare and organize for a concert and then share their abilities with the public. Similarly, Curtis and Mercado (2004) wrote about community performances for individuals with and without developmental disabilities. The inclusivity provided for the opportunity to promote socialization by bonding over a common interest of performing and music. Additionally, the study gave the chance for individuals with developmental disabilities to teach and share their own musical knowledge with their peers, which also provided an opportunity to explore leadership roles and advocate their skills as a leader.

Process-Oriented Approach. Diving deeper into the self-determination scaffolding requires a shift in focus from goals to the process of music therapy. Placing an emphasis on the process requires the music therapist to think not so much about *what* goes on in the session, but *how* it goes (Pickard et al., 2020). This perspective calls for a focus on the relationship and the therapy setting itself above the goals and interventions. In Graham's (2004) case study of music therapy with individuals with I/DD who are extraverbal, a focus on the relationship can be seen as *how* the music therapist is enhancing self-determination. Through vocalizing and responding with the individuals, the music therapist built a relationship with the individuals and also noticed the nuanced ways in which the clients communicated desires and feelings through vocalizations or gestures.

In addition to rapport-building, structuring the session to include listening, respecting communication, and encouraging decision-making and problem solving can help enhance advocacy skills (Bascom, 2012; Ryan & Griffiths, 2015; Wehmeyer, 2005). A music-centered approach to music therapy also fits nicely along with the ideas of the social model

and promoting self-determination by focusing on the music first (Gross, 2018). Aigen (2001) and Næss and Ruud (2007) also mentioned the promotion of self-awareness within disabled individuals, including those with limited speech or who communicate extraverbally. By placing the emphasis on the music, doors of support are opened to encourage the individual to interact and communicate through music. The skills seen in self-advocacy could be promoted by limiting the other social barriers and creating an equal and even playing field in which to make music, socialize, and communicate. Through the music-centered approach, these individuals may be able to use music as a form of self-expression, explore their own identity, and take agency within their lives.

Additionally, this approach emphasizes the *how* of the interaction between client and therapist rather than focusing on the *what* will happen in the session. This shift in focus can also be applied to music therapy groups, where it is important to consider how the group is conducted. Rickson (2014) discussed considering disability perspectives within music therapy groups with individuals with I/DD. It is important to consider the way the group is run and where the power in the group may lie. Rickson stated that in order to increase self-determination, it is important to minimize control or dominance as the group "leader" or music therapist, and to allow the group to be a client-directed and collaborative process. By encouraging client-directed groups and minimizing music therapist intervention, the group members can learn to advocate for their own needs, communicate what they would like, and learn about group roles, as previously mentioned in the Test et al. (2005) self-advocacy framework.

Again, as the music therapist scaffolds their sessions to promote self-determination, they must consider the *how* the session is conducted and the *why* it is done in this way

(Bascom, 2012; Pickard et al., 2020). Bascom (2012) stated that the intention behind therapy and the process is critical to what comes out of the session. This involves working beyond surface level goals towards self-determination and studying and researching perspectives in which the music therapist can best serve the individuals within music therapy. Pickard et al. (2020) laid out different perspectives within the disability movement and neurodiversity movement and call for music therapists to bring this knowledge into their practice when working with individuals with developmental disabilities or I/DD. In order to best serve these populations, music therapists should understand the *why* of the therapy, the *why* of goals or outcomes, and *why* it is important to promote self-determination.

Conclusion

There are many components that make up both self-advocacy and self-determination. While the distinction between what qualifies for each may be a bit of a gray area, the most important aspect of both is expressing one's needs and desires (Schreiner, 2007). In working with individuals with I/DD, it is important to focus on both self-advocacy and self-determination, especially when viewing disability within a social or affirmative model (Gross, 2018; Rickson, 2014). It is also important to acknowledge that anyone, regardless or IQ, disability, or communication skill can be an advocate or be self-determined (Bascom, 2012; Wehmeyer & Garner, 2003). Music therapy can also provide a safe and creative space for individuals with I/DD to explore self-advocacy and the power of their own voice. As music therapists consider providing opportunities to promote self-determination or self-advocacy, it is important to ensure that individuals have the chance to share their preferences, to lead the session, to observe themselves, and to make decisions (Wehmeyer, 2005). Even so, it is not so much what songs music therapists bring to the session or what interventions

they select, but how the music therapist provides opportunities for a client and the music therapist's own understanding of disability perspectives (Pickard et al., 2020).

CHAPTER 3

Method

Design

I utilized a social constructivist epistemology, in which I looked for a complexity of views to understand self-determination (Creswell & Poth, 2018). Further, I used a disability interpretive lens employed through an action research methodology and process (Stige & McFerran, 2016). Lewin (1946) described action research as a continual spiral of steps in which values and ideas guide the process of revision, reformulation, and reflexivity. Due to the emergent nature of this type of research, the data collection methodology evolved as the study progressed. Additionally, action research in music therapy commonly uses group discussions and interviews with co-researchers or participants (Stige & McFerran, 2016). Stige and McFerran noted that music therapy with individuals who communicate extraverbally could provide a unique approach within action research for their voices to be heard; however, it is also important for a critical lens of reflection to be employed during this process. I utilized a disability studies interpretive framework through which to view the data in the spiralized process (Lewin, 1946).

Informed Consent

Appalachian State University's Institutional Review Board approved this study prior to recruitment, and all guardians signed consent forms for the participation of individuals in this study (see Appendix E). Individuals and their guardians also received interview questions and materials approximately one week before the scheduled interview time. Individuals had the chance to indicate assent consistent with their preferred method of

communication to eliminate identification on a signed consent form. See Appendices A and B for consent forms.

Researcher and Participants

Researcher/Music Therapist Positionality

With the reflexivity of action research, my position as researcher and music therapist needed to be addressed. I am a white, European-American, affluent, educated, English-speaking, non-disabled, neurotypical, person with an anxiety disorder, Christian-raised, straight, cisgender woman. I am writing this thesis in pursuit of a Master of Music Therapy degree. As a board-certified music therapist, I practice primarily with a humanistic perspective, also borrowing from perspectives within the resource-oriented model (Rolvsjord, 2010). Additionally, I view disability from both a social and affirmative model. Advocacy and inclusivity guide my values as a music therapist and as a human being. As this study progressed, my role was not so much as an expert or a therapist, but as a companion and co-researcher. Self-reflection upon my values, my identity, and my role within the study were critically reflected upon throughout the process through reflexive journaling as well as research supervision.

Participants

Participants included four young people between the ages of 16-30 who self-identified or were identified by their guardians as having a diagnosis of I/DD and communicating using methods beyond words. Some individuals also had another diagnosis of autism spectrum disorder. I invited one past client to participate in this research, acknowledging the ethical complexity of being both researcher and clinician. For the purposes of this study, participants are referred to as “individuals” in keeping with a humanistic perspective due to the active

involvement of individuals in the process of this study. Individuals involved in the study were assigned pseudonyms to ensure confidentiality. Individuals' pronouns used in this study are based on those the parents and caregivers used, acknowledging that this may differ from the individuals' preferred gender identification. Information about each individual and their music therapy sessions is included below and in Table 1.

Table 1

Overview of Participants and Music Therapy Sessions

Names	Age	Types of Experiences	Caregiver/Parent Present	Communication Style	# of Sessions Attended	Length of Sessions	Types of Session
Nick	16	receptive and active listening, singing/vocalizing, choosing songs	Caregiver	facial expressions, vocalizations, gestures	7	20-30 minutes	In-person
Sean	22	singing/fill-in-the-blanks, watching music videos, and movement, presenting session outline/expectations, receptive listening, selecting songs/videos	Parent (father)	one-word verbalizations (sometimes echolalia), pictures, words, low tech AAC	7	15-25 minutes	In-person
Austin	26	improvisation, receptive listening, song writing, selecting songs or activities	Parent (mother) and caretaker (during first 3 sessions)	high tech AAC: (iPad app - Proloquo2Go) gestures	7	40-50 minutes	In-person
Samantha	30	collaborative singing, receptive listening, active music making, requesting songs	Parent (mother)	singing/vocalizing, facial expressions, gestures, adapted sign language	7	25-30 minutes	Virtual (Zoom)

Nick. According to initial parent contact, Nick had a communication device, but it was not brought to any music therapy sessions. He was a student at the local high school and enjoyed a variety of music, alone time, and sensory stimulating objects. Sessions took place inside a clinic room or outside of the clinic building, based on Nick's comfort level that day.

Throughout music sessions Nick wore a weighted vest and had his shirt sleeves tied at his hands. He had difficulty adjusting to new environments and transitions and engaged in self-injurious behaviors when he was upset or distressed. His interview took place after our final session together, due to emotional distress experienced during the session.

Sean. Sean was a young man whose verbalizations were often echolalic, and his parents identified him as communicating primarily extraverbally. He enjoyed watching music videos, particularly from Veggietales and Sesame Street. At the beginning of each session, Sean routinely went to the bathroom before and after walking into the music therapy room.

Austin. Austin was a young man who enjoyed music from a variety of television shows, including Sesame Street, Bear in the Big Blue House, and Mister Rogers' Neighborhood. During sessions, Austin moved instruments, magazines, and objects around the room into a pile. He occasionally played instruments like the drums, piano, xylophone, and egg shakers, and he also enjoyed looking through magazines.

Samantha. Samantha was a woman who is visually and had a great interest in interacting with music. She enjoyed music of all genres and styles and sang verses, choruses, and whole songs. Samantha was a client whom I worked with during my internship six months prior to the start of this study. Sessions took place using Zoom, since she lived in a different state.

Procedure

Sessions were held at the Institute for Health and Human Services (IHHS) or through a secure telehealth portal (i.e., Zoom). Typical sessions included a welcome song, preferred experiences (See Table 1 above), and a closing song or experience. Sessions lasted over the course of 10 weeks, and all individuals in the study attended seven sessions. Based on safety

and familiarity, some individuals' parents and/or caregivers attended session with the individuals in this study. This choice was left open to the parents/caregivers, and some specifically requested attending sessions due to medical and behavioral needs and safety for the client and me as an unfamiliar individual.

Due to the activist nature of this research, a treatment manual was used to maintain my principles as the music therapist while the research was conducted. Rolvsjord et al. (2005) outlined a therapy manual for research for therapists working within multiple therapeutic perspectives. As with standard study procedures, working within a fixed therapy manual can be limiting and not conducive to the progressive nature of music therapy, nor does it support the continually evolving process of action research (Lewin, 1946); therefore, I used this therapy manual to maintain and develop principles rather than focusing on structured procedures. The therapy manual principles provided the opportunity for both flexibility and consistency by outlining what is to be expected and not included within the therapeutic process. Four categories of principles are outlined within the manual, as adopted from Waltz et al. (1993): (1) unique and essential; (2) essential but not unique; (3) acceptable but not necessary; (4) not acceptable (as cited in Rolvsjord, Gold, & Stige, p. 23). Chosen principles are based on clinical experiences as well as therapeutic models of therapy. The principles for this study are outlined below, and are based upon humanism (Hadley & Thomas, 2018), resource-oriented music therapy (Rolvsjord, 2010), the affirmative model of disability (Swain & French, 2000), and self-determination theory (Ryan & Deci, 2004). The guidelines for the principles are included in the appendix (See Appendix D).

Therapeutic Principles

1. Unique and Essential Therapeutic Principles
    1. Focusing on the person's strengths and potentials
    2. Recognizing the person's competence related to their therapeutic process
    3. Collaborating with the individual concerning goals, music experiences, and musical instruments
    4. Being emotionally involved in the music
    5. Acknowledging the person's musical identity and preferences
2. Essential but not Unique Therapeutic Principles
    1. Engaging the person in music interplay (such as musical improvisation, creating songs, playing pre-composed music, or listening to music)
    2. Acknowledging and encouraging musical skills and potentials
    3. Reflecting verbally on music and musical interplay
    4. Listening and interacting empathically
    5. Tuning into the person's musical expressions
    6. Prioritizing rapport and relationship
3. Acceptable but not Necessary Therapeutic Principles
    1. Sharing one's own experiences
    2. Having music as the primary goal of therapy
    3. Reflecting verbally and musically on problems
    4. Teaching instruments/music
4. Not Acceptable - Proscribed Therapeutic Principles
    1. Neglecting the person's strengths and potentials

2. Having total control over the session's contents
3. Avoiding emerging problems and negative emotions
4. Directing in a non-collaborative style.
5. Disregarding or ignoring a person's preference or need

The music therapy experiences within sessions took on different forms, depending on each individual. Individuals chose to engage in a variety of different types of music therapy experiences, ranging from songwriting to recreative music making. Individuals also engaged in musical exploration with new and familiar instruments. Sessions were primarily individual-lead, and I, as the music therapist, provided structure, experiences, or support as needed. The treatment manual was used and reflected upon throughout the process to re-evaluate the contents of sessions and to ensure the principles and focus of self-determination and individual centeredness was maintained.

Table 2 (below) outlines how each interview was conducted based upon participant engagement and communication style. Interviews with individuals were conducted during the final session or afterwards at a mutually agreed upon time. Parents responded to similar interview questions during, afterwards, or immediately before the final session.

Table 2

Individualized Interview Formats

Interview Format	Yes/No Questions	Questions verbally presented, with visual supports	Verbally presented questions only	Used 6-option emotion visual	Conducted over zoom	Parent/ caregiver assisted	Conducted over zoom
Nick	X	X			X	X	X
Sean	X	X		X		X	
Austin	X	X		X		X	
Samantha	X		X		X	X	X

Data Collection and Analysis

Data was collected through session notes, interviews with individuals, reflections and notes about the treatment guideline principles, and my reflections as the music therapist. Based on parent/caregiver involvement in the sessions and their role as the individual's communication partner, they were also interviewed using the same questions as individuals. Interviews were video recorded using a laptop video camera and then transcribed for further data analysis.

Table 3

Sources of Data Used to Address Research Questions

Research Questions	Sources of data
In what ways can a music therapist promote self-determination for individuals with I/DD who communicate extraverbally?	• Session notes • Therapeutic guidelines reflections • Personal journal reflections • Interviews
How do individuals experience self-determination outside of the music therapy session?	• Interviews • Session notes
What social change needs to occur as a part of or product of these sessions?	• Interviews • Therapeutic guidelines reflections • Personal journal reflections

Note. This table presents the research questions in this study and how the different sources of data were used to address the questions.

Using a content analysis approach (Ghetti & Keith, 2016) session notes, interviews, personal reflections, and notes on the treatment guidelines were coded and analyzed for common themes. Themes emerged inductively, such as observing and noting different forms of communication, and deductively, such as using Stige's styles of self-presentation (2009). The definitions Stige included are offered below compared to my interpretations of these different styles of self-presentation throughout music therapy sessions (See Table 4).

Table 4

Styles of Self-presentation

	Stige's (2009) definitions	My Interpretations
Non-participation	Not being there (physically or psychologically/socially)	Leaving the session space, absence of awareness or presence in what is happening in the music space
Silent participation	Being there but not joining in or taking part in any conventional way	Listening to music or interactions but not actively participating and engaging
Conventional participation	Joining in but not standing out, or joining in and performing what is expected in the situation in a role that is available	Engaging in a way that is expected or is "typical": playing instruments, singing, engaging with objects or people in the room
Adventurous participation	Standing out but not going across, or a deviation on what would be expected that contributes with something new in the situation	Contributing new or different musical expression, interactions, or ideas in the group; actively engaged and changing their music experience
Eccentric participation	Going across what is happening in the group, more dramatic than adventurous participation.	Where engagement appears incoherent or disruptive, changing the existing flow or structure of the experience.

Note. This table compares brief definitions of styles of self-presentation to my interpretation of the definitions. Definitions taken from Stige (2009, p. 130-131).

I analyzed the latent content from the session notes by applying my interpretation of Stige's styles of self-presentation (2009). Due to time limitations, my analysis of the session notes was reviewed by my thesis supervisor rather than doing a traditional member check with the individuals in the study.

CHAPTER 4

Results

Since I served in dual roles for the duration of this study (e.g., music therapist and primary researcher), data collected from this study were analyzed with both roles and perspectives in mind. The results chapter is presented as follows: analysis of session notes, interviews, reflections of the therapeutic guidelines, and reflections on my personal experience throughout the study.

Session Notes Themes

Following every session, I compiled narrative-style documentation on observations, conversations, and interactions throughout sessions. Using a content analysis approach (Ghetti & Keith, 2016), I compared, analyzed, and coded session notes for common themes. Themes that emerged from the analysis of session notes included communication, styles of self-presentation, parent/caregiver inclusion in the session, and contextual events.

Communication

Addressing communication during music therapy sessions was one theme that emerged from session note analysis. Subthemes of communication included types and styles of communication and communicating/advocating for self.

Types of Communication. Types of communication was a main theme that emerged throughout sessions. The individuals used a variety of approaches and means of communication. Two individuals, Austin and Sean, utilized both high-tech (e.g., iPad applications) and low-tech AAC devices (pictures or photorealistic images). Austin used the application Proloquo2Go, which utilized images and words, to express current feelings, wants, songs requests, and perceptions of the music experience. Sean used an iPad and laptop

to select music videos by pointing at or touching images with links to music videos that were included via a PowerPoint I created. Low-tech devices in the sessions included a 5-point preference scale with photorealistic pictures and song lyrics with corresponding images. The 5-point preference scale was utilized to assess the individuals' opinion of an activity or song. Austin used the scale to indicate that he enjoyed listening to songs during a couple of sessions.

Other types of extraverbal communication were exhibited by all individuals, mainly using body language, facial expressions and changes, and gestures. Nick often indicated a song choice by smiling or looking at me. When no change in expression or eye contact was made, the communicated choice was interpreted as "no choice," indicating that I would select the song. During another instance of offering a couple of song options, Nick looked at his caregiver, and this was interpreted as allowing the caregiver to choose the song during that instance. Individuals used eye contact or gaze to communicate a need or choice with individuals or objects in the room, such as when Austin looked at his parent when he was asked a question, or when Sean looked at my laptop across the room, which had been used to watch videos during previous sessions.

I also observed gestures or actions as communicating needs, preferences, or as participating in the songs. A couple of individuals utilized adapted sign language. Samantha used a sign for "yes" as well as associated signs to communicate song choice (e.g., "king" for "I Just Can't Wait to Be King"). Austin also used adapted sign language and gestures to signify "goodbye" or "all done for sessions". He also took his parent's, caregivers, or my hand to guide us to a specific object, place in the room, or choice on the iPad.

A couple individuals also used other types of vocal or verbal communication. Sean used verbal communication occasionally, typically using one-word phrases or echoing statements by other individuals or song lyrics. I interpreted these verbalizations as verbal stimming or echolalia, but occasionally Sean verbalized “goodbye” during the goodbye song or verbalized words that were written out on the session outline. Samantha requested songs throughout sessions through vocalizations and/or singing. She often sang the verse or chorus of a song prompted or unprompted when she requested a song.

Communicating and Advocating for Self: Preferences and Boundaries. Another theme that emerged from session notes was related to individuals communicating limits or boundaries throughout sessions. These limits often included preferences against the use of instruments or for the conclusion of the session. When offered a cabasa, Nick pushed it away from himself. In multiple sessions, Austin took instruments handed to him and placed them across the room, hiding them under chairs or tables. Similarly, Sean verbalized “all done” towards the middle of the session, communicating a desire to be finished with music therapy.

Communicating preferences for songs was often exhibited in several individuals. Often a choice between two or three songs was provided, but occasionally individuals requested specific songs, either by singing the song, like Samantha, or choosing it on a device, like with Austin and Sean. Samantha often requested two songs, one of which was a goodbye song and the other one was “saved for Mondays”, as requested by the mother. I acknowledged these two specific requests then redirected them, communicating that the song would be sung at the end of the session or at another time. Samantha then requested these songs throughout the session and sometimes sang a verse of the song by herself. Occasionally she changed how she requested these songs, by switching from singing one

song to the goodbye song halfway through a phrase, or by changing the style in which she sang a song.

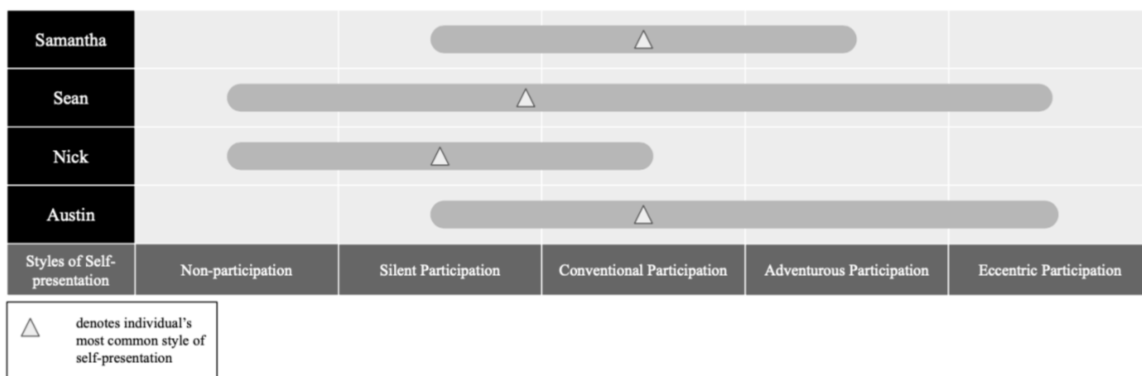
Clients also communicated boundaries between themselves and others in the session, such as their caregiver or parent. When Nick's caregiver sat next to him on a bench, Nick pushed the caregiver away and off the bench, communicating that he needed space from the caregiver. A similar situation occurred when I sat in front of Nick, singing, and playing a tambourine and guitar and Nick stood up, walked away from me, and began to engage in self-injurious behaviors. Austin also exhibited this need for separation when he handed keys to and guided his parent out of the session room.

Styles of Self-presentation

I observed different styles of self-presentation across individuals and sessions. Using Stige's (2009) terms for styles of self-presentation, the following results will provide examples of self-presentation and participation in the music therapy sessions.

Figure 2

Styles of Self-presentation



Note. This figure displays the styles of self-presentation for individuals over the course of this study. The triangle denotes the most common style of self-presentation the individual exhibited.

Non-participation. The first style of self-presentation exhibited pertains to non-participation, or the observed absence of participation. During these moments, individuals were either physically absent or were not fully aware of the music therapy space. For Sean, he had an established practice to visit the restroom before entering the music room. Sometimes this occurred immediately after first walking into the room that day and other times when he was distressed, uncomfortable, or anxious, as exhibited by his vocalizations, verbalizations of "goodbye," hand flapping, running around the room, and statements his parent made. I also observed non-participation during sessions with Nick, when he would physically move away or face a different direction than me.

Other instances of what I considered non-participation included moments when individuals were emotionally distressed. Like mentioned previously, Sean would loudly vocalize, flap his hands, and run and jump around the room when he was anxious. Nick had moments when he was distressed where he would loudly vocalize, cry, and engage in self-injurious behaviors. I considered these moments of self-presentation to be non-participation because of the distance of the individual from the session. While they were physically present, they were not aware of or engaged in the session.

Silent Participation. I observed moments of silent participation when individuals were quietly or distantly engaged in the session. Clients engaged in the environment by moving magazines, looking through magazines, or moving objects around the room. Austin and Nick often took magazines and looked through and held them. Austin moved objects across the room, under chairs, under tables, and in bags. Occasionally I incorporated these actions into the music and songs by singing what the individual was doing, such as if the individual chose to put instruments in a pile or under the table.

Other types of silent participation included observing and listening to me play the guitar or watching music videos. All individuals exhibited this at some point during sessions, where they silently watched or listened to me sing and play the guitar. This also occurred during moments of emotional distress or anxiety when individuals were crying. During a few sessions, Nick exhibited some distress and anxiety while I quietly played songs and matched his emotional state. While Nick did not vocalize or sing along to the music, he listened to the music and his emotional state became less distressed and more relaxed, as exhibited when he stopped crying and began taking slower and deeper breaths. Austin and Sean enjoyed watching familiar and favorite videos of songs. During these times, they quietly watched and listened to the music video. Similarly, sometimes individuals listened to and watched parents or caregivers play instruments nearby. Nick's caregiver played several instruments near Nick, such as a paddle drum or xylophone, while Nick observed quietly and listened.

Conventional Participation. I observed conventional participation when individuals participated and interacted with the music in some way, musical or nonmusical. This included individuals singing or vocalizing along to songs, filling in notes, pointing to images, or saying single words along to the song. Clients also participated in songs by gesturing or using adapted sign language in songs. Samantha used adapted signs for words like "walk" and "love" when used in song lyrics, and Austin and Sean often waved "hello" and "goodbye" during the opening and closing songs. Additionally, individuals like Samantha, Sean, and Nick interacted with the music by smiling, shaking their heads, and clapping.

Interacting with instruments in some way was another example of conventional participation. The interaction was either rhythmically and directly linked with the music, or by exploring instruments. Sean and Nick played instruments briefly, quickly trying them out

and then moving on to something else. Austin explored the sounds and feelings of instruments like the piano, xylophone, and egg shakers by tapping them rhythmically or briefly. Caregiver/parents and I also assisted instrument playing, often when the individual requested hand-over-hand guidance or used eye contact or gestures to play an instrument. Individuals initiated supportive instrument playing, such as when Austin reached over to touch his parent's hand.

Additionally, conventional participation included extra-musical interactions, not always accompanied by instruments, vocalizations, or singing. Several individuals interacted with me and music using props like magazines, stretchy noodles, or chairs around the room. Nick brought his own magazines into the session a few times and would shake, throw, stomp, and tap on the magazine. These magazine movements were occasionally in time with the beat of the song. Austin brought magazines into sessions and looked through them and tapped images to the rhythm of the song I sang. Austin also tapped chairs, tables, and other objects in the room to the rhythm of songs. Sean interacted with me and the music through a stretchy noodle, following and repeating my movements.

Adventurous Participation. A few individuals exhibited adventurous participation in the sessions. This was evidenced by their independence in participating and guiding the session. For example, Samantha sang and requested songs independently. When a space was left open in a song, she continued to sing the following line or entire chorus without prompting. She often requested songs other than ones that I suggested. Samantha also participated in songs by singing back up or accompanying parts of a song, as they appeared on the recording of the song, or would play accompanying rhythms using woodblocks. Sean exhibited some independent participation in selecting his own music videos and initiating

how to move props during sessions. I observed adventurous participation in Austin when he initiated playing different instruments and by moving objects and instruments into distinguished piles.

Eccentric Participation. Eccentric participation involved participation that went beyond what was occurring in the session at the current moment. For a couple individuals, their self-presentation diverged from what was currently happening in the session. Similar forms of participation were sometimes integrated into the session musically, but with eccentric participation, the engagement went beyond or opposed to what was happening in the session.

In sessions, Austin occasionally interacted with objects in the room by moving them or holding onto them in a way that prohibited further participation. Instead of being able to bring the music into these situations, Austin continually reorganized and kept materials in the room from being moved or used for other purposes. Sean exhibited some forms of eccentric participation, when vocalizing loudly, jumping, running, or flapping when an unpreferred song was played or sung. While these situations were like other instances of participation, what made them different was their going beyond and across what was happening in the music space.

Parent/Caregiver Involvement

All individuals came to music therapy sessions with a parent and/or caregiver, as requested and indicated by individuals, parents, and caregivers. During most of these sessions, the parent/caregiver remained in the music room throughout the session. Main themes from session documentation related to involvement included parent/caregiver active

participation in sessions, parents/caregivers being a source of familiar regulation/stimulation and providing insight throughout the process.

Active Participation. Many parents and caregivers found ways to interact with individuals and engage with the music in an active way, either through singing or playing instruments. Austin, Sean, and Nick's parents/caregivers found opportunities to engage with the music by playing drums, xylophones, or shakers while listening to songs. Active participation sometimes involved the individual, such as when Nick's caregiver played the paddle drums above and around Nick, or by encouraging the individual to play with them, like when Austin's parent tapped on the drum and encouraged Austin to do so as well. Other times, parents/caregivers played and sang along independently and parallel to the individual. Sean's parent played the drums during the final sessions while Sean watched and listened to several videos.

Samantha's parent actively participated in the music activity by choosing and putting boundaries on song requests. When Samantha requested the song, "Ants Go Marching", her parent stated that that song was to be saved for music therapy on Mondays. Other times, parents or caregivers actively participated in song selection, either when prompted by me or the individual. When given choices for songs, Nick looked at his caregiver, which was interpreted by the caregiver and me as letting the caregiver select a song.

Providing Client Insight. Parents and caregivers provided insight into aspects of the individuals life in several ways, including providing strategies or suggestions, disclosing perceptions of the session, discussing the individuals' music preferences, and disclosing individuals' current feelings.

Strategies and Suggestions. With individuals whom I had not worked with previously, parents/caregivers provided strategies and suggestions. Caregivers and parents disclosed insights about how to structure the session and ways to promote success with the individual. Nick's caregiver explained that placing low or no expectations can sometimes be helpful, especially in new environments and situations. Additionally, the caregiver mentioned that Nick prefers to protect his personal space and alone time, which was observed when he pushed on the caregiver to get off the bench he was sitting on. Sean's parent shared that being animated and energetic with Sean was often a helpful way to keep him engaged in an activity. Some parents also suggested intervention ideas, like Austin's parent who suggested making games out of magazines in the room and rewriting lyrics to a familiar song.

Perceptions During the Session. Like sharing strategies, parents and caregivers often shared their perceptions of events and actions that occurred in music therapy sessions. Perceptions were often related to how the individual reacted or responded to a particular interaction. In the first session, Austin's parent shared that waving goodbye was an important interaction. Similarly, when introduced to a new song in a session, Samantha's parent mentioned that it was probably the first time Samantha had been introduced to a new song in music therapy. Samantha's parent also shared her own perception of why Samantha requested the goodbye song throughout the session, stating that it was because she liked the song, not because she wanted the session to be over.

Parents and/caregivers often disclosed their perceptions of the individuals' current mood on that day, including events that had occurred throughout the day or week. Samantha, Austin, and their parents all shared when they were having a difficult health day or were tired. During one session, Nick's caregiver shared that Nick was feeling particularly happy

and “goofy” that day, which was followed by a smile from Nick. Other times, parents shared individuals’ emotional states during sessions, especially when the individuals were getting agitated or distressed. Sean and Nick’s parent and caregiver both shared that it may be best to end the session when the individuals were upset, anxious, and distressed.

Sharing Music Preferences. Almost all parents and/or caregivers shared music preferences throughout sessions. Some individuals, like Sean and Austin, had specific versions of music videos and songs they enjoyed. Their parents shared these preferences and helped find the specific videos. Samantha’s parent shared music that Samantha had been requesting at home and in other music therapy sessions and listening to on the radio. Nick’s caregiver did not share Nick’s specific music preferences but mentioned throughout several sessions’ specific songs and genres that his family members listened to.

Providing Familiar Regulation. Parent/caregiver involvement in sessions became a resource of familiar regulation for individuals when they were distressed and/or distracted. Sean requested “tickles” from his parent while watching music videos and listening to music. Nick’s caregiver provided tactical stimulation through drumming and patting Nick’s arms and chest, and “snugging”, which was what the caregiver called tightening the individuals’ tied shirt sleeves and weighted vest. His caregiver also talked through and processed potential anxious thoughts and emotions with Nick when he was upset and distressed.

Contextual Events

Several contextual factors occurred simultaneously to music therapy sessions were included in the session notes. Samantha experienced some daily schedule disruption as she returned to her day service activities a year and a half after the COVID-19 pandemic began. She returned to these services during the second week of sessions, and during the last week

went back to staying home full time. Austin's parent disclosed some additional information about conflict with one of Austin's caregivers who had taken away his iPad. This incident had upset Austin and his parent stated that he had been very protective of his iPad since that event.

Transitions and new environments were particularly difficult for Sean and Nick. Sean often left the music therapy space when anxious, and anxiety increased as the session went on. Nick also had difficulty transitioning to and from the sessions. During our first session, Nick became distressed with the new, unfamiliar music space. For all the following sessions, he helped decide whether to do sessions outside the clinic building or inside.

The final session with Nick took place outdoors since he was exhibiting some distress and anxiety, as exhibited by loud vocalizations, self-injurious behaviors (SIB), and crying. About 15 minutes into the session, a police officer showed up and mentioned that he had received a distress call about someone loudly yelling. The police officer left after he noticed that Nick was becoming agitated again.

Interview Results

Interviews with individuals in this study took place either during the final music therapy or during a follow up meeting. I asked individuals interview questions throughout the session, which were video-recorded and transcribed. For information about the individualized formatting of interviews, see Table 2 on page 34. Parents/caregivers were also given a paper or online questionnaire with similar interview questions as the individuals in the study. Interview responses were grouped based on questions and compared with the corresponding parent/caregiver response.

Warm-Up Questions

At the beginning of interviews, I asked individuals a few warm-up questions to prepare them for answering questions. The questions were related to activities that we did during sessions. All warm-up questions were individualized based on activities that occurred in the music therapy session. Examples of questions included: Did you play instruments in music? Did you watch videos? Did you listen to music? The responses to the warm-up questions varied in accuracy, with some individuals answering “no” when they watched several music videos throughout the sessions. Because they were used as a warm-up, I allowed parents/caregivers to support and guide answering these questions to prepare individuals for answering further questions.

What was your favorite activity? How did you feel when you did this activity?

Two of the four individuals responded to which activities they liked the best. Austin selected that he liked playing with the instruments the best. He also selected that the instruments made him feel “surprised”. His parent communicated that this might be because the instruments sometimes made surprising sounds. Additionally, Sean communicated that he enjoyed watching videos during music. This choice was guided verbally by his parent. Sean also selected that watching videos made him feel “happy”. Sean’s parent agreed in his interview that Sean enjoyed watching videos during the sessions. While Samantha did not communicate a favorite activity, Samantha’s parent stated in the interview that she enjoyed singing songs more than playing instruments.

Did you like music time? How did you feel during music time?

Nick, Austin, and Samantha all responded “yes” to liking music therapy sessions; Sean selected “no”. Austin communicated that he felt “silly” during music time. Sean

selected several responses after I prompted the question a couple of times, communicating that he felt “happy”, “sad”, and “scared” in music time. Samantha responded to the question by communicating that she felt happy during music but gave no response when asked if she felt sad. Her mother mentioned that when she does not respond to a question, it is usually her way of saying “no”. Nick’s caregiver responded to this question when Nick provided no response stating that Nick may have felt frustrated but also happy, to which Nick vocalized after his caregiver stated this. The caregiver also stated that it “was tough to get there but fun to be there.” During the caregiver’s interview, he mentioned that Nick often feels overwhelmed when trying something new.

Did you make choices in music time?

Nick communicated that he did make choices in music therapy. His caregiver expanded on this response in their own interview by communicating that Nick chose where to do therapy and provided input on song choices. Both Sean and Austin responded that they did not make choices in music, but then switched their answer to “yes” after prompting from their parents. In their interviews, the parents stated that Austin chose songs and activities, and Sean selected videos. Austin’s parent expanded on his choices in their interview, stating that the choices provided “freedom” for Austin. While no response was received from Samantha, her parent discussed in the interview that Samantha “chose between songs and would sing the beginning of songs she wanted to sing.”

Did you like making choices in music time? How did making choices make you feel?

Austin and Samantha both communicated that they liked making choices in music. In her interview, Samantha’s parent expanded on Samantha’s response to liking making choices by stating that she enjoys making choices, “some days more than others.” Austin’s parent

shared in the interview that Austin enjoys "having the ability to express himself and make choices." When asked how making choices made him feel, Austin selected "happy". Did you like making choices in music? Sean did not respond to this question; however, his parent stated that Sean "somewhat" enjoyed making choices in music. Nick responded "no", he did not like making choices in music time. I expanded on this by stating and asking if it was because of the pressure and having "too many choices", to which the caregiver responded, "Yep." In the caregiver's interview, he stated that Nick does not enjoy forced choices.

Do you make choices at home? In the community? Or at school?

Several of the individuals' responses from this question differed from those of the caregiver or parent. Nick responded "no", he does not make choices at home, in the community, or at school; however, his caregiver stated in his interview that Nick makes "familiar choices at home and in the community." Sean also responded "no", but then changed his answer to "yes" when prompted by his parent. When asked in the interview, Sean's parent responded "yes" to Sean making choices at home and in the community. Samantha communicated "yes", she did get to make choices, while parent repeated the question twice and then added, "Sometimes." Her parent expanded on this in the interview, stating that most of Samantha's choices "are related to music," and sometimes other choices are made, if prompted. No response from Austin was given during his interview, but his caregiver stated in the interview he uses his iPad at home to make choices.

General Feedback from Caregivers and Parents

Parents/caregivers provided additional feedback and information, except for Sean's parent. Nick's caregiver shared in his interview that the "therapist was very comforting for the individual, especially with the accommodations to make things easy and peaceful for the

individual." Samantha's parent shared about how Samantha responds well in music, "even if it is by zoom calls." She went on to state that music therapy sessions provided a space to "see how many songs she does know. Which seems to be endless." Additionally, Samantha's parent provided some context to Samantha's participation in sessions, stating, "She didn't use to sing back and forth like that." Austin's parent shared a benefit from music therapy sessions was that he "developed a therapeutic relationship outside his trusted caregivers." His parent added that she learned more about Austin during the sessions: "I learned [Austin] was more sensitive than I believed and more independent than I thought!"

Therapeutic Principles Guidelines Results

Analysis of the treatment guidelines involved reviewing notes and reflections on each principle that were made after each session for everyone. Reflection of the principles are presented from my perspective, as both therapist and researcher. Check marks were made on the principle when it occurred in the session. Totals of the checkmarks from all seven sessions for everyone were then averaged together, with ranges noted. Table 5 lists the averages and ranges of how many times these principles occurred in the session as well as comments and reflections from the sessions. The results below highlight the principles with the largest ranges and are almost homogenous. Comments included were coded and organized based on similarities and how often they came up during sessions and across all individuals in the study.

Table 5

Therapeutic Principles Guidelines Reflections and Results

Therapeutic Principles Guidelines	Austin	Nick	Samantha	Sean	AVG	Range	Comments
1. Unique and Essential Therapeutic principles							
1.1 Focusing on the person's strengths and potentials	6	6	7	6	6.25	1	- Consider my expectations I place on individuals - Providing space to explore and express themselves - Accepting of all participation
1.2 Recognizing the person's competence related to their therapeutic process	4	5	7	7	5.75	3	- Sharing choices, collaborating, having a say in the session - Expressing/communicating opinions and preferences
1.3 Collaborating with the individual concerning goals, music experiences, and musical instruments	7	4	7	4	5.5	3	- Dependent on rapport: do they feel comfortable collaborating? - Difference between choice and collaboration? - Choice offered but not always made
1.4 Being emotionally involved in the music	2	6	3	1	3	5	- Dependant on rapport - Song selection/choice - Emotional attunement - Clearly defining this category more?
1.5 Acknowledging the person's musical identity and preferences	7	6	7	7	6.75	1	- Parents/caregivers helped - Rapport dependent as well
2. Essential but not Unique Therapeutic Principles							
2.1 Engaging the person in music interplay (such as musical improvisation, creating songs, playing pre-composed music or listening to music)	5	4	7	4	5	3	- Considering different styles of self-presentation as musical interplay - Receptive/listening to the music? - Directed/prompted vs. self-initiated musical interplay

2.2 Acknowledging and encouraging musical skills and potentials	6	4	7	6	5.75	3	- Encourage any style of self-presentation/participation - Improvisation: reflection, bringing interactions into the music
2.3 Reflecting verbally on music and musical interplay	6	5	7	6	6	2	- Musical and/or verbal comments (reflecting it in the music)
2.4 Listening and interacting empathically	6	6	5	4	5.25	2	- Emotional and musical attunement - Acknowledgement of emotions may be missed sometimes - Providing space for emotional expression and empathic responses?
2.5 Tuning into the person's musical expressions	6	4	6	3	4.75	3	- Explicitly music or not, bringing those expressions into the music.
2.6 Establishing a strong and trusting rapport with the person	6	5	7	4	5.5	3	- Difficult to measure - Takes more than 7 sessions to build this? - Acceptance of the individual and whatever they enter the room with or as - Resources: such as bringing in magazines, sending home song books, or sending videos in place of sessions missed - Impact on promoting self-determination?
3. Acceptable but not Necessary Therapeutic Principles							
3.1 Sharing one's own experiences	0	1	0	2	0.75	2	- Didn't happen very often
3.2 Having music as the primary goal of therapy	3	4	7	4	4.5	4	- Sometimes the goal was emotional regulation, facilitating emotional expression, and/or providing individuals the space to be comfortable and expressive
3.3 Reflecting verbally and musically on problems	2	6	2	3	3.25	4	- Occurred when difficulties or problems occurred in sessions, such as: anxiousness, nervousness, having a bad day, new experiences
3.4 Teaching instruments/music	0	0	0	0	0	0	- Did not happen.

4. Not Acceptable - Proscribed Therapeutic Principles	
4.1 Neglecting the person's strengths and potentials	- How they feel vs. what I (therapist) expect or want to happen - Unconditional positive regard and acceptance.
4.2 Having total control over the session's contents	- Power roles: me (MT), individual, and the caregiver/parent - Is rapport needed to collaborate? - Individual-informed choices by me (MT), when individual is not in control
4.3 Avoiding emerging problems and negative emotions	- Acknowledging and accepting the individual no matter how they enter the room.
4.4 Directing in a non-collaborative style.	- Choice vs. collaboration?
4.5 Disregarding or ignoring a person's preference or need	- Distinction between boundaries vs. disregard of need/preferences: acknowledging the choice but not disregarding the choice.

Note. This table presents reflections on the therapeutic principles, with the total number of occurrences that each principle happened during over the course of the study for each individual. Averages of each principle, range of occurrences across individuals is also presented, as well as common comments that occurred in the reflections from each individuals' session.

Unique and Essential Therapeutic Principles

A couple of the principles in the “Unique and Essential” category that were almost homogeneous were principles 1.1: *Focusing on the person’s strengths and potentials* and 1.5: *Acknowledging the person’s musical identity and preferences*. My reflections from principle 1.1 were related to the acceptance and expectations with which I came into the sessions for each individual. Additionally, I thought about how I was providing the individual with the space to explore and express those strengths. Regarding principle 1.5, acceptance was also noted as an important consideration when thinking about the type of music to include in sessions. Parent and caregiver presence in the sessions helped be a resource for me to discover and find their most preferred and familiar songs. Several other principles in the category occurred frequently throughout sessions.

Principle 1.4: *Being emotionally involved in the music* was both noted to have occurred less frequently and had the largest range in occurrences among individuals. From the analysis, session reflections and comments contained being unsure of what exactly qualified as being “emotionally involved in the music”. For some individuals, like Nick, who was distressed during several sessions, the opportunity to incorporate emotional/musical attunement and emotionally relevant songs happened quite often. For individuals like Sean, there was a clear need to address this during his sessions; however, there appeared to be a disconnect between the songs and activities he was comfortable with during sessions and making them relevant to his current emotional state. Other comments reflected the potential impact of rapport building and development on this category. I reflected that perhaps with comfortability, trust, and relationship, the individuals would begin to feel more comfortable expressing themselves in their musical interactions and choices.

Essential but not Unique Therapeutic Principles

The principles in this category were diverse in how often they were recorded during sessions, differing between individuals. There was not a clearly homogeneously represented principle nor a significantly larger range in any one of the principles. However, some themes did emerge in a few of the principles that can be elaborated upon.

The principles 2.3: *Reflecting verbally on music and musical interplay* and 2.4: *Listening and interacting empathically* both had close ranges and were the closest to being homogenous. Both principles had comments reflecting on providing space for the individual to express and explore themselves, as well as bringing those expressions into the music. While principle 2.3 specifically states "reflecting *verbally* on music and musical interplay", interplay was occasionally musically rather than verbally reflected upon. My comments questioned whether that was related to principle 2.4, which was focused on interacting empathically, accepting, and acknowledging those expressions through attunement, rather than just verbally validating them.

Other principles in this category discussed musical interplay, interactions, and expressions, as is listed in principles 2.1, 2.2, and 2.5. Several of the individuals who participated in sessions did not participate in playing musical instruments or singing very often. Therefore, I wondered about what this boundary was considering: Do receptive interventions and listening have a place within this principle? What about different styles of self-presentation, and interplay? Do I consider an individual smiling in response to a song "musical interplay"? As the study progressed, I began to document all types of interactions for these principles, whether the individual vocalized the melody or moved magazines around on the floor. I also attempted to acknowledge and encourage these interactions by

musically reflecting and/or singing about the individual's actions using improvisational techniques.

Principle 2.6: *Establishing a strong and trusting rapport with the person*, had modest range after analysis. One individual, Samantha, had received clinical services with me in the past year, while this was my first experience working with the other three individuals. A comment about the development of trust and rapport was recurring throughout most of the individuals' sessions, specifically questioning how to measure rapport and how long it takes to "establish a strong and trusting rapport". It felt like some individuals developed trust in the music therapy process and with me quickly, as with Austin, but others took a while longer. Because of the length of time required to develop rapport, I wondered how this impacted the individuals' comfortability to practice self-determination. Although the sessions took place over a short period of time, I attempted to focus on rapport beyond the music therapy session by providing resources, like short, recorded sessions when sessions were missed or cancelled, creating activity songbooks, and bringing magazines into the sessions.

Acceptable but not Necessary Therapeutic Principles

While principles for this category were represented differently for each individual, principles 3.1 and 3.4 appeared to show up similarly across individuals. Principles 3.1: *Sharing one's own experiences* and 3.4: *Teaching instruments/music* occurred the least often, with principle 3.4 never occurring during these sessions. Principle 3.1 occurred a few times per session, typically when relevant to discussions between me, the individual, and their parent/caregiver and to build rapport. For example, sometimes I shared my own experience with the anxiety and nervousness that comes with new experiences, places, and people with Nick and Sean.

Principles 3.2: *Having music as the primary goal of therapy* and 3.3: *Reflecting verbally and musically on problems,* occurred more homogeneously for some individuals than others. For principle 3.2, music operated as the main goal of the sessions as that was their interest. Particularly for Samantha, singing, choosing songs, and playing instruments was her focus during sessions. For other individuals, sessions tended to vary from primarily goals with music to emotional expression, social interaction, collaboration, or autonomy. Likewise, principle 3.3 was more often addressed with individuals who expressed more distress or problems than those who did not. Nick often exhibited anxious and self-injurious behaviors; therefore, attention and empathy was provided to these specific challenges. For others, this principle occurred whenever a problem or discomfort did emerge in the session, which was not very often for some.

Not Acceptable - Proscribed Therapeutic Principles

For the Not Acceptable principles, reflections were coded for themes across individuals' sessions. Reflections on these "not acceptable" principles were mainly related to my therapeutic presence, power dynamics, control, and the meaning of collaboration versus choice. Principles 4.1: *Neglecting the person's strengths and potentials* and 4.3: *Avoiding emerging problems and negative emotions* involved me questioning whether I had welcomed and accepted the individual as came to the session, not how I wanted them to be engaged. I noticed that these principles weighed heavier on my mind throughout initial sessions but eased out as I learned more and developed relationships with the individuals.

Principles 4.2: *Having total control over the session's contents*, 4.4: *Directing in a non-collaborative style*, and 4.5: *Disregarding or ignoring a person's preference or need*, had similar themes of power dynamics, control, and collaboration throughout my reflections.

I often reflected on what it meant to have "total control", and if individuals chose not to collaborate, choose, or provide feedback, if that meant I was in total control. During a session with Nick, I commented that I felt I was not totally in control because I was choosing songs based on what I knew he enjoyed. Does this informed choice take the place of control?

Also, I reflected on how power dynamics played a role in having control and being collaborative. I questioned who was in power during our sessions, and whether the individual actually felt they were collaborating within the space. I provided a lot of choices and opportunities to choose songs, but choice did not always feel collaborative: sometimes it felt forced. There were situations when the individual did not make a choice when it was provided, they explicitly chose not to have an answer. There were other times where individuals requested a preference of a song, but I had to have boundaries as a therapist. Regarding principle 4.5, I wondered if this meant I was disregarding their need or preference. In these situations, I attempted to acknowledge anytime a preference or need was made but had to be put aside for the moment.

Journal Reflections Results

As the music therapist and the primary investigator, the journal focused on my own reflections and perceptions of the process of leading these sessions while considering self-determination theory, affirmative and social models of disability, and humanistic perspectives. From the journal, three main topics emerged: reflections on the therapeutic relationship, being *with* and not doing *to*, and power in the music therapy session.

The Therapeutic Relationship

Reflections on the therapeutic relationship between the client and me were about the importance of rapport, acceptance, and trust. Questions arose about what it meant to practice

with relationship and rapport in the forefront of the therapeutic process: when to promote comfortability, provide challenges, and push boundaries a little bit. Most reflections were reminders and reflections that acceptance of the individual, empathy, and an unconditional positive regard were central to this relationship-driven process. Similarly, questions arose about why it was sometimes difficult to empathize and provide some responsibility to the individual, and what that said about me as a therapist and a person.

Similarly, I reflected on what it meant to accept and validate a person the way they come into the room. Accepting how the individual presented, their emotions, their actions, their feelings related to new experiences, people, and environments. Additional questions popped up, like “Am I *always* receptive and open to accepting emotions?”, “Am I addressing and validating the individuals’ emotions?”, and “Am I more concerned with doing things for and to individuals than I am concerned with being present and supportive?”. By accepting individuals and focusing on developing my rapport with them, I noticed that I had to come to the session with fewer expectations and accept within my own role that I did not know everything about the individual and what to do. In this sense, it is my role as the music therapist to accept the individual as their own expert and learn from them.

Being With, Not Doing To

Following the topic of acceptance came the reflection and distinction of not always *doing* but thinking more about *being with.* In the journal I reflected on observations of my own tendency to put value and qualities on different types of interactions and participations. For example, if the individual did not engage with the instruments in a way I was expecting, I questioned what I was doing wrong and what I needed to do better. I expected myself to come up with an “answer” or “response” to the individual to help them engage and interact

with the music. If they were upset or distressed, what was I doing that was not enough? What could I do to help the individual not be so distressed? I reflected that it did not feel good to be in the space with a distressed individual and not know what to do or be able to do anything.

Among these journal reflections I began to question why I was getting stuck on questions like "What should I do?" and "What would help?" What did this desire to *do to and for* people say about me and my own needs? Was I okay with the vulnerability that comes with depending on therapeutic presence and *being with* rather than depending on structured activities and *doing to?* My reflections emphasized a desire to focus on "being" more than "doing" and to allow space in my sessions. I reminded myself of these ideas frequently and reminded myself to have faith and trust in myself and the process.

Reflections on Power

My final reflections from my journal focused on the topic of power in the sessions. Bringing back the topic of not knowing and wanting to learn from the individual, I questioned what role this played in the power dynamics of my sessions. There was a vulnerability with displaying that I was learning along the way, that it was the individual not the therapist who was the expert, and to ask for suggestions, advice, and help from parents and caregivers.

Other reflections on the power dynamics revolved around me, the individual, and the caregiver/parent and our roles in promoting self-determination. I wondered how our power dynamics played out. Were we all equal individuals? Who was in control? Was there an unequal distribution of power at times? The focus on self-determination and collaboration often meant I tried to give power and responsibility to the individual, but I questioned whether this happened and whether it was beneficial. And then, how did including

parents/caregivers in sessions impact power? Did the individuals feel comfortable being responsible and acting self-determined with their parent in the session? I wondered if the individuals ever felt like the parents were intruding on their space and time to be independent.

Finally, how did the parent's/caregiver's presence affect me as a therapist? In my journal I noted that with the parent's and caregiver's presence, there was a sense that I had to prove myself, my skills, and the benefits of music therapy to them. I felt I had to be knowledgeable about what I was doing and that I had the answers and responses to problems. This was exacerbated by receiving comments sometimes about things I could do better and questions about my profession and my job prospects. In these self-reflections I discovered that I had to practice and implement my own sense of self-determination. I had to trust my own instincts and the process of learning, but also advocate for my own needs, my own understanding, and ask for guidance and support.

Summary

The above results are a collection of analyzed session notes, interviews about sessions, review of the treatment guideline principles, and my personal journal reflections on the experience. Through session notes, themes about communication, styles of self-presentation, parent/caregiver involvement in the session, and contextual events were addressed. Interviews with individuals and their parents/caregivers addressed topics about preferred activities, how the individual liked the music therapy experience and making choices, and how these made them feel. While some individuals shared that they enjoyed the music experience and making choices, others expressed they did not like them, expressing emotions of frustration and fear. Reflections upon the treatment guidelines and therapeutic

principles demonstrated areas that needed to be addressed (such as being emotionally involved and reflecting on the musical experience) and principles that were homogenous for most individuals (such as focusing on the person's strengths). Considering elements of interplay as well as reflection on the musical properties of sessions were also observed in varying levels across individuals' sessions. Finally, my own journal reflections centered on themes of the therapeutic relationship, power in the music therapy session, and the idea of being *with*, not doing *to*.

CHAPTER 5

Discussion

In this research, I discovered and considered ways in which music therapists can promote self-determination in individuals with I/DD who communicate extraverbally, which was presented above through analysis of session notes, individual and parent/caregiver interviews, personal reflections, and reflections on a treatment guideline of principles. In the following chapter, I will discuss these findings in context of the initial research questions as well as look at the universality of self-determination and limitations of this study.

Research Question 1: In what ways can a music therapist promote self-determination for individuals with I/DD who communicate extraverbally?

Communication

Several themes that emerged from the results discussed different aspects of how to promote self-determination in these music therapy sessions. The first theme to be discussed is related to respecting different forms of communication and participation in the sessions. For the individuals in this study, communication included technology, gestures, vocalizations, and affect. As rapport and relationships were built, I learned how each person preferred to communicate, and learned more about their specific style of communication. It was important to understand, accept, and respect each person's preferred style of communication and bring it into the music therapy session in various ways: Sean picking songs using PowerPoint slides, Samantha singing her song choice, or Nick looking to the caregiver in the room to let them have a choice within the session.

Participation or Self-Presentation

Similarly, recognizing and honoring how each individual engaged and participated in the music experience was essential to promoting self-determination. Every music therapy experience looks different, across and within each population and developmental stage. As with communication, I recognized how and how much each individual desired to engage with the music in the session. Varieties of participation included singing preferred songs to indicate song requests making eye contact to indicate a choice between two songs, moving instruments and objects across the, and listening while favorite music videos were played on the iPad or laptop. Each individual's self-presentation in music looked different, and moments of engagement and participation varied based on how they interacted with the music: Did they smile to the song? Are they tapping to the beat of this song? I questioned whether principles from the guidelines about musical interplay and interaction had to relate only to musical interactions and started to consider any type of connection to me or the music as a form of participation and interplay.

Stige's styles of self-presentation (2009) call into question the different ways we perceive engagement within sessions. In a way, the style of self-presentation differs from group to group and individual to individual. By contextualizing the people in this study's musical self-presentation, I began to view their participation as valid no matter how it appeared in the session. The idea that participation does not just have to be conventional or adventurous, but the individual may choose or prefer to participate in a "non" or silent way. Additionally, respecting and accepting the way the person communicates or participates in the session can increase competence, which is one of the three criteria of self-determination theory (Ryan & Deci, 2004). By individualizing the music experience and catering to a

person's specific style of interaction, they may feel confident and comfortable to engage, explore, and express themselves more fully.

Being With, Not Doing To

Another major theme that emerged from personal reflections and reflections on the therapeutic guidelines related to a shift of thinking from "what" to "how". Many of my reflections about the process related to addressing this idea of needing to know *what to do*: what interventions would be helpful, what song would the client best like to hear, what instrument would they enjoy interacting with. However, reflecting upon certain therapeutic principles related to rapport, empathy, and acceptance made me consider how much more essential my therapeutic presence and being was than what I was doing. The shift in focus during sessions became, "*How* am I *being,"* and less, "*what* am I *doing*."

This shift in focus also spoke to the relational component of the therapeutic interaction. For humanistic perspectives in therapy, the relationship drives the process. It can provide a safe and familiar container through which individuals can be encouraged to explore and express themselves, as is indicated in client-centered therapeutic practices like play therapy (Landreth, 2012). Within music therapy, focusing on an individuals' resources of strengths and competencies is also often drawn upon from resource-oriented approaches (Rolvsjord, 2016; Swaney, 2020). Additionally, self-determination theory indicates that relatedness can help promote self-determination by providing a sense of connectedness and safety (Ryan & Deci, 2004). Thus, rapport and relationships are critical in promoting self-determination for anyone, but especially with individuals with I/DD who may take longer to develop that sense of trust (Cameron, 2017).

The therapeutic relationship within humanistic perspective is related to unconditional positive regard, genuineness, and congruence (Corey, 2005). As mentioned above, acceptance of the client is an essential part of promoting self-determination in encouraging not only the relationship but also competence (Ryan & Deci, 2004). Additionally, being empathetic with the individual's current needs and emotions is pertinent. As noted in my reflections of the therapeutic principles, throughout the study I recognized a need to reflect on my own empathic responses musically, verbally, and with my body language. Empathy, genuineness, and acceptance needed to take place in my words and be a part of my emotional and musical presence as well.

Client-Directed Approach and Choices

Similar to the idea of respecting and accepting communication and participation, approaching the sessions from a client-directed perspective and providing choices was a primary focus of mine throughout sessions. Following each session, my reflections from the therapeutic guideline principles addressed different aspects of collaboration or choices throughout sessions. I provided opportunities for people to have a say in what happened in their music therapy experience and to direct it and explore however they needed.

Other opportunities for individuals to have a say in their music therapy experience included using client feedback or interviews. This provided the opportunity for me to assess whether the individual enjoyed the instruments or experiences, whether they liked making choices, and whether they liked the music therapy experience. For instance, Sean indicated that he did not enjoy the music therapy experiences and expressed a range of emotions he felt when he came to sessions. Similarly, Nick did not directly indicate a response to whether he enjoyed sessions, but his caregiver indicated that there was both frustration and enjoyment

throughout the process. Since the time frame for this study was short and interviews were completed at the end of the study, individuals' feedback did not directly impact their music therapy experience. However, providing an opportunity for individuals in this study to express their opinions allowed me to understand more about their preferences and opinions, which I may not have known otherwise.

While there were opportunities for expression of choice and exploration, I also discovered that sometimes these opportunities for client freedom were not always preferred. In his interview, Nick indicated that he did not like making choices in music, and his caregiver expanded on this by stating that expectations of making decisions and participating in certain ways led to increased frustration and anxiety. Sean also experienced distress in the music therapy setting without some familiarity and structured musical experiences. In his case, music therapy sessions became increasingly more structured and familiar, providing opportunities for Sean to choose his own preferred music videos while challenging him with new versions of his favorite songs.

The idea of client-directed or self-directed music therapy relates to another criteria of self-determination theory: autonomy (Ryan & Deci, 2004). Encouraging freedom to choose and select songs, instruments, and types of engagement throughout the session encouraged individuals to have autonomy and ownership of their own music therapy experience. Also, gathering feedback and interviews about the music therapy sessions allowed individuals to share their opinions, preferences, and concerns.

However, it was also evident that a certain degree of structure was needed for some people to be more successful in making choices and decisions and having that autonomy during their sessions. Supporting this idea, Jang et al. (2010) stated that autonomy support

and structure were positively correlated. Providing the safe space for individuals in this study to make choices in a familiar and comfortable way was necessary for them to practice that autonomy and self-determination component, especially since rapport may not have been built during these few sessions. As mentioned in the previous section, rapport can serve as a safe container in which the client can work autonomously and explore. However, sessions took place over the course of 7 weeks, so rapport may not have been sufficiently built and thus not provided a safe container of exploration. Therefore, structure may be needed to provide this safety when rapport has not yet been sufficiently established. For this reason, it is important for music therapists to recognize their responsibility to provide safe and familiar structures for making decisions and choices in music therapy. If music therapists can provide safe and familiar ways for individuals to practice decision-making, choice-making, and self-awareness, music therapy may help promote autonomy and thus self-determination.

Experience with Self-determination. It may also be interesting to consider whether individuals who do not have much experience with practicing self-determination feel comfortable when opportunities to make choices, decisions, and be autonomous are provided. In their interviews, Sean, Samantha, and Nick all responded differently than their caregivers and parents to whether they make choices at home, in the community or at school. Sean and Nick both initially indicated that they did not make choices at home, in the community, or at school, but their parent/caregiver stated that they did. Nick's caregiver stated that Nick makes "familiar choices" at home and in the community. Samantha indicated that she did make choices at home and in the community, while her parent explained that most of her choices were music related.

Whether or not the individuals agreed with their parent/caregiver about making choices at home, we should consider the individual's perception of making those choices an important factor when promoting self-determination. If the individual does not perceive themselves to be in control of their life or session or have opportunity to make choices, our steps toward client-directedness should be reevaluated. In a study by Shogren and Broussard (2011), individuals with I/DD shared frustrations of barriers towards their ability to be more self-determined, including differing perceptions about their own abilities and capacity towards self-determination. These biases and misconceptions can place barriers towards an individual's self-determination journey unless we reevaluate and seek their perceptions and opinions on their own situation.

Research Question 2: How do individuals experience self-determination outside of the music therapy session?

Through interviews and conversations with individuals and their parents/caregivers, some insight was gained as to regular opportunities for practicing self-determination. Most individuals and their parents/caregivers shared they made choices outside of sessions that they considered "familiar" and structured, either using communication devices, routines, or musical choices, as was the case with Nick, Austin, and Samantha. However, parents and caregivers seemed to have different opinions on how individuals experienced these choice-making opportunities in their daily life, as some clarified that the individuals' provided choices were limited in scope.

Beyond this, measuring how individuals experienced self-determination outside of music therapy was difficult. While including parents and caregivers in the music therapy sessions provided some insight into how others interacted with the individuals on a regular

basis, the context of these opportunities was limited to a small amount of time in which I was able to observe this interaction in a specific setting. For instance, some interactions with parents placed boundaries on the individuals' requests or choices, such as with Samantha's parent declining her song request. In other ways, parents were able to be supports and communication partners, demonstrating how they typically offer choices and interact with their client, like with Sean's parent offering verbal validation and physical stimulation to Sean when he was anxious. Addressing this question was somewhat challenging, as my encounters with these individuals were limited to seven music therapy sessions. However, outside of the session, it was difficult to expand on the frequency and types of opportunities people with I/DD must practice self-determination.

One incident occurred that gave some insight into the perceptions of people with I/DD when they are emotionally distressed. When a police officer showed up to Nick's last music therapy session while he was emotionally distressed, the interaction made me pause and question the rationale behind someone making this phone call and the frequency of how often this occurs. For Nick, this emotional distress communicated and expressed his frustrations and anxieties at that moment, but for others, it was perceived as a danger. Dangerous enough to call a police officer. I questioned how this is different for disabled versus nondisabled people. If I, a not visibly disabled white female, was outside crying, would it still cause concern in strangers? Would expressing my emotional state warrant a phone call to the police? This situation was a striking image of my own privilege and ableism in action.

Thinking about how people with I/DD who communicate using methods other than verbal experience self-determination outside of a music therapy or clinical setting, it is

necessary to consider these biases, stereotypes, and fears that exist in society. The fact that one individual received a police visit based on how he was expressing his emotions shows a need to educate about the disability community.

Research Question 3: What social change needs to occur as a part of or product of these sessions?

From the results of this study, I want to propose several suggestions for social changes we can work towards promoting self-determination in individuals with I/DD who communicate extraverbally. These suggestions are primarily focused on encouraging social change in music therapists and the music therapy profession, but they may also be applicable beyond the scope of our professional work.

Active Engagement in the Therapy Experience

In promoting self-determination, it is helpful to provide those who are in music therapy with the opportunity to share opinions and feedback on their own music therapy experience. Often, we give individuals a choice of instruments, songs, or experiences, but how often do we inquire about their experience of the music therapy process? Especially for individuals with I/DD, this may be an area that is overlooked. Moving forward, it could be beneficial to ask how the individual feels about the music therapy experience through interviews, assessments, or informal routine check-ins. Additionally, having individuals with I/DD more actively involved in their music therapy process, goals, and even in research could be helpful for them as they work towards self-determination and providing personal insight into the profession (Baines et al., 2014).

Including service-users or clients in research is becoming more common in the field of music therapy, especially with mental health populations (Baines et al., 2014). Client

involvement and cooperation in methodology is an element of participatory action research; however, this approach is not often used with individuals with I/DD, particularly if they communicate extraverbally (Stige & McFerran, 2016). There are some studies in music therapy literature that focus on including individuals with I/DD in research design and studies (Noone, 2018), but there is a need for more inclusion in research. Additionally, Stige and McFerran (2016) stated that including individuals who communicate extraverbally in music therapy action research could be a unique approach and allow their perspectives to be heard. It is also critical to reflect upon including individuals who communicate extraverbally and the purpose that plays in the study.

For the purposes of this study, client involvement took place through client-directed sessions and opportunities for individual feedback via interviews. As with action research, reflexivity, flexibility, and evolution was a critical component of this process. Through journaling and reflecting upon the therapeutic guidelines, I often considered how I was giving individuals the opportunities for active client participation and engagement. My reflections led to questions, like how I was giving opportunities for autonomy and self-determination and the feedback I was receiving from the individuals in the study. I also reflected upon whether these opportunities for autonomy were conducive to my agenda in the study or because the individual wanted to have ownership over the session.

Types of Choices

When thinking about self-determination, it is often assumed that providing choices helps the individual become more self-determined. However, the types of choices and the situation in which they are provided can affect how an individual exhibits their own determination. Additionally, choice-making is only one aspect of self-determination

(Wehmeyer, 2005). Sometimes providing these small, safer, familiar options of choice allows the individual to best make the decision, as some people with I/DD need smaller, safer, and more familiar choices. Additionally, it is often our responsibility as music therapists to provide structure for those who need it. This structure may allow individuals a safe space and container for which to explore their choice and decision-making abilities. If we want to promote self-advocacy, autonomy, and/or self-determination, we must consider what structures and supports the individual needs to be successful.

However, it is also important to consider whether these simpler, safer, and familiar choices are actually promoting self-determination. Is the idea of a forced choice between two options still allowing the client to best advocate for their preferences or needs? In thinking about self-determination, it can be helpful to reflect on how we provide choices for individuals with I/DD who communicate extraverbally. Are most of our choices and decisions presented in just yes/no questions? Are individuals only making familiar decisions and not getting the chance to try out new opportunities for choice? Also, how often do individuals with I/DD get an opportunity to make increasingly more complex choices? Relying upon strict and forced choices may be helpful and safe, but it can also give the illusion of a false sense of autonomy or self-determination. Thus, we should continually reflect on how we are providing opportunities for self-determination, choices, or decision-making.

Rethinking Engagement and Self-presentation

It is especially critical for us as music therapists to rethink our expectations of engagement with people with I/DD who communicate using methods beyond verbal. As addressed above, respecting and accepting the whole individual as they enter the room is

critical. It is also necessary to reconsider what we think of as "successful" engagement and interactions in the music therapy room. People who communicate in extraverbal ways may not be perceived as engaged as those who are verbal; therefore, it is critical that we reframe and individualize what engagement means for each person who walks into the music therapy space. Additionally, we must reflect on those expectations with which we enter the room. How a music therapist perceives and expects an individual to engage in the music will color the way they understand the individual's abilities, growth, and uniqueness. Using resources like Stige's (2009) styles of self-presentation, we can work on reframing our perceptions of the client's participation and self-presentation.

Focusing on Rapport and Presence

From the results presented above, the relationship component of the music therapy experience was a key focus throughout this study. As relatedness is also listed among the criteria in self-determination theory, it is necessary to reflect upon this whenever working to promote autonomy, self-advocacy, or self-determination in the music therapy process. Therefore, it is paramount to stress the importance of rapport in music therapy with individuals with I/DD. While interventions, developmental, and behavioral approaches can be helpful in working towards various goals with this population, we also must focus on our relationship with individuals as another factor in the therapeutic process. Most of the research discussing rapport, relationship, and relatedness in music therapy is primarily within mental health populations. While focusing on rapport might be implied in music therapy literature with individuals with I/DD, it is not explicit nor as emphasized as developmental and behavioral interventions. Focusing on the therapeutic relationship in music therapy needs to be integrated into literature on individuals, adults and children, with I/DD.

It is also essential to consider our empathy within the relationships with people with I/DD, and how we as music therapists show this in the music and our presence with others. Incorporating and normalizing emotional expression in music therapy can help encourage individuals' self-awareness about their own emotional being and thus promote self-determination (Roth et al., 2019). Improvisation and music-centered approaches, such as DIR-Floortime, emphasize the relational and empathic component within these interactions (Carpente, 2012); however, empathy and relatedness have a place in all music therapy settings. It is important that we do not neglect to include this in our approach to therapy with individuals with I/DD.

Power in Music Therapy Sessions

Related to presence and rapport in therapeutic processes, it is also necessary to consider the power dynamics within the session, particularly when promoting self-determination. In the sessions involved in this study, there were three, or more, individuals involved in power dynamics: a music therapist, the client, and a parent/caregiver. This interaction led me to reflect upon who held the power and control in the session. Disabled individuals are often placed in positions without power, and especially so when they are extraverbal communicators (Bascom, 2012; Davis, 2013). As a music therapist, I already am placed in a position of authority, and certainly parents/caregivers also hold these positions as well. Keeping this in mind, we must reflect upon how we may hold power in the session.

Topics mentioned above can be essential into our reflections on the power in the music therapy session: presence and relatedness, as a music therapist; opportunities and respect for various types and styles of communication; valuing and accepting all forms of participation and engagement; opportunities for choice-making, decision-making, and

problem-solving. Reflecting upon these topics can be useful to bring up in professional supervision and personal self-reflection. Additionally, using tools like the Rolvsjord et al. (2005) therapy manual and therapeutic principles can help music therapists reflect upon these elements throughout sessions. Regardless of the mode you take to be self-reflective, this idea of reflexivity is centrally important when providing opportunities for people to work on self-determination in therapeutic settings.

Universality of Working on Self-determination

Throughout the process of this study, I reflected upon self-determination within the individuals I was doing music therapy with as well as my own self-determination as a human and music therapist. There were several opportunities throughout this process of trying new things, being vulnerable, and interacting with parents and caregivers that I found myself reflecting upon self-determination. Too often we assume that certain topics in therapy or education are reserved for those whom we provide services. This is not the case. The idea that I do not need to work on self-determination as a person is an ableist perspective, and quite limiting to my skill set as a music therapist.

During this process, I found that the reflections I took part in every week were helpful to think about my own concept of self-determination. This study was an especially vulnerable process, where I challenged my view and familiar perspectives of music therapy. Existing in this space of newness and vulnerability took a lot of courage, but it also caused me a lot of anxiety. I found myself questioning my ability, my reasoning, and my rights to conduct this study. But as I engaged in the reflexive processes, I found my courage and self-efficacy growing. The reflection processes and the support of my personal counselling and Guided Imagery and Music sessions allowed me to re-root and consider my own self-determination

and ability as a music therapist. It was through this process that I realized I was also promoting my own self-determination throughout the course of this study.

While our processes of self-determination may look different, we are still working toward a similar goal. We also must consider how often we are allowed to make our own choices, as nondisabled or disabled people. There are external or internal systems that may be hindering us from fully engaging in our daily choices, whether those are societal, interpersonal, or intrapersonal. No matter the hindrance of self-determination, we must understand that we are all on a journey towards self-determination. If we are to promote self-determination in others, we must recognize the need to promote it in ourselves.

Limitations

There were several limitations that appeared in this study. Such limitations include but are not limited to rapport, types of self-determination opportunities offered during sessions, parents and caregivers in sessions, and the ethics of imposing a theoretical perspective on individuals.

This study took place over the course of 10 weeks, during which each individual attended seven sessions total. I decided to provide a total of seven sessions due to several factors influencing session attendance and length: length of recruitment process, individuals' absence for vacations or other appointments, and the summer break ending. Seven sessions are a short amount of time for therapeutic rapport to develop and be established to provide a supportive environment of exploration and self-advocacy. It is possible that this shortened time frame did not allow for an appropriate amount of rapport to be established to fully support and provide opportunities for self-determination.

Additionally, it is necessary to note that choices provided may have been too complex or simple for certain individuals. The choices and opportunities for self-determination evolved as the relationship with individuals was built, and I continually learned how to best present options for each individual, such as providing two, three, or more options and whether to verbally explain the options. As with rapport, I may have not best provided choices and options for each individual, as I had not fully learned how they best receive and communicate choices. Also, the choices that were provided could be seen as being too deterministic or forced and not fully encouraging self-determination. This is especially the case when only two choices were offered to individuals. A pre-participation survey or interview may have been helpful to address these concerns and to appropriately prepare and provide choices that best matched the individuals' needs.

Another limitation could include allowing parents and caregivers to join music therapy sessions. While often they were a familiar and comforting presence in the room for individuals, it is possible that they did not feel comfortable making choices on their own while the parent/caregiver was also in the session. A parental/caregiver presence may have influenced the power dynamics of the session. It would be beneficial in future research to analyze the effects of having another person in the room and its effect on promoting self-determination. Additionally, my analysis of the session notes was reviewed by my thesis supervisor rather than doing a traditional member check with the individuals in the study. Gathering individuals' perceptions on my analysis would have been helpful as another level of the action research cycle.

Finally, it is necessary to acknowledge that I came to this topic with a humanistic and social/affirmative disability models perspective. It is possible, and likely, that all the

individuals who participated in the study do not agree with this approach. Especially for self-determination, parents or caregivers may have had cultural differences in understanding and promoting self-determination (Dileo, 2021). While no one in the study, parent, caregiver, or person with I/DD, explicitly indicated a difference in perspective or approach, it should be addressed that we must address the ethical considerations when approaching therapy with such perspectives. While we may not agree with the perspectives of others, we cannot force our own philosophical and theoretical perspectives onto our clients and their families.

Reflections on Action Research

The aim of action research is to engage in a reflexive, flexible, and evolving process to provide suggestions for social change (Stige & McFerran, 2016). This study used personal journaling and reflections upon therapeutic guidelines as means for reflection. Reflections on the therapeutic guidelines specifically prompted adjustments in how I approached sessions and the music therapy experiences each week. As both the music therapist and researcher, I was continually confused, frustrated, and enlightened by the reflexive process. It also allowed me to reflect upon my role as a music therapist, my philosophy and theory of music therapy, the well-being of the individuals with whom I was interacting, and the meaning of self-determination. Through these reflexive processes as well as interviews with the individuals in the study, themes emerged as needs for social change, within music therapy sessions and as a society. While the suggestions for change provided are individualized and may not be applicable to all people, they provide suggestions for the field of music therapy.

Recommendations for Future Research and Practice

As we move forward as a profession and continue to engage with theories of disability and definitions of self-determination, we should continue to address the whole

being of disabled individuals. Research is needed that addresses beyond the developmental and behavioral needs of individuals with I/DD, and focuses on the emotional, social, and self-advocating components of this population. Additionally, more research is needed that includes and addresses the potential growth for individuals who communicate extraverbally. Participatory action research may be an effective means to share the perspectives and opinions of individuals with I/DD. It could also be beneficial to include more research about the reflexive practices of music therapists as they work with individuals with I/DD and other disabilities. It is also critical that we consider ways to implement these theories of disability and differing models of music therapy into our clinical training programs.

Conclusion

Self-determination is a varied and complex term that focuses on awareness, intentional engagement, decision-making, and opinions of the individual. For individuals with I/DD who communicate extraverbally, self-determination and self-advocacy are important concepts that are often not addressed in music therapy literature. Music therapy can provide the space for individuals to explore themselves and their choices within a structured and potentially safe environment. As music therapists and society members, we must consider the opportunities we provide individuals to practice self-determination and the responsibility we must provide them in a structured and safe way. Additionally, music therapists should be reflexive in their practice with individuals with I/DD who communicate extraverbally. We must consider our role and power, the opportunities we provide, and our relationship with the individuals with whom we work.

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Appendix A

Consent to Participate in Research

Information to Consider About this Research

Self-Advocacy, Self-Determination, and Music Therapy,

Principal Investigator: Anna Laura McAfee
Department: Music Therapy
Contact Information: mcafeeal@appstate.edu. Phone: 479-650-7392
Melody Schwantes (Reid), Faculty Supervisor, ms18994@appstate.edu. Phone: (828) 262-8216

I am asking you, your child, or the person for whom you are a legal guardian to be in a research study. This form will tell you about the study procedures, risks, and benefits. By signing it, you are agreeing for you, your child, or the person for whom you are a legal guardian to be in the study. You can ask questions about the research at any time before you sign it. This process is called informed consent. Although the form is addressed to the person reading, if your child or the person for whom you are a legal guardian is being asked to be in the study, the form refers to them.

What am I being asked to do?

You are being invited to take part in a research study about how people ask for what they want and need in music therapy. This study will include participants diagnosed with intellectual and developmental disabilities. Self-determination is a person's ability to make choices and ask for what they need. If you take part in this study, you will be one of about 15 people to do so. By doing this study we hope to learn how people make choices ask for what they need and want during their music therapy sessions.

You will be asked to answer some questions about what you do in music therapy. There will be 7 questions. There may be some additional time to talk and give a longer answer if you want to share more information. This interview can happen just once. You can choose to take breaks between questions. If you choose to take breaks your interview can happen up to four times. It will not last longer than 10-15 minutes total.

What are possible harms or discomforts that I might experience during the research?

There are risks when taking part in research. There is a risk of a loss of confidentiality in this study. If this happened other people could find out your answers to the interview. The

researchers will protect your identity by removing your name from the information shared during interview. The researchers will use a code instead.

What are the possible benefits of this research?

There may be no personal benefit from your participation. The information gained by doing this research may help other people in the future. People can learn from hearing what you share about making choices and asking for what you want and need in music therapy sessions.

Will I be paid for taking part in the research?

We will not pay you for the time you volunteer while being in this study.

How will you keep my private information confidential?

We will make every effort to prevent anyone who is not on the research team from knowing that you gave us information or what that information is. The researchers will protect your identity by removing your name from the information shared during interview. The researchers will use a code instead. The information you share will be protected under the full extent of the law.

The information gathered may be used in future studies. The names and other information that could identify you will be removed. Information or quotations from the transcript will be published. The researcher will not use your name. The information gathered from the interview and any recordings will be kept by the researcher for 3 years after the interview and then destroyed.

Who can I contact if I have questions?

The people conducting this study will be available to answer any questions concerning this research, now or in the future. You may contact the Principal Investigator at 479-650-7392. If you have questions about your rights as someone taking part in research, contact the Appalachian Institutional Review Board Administrator. They can be reached at 828-262-4060 (days). You may also contact them through email at irb@appstate.edu or at Appalachian State University, Office of Research and Sponsored Programs, IRB Administrator, Boone, NC 28608.

Do I have to participate? What else should I know?

Your participation in this research is completely voluntary. If you choose not to volunteer, there will be no penalty. You will not lose any benefits or rights you would normally have. If you decide to take part in the study you can still decide at any time that you no longer want to continue. There will be no penalty and no loss of benefits or rights if you decide at any time to stop participating in the study. If you decide to participate in this study, let the research personnel know. A copy of this consent form is yours to keep.

This research project has been approved by the Institutional Review Board (IRB) at Appalachian State University.

Check here if you do NOT wish for your interview to be video recorded __________

____

Participant's Name (PRINT)

____

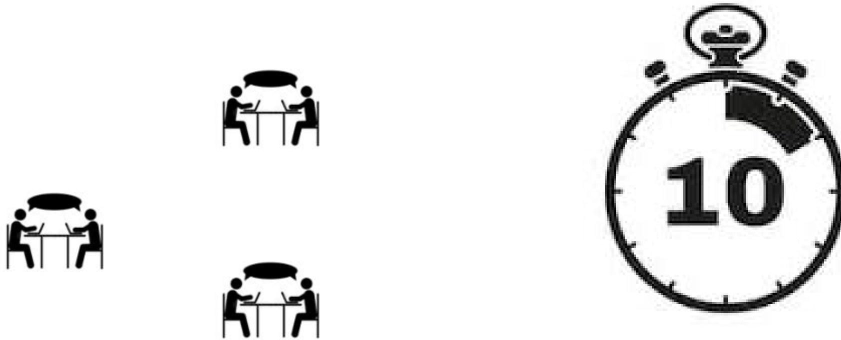
Guardian's Name (PRINT) Signature Date

Appendix B
Visual Assent Form

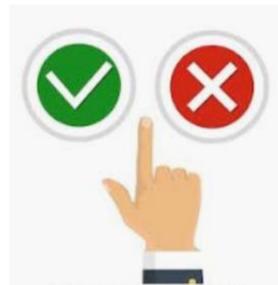
You are being asked to participate with me in an interview. You can say Yes or No. Whatever you choose is OK. This interview may happen up to 4 times if you choose to take a break in the middle and will last about 10 minutes. It is about your time in music therapy and how you make choices and decisions. By answering these questions, you will help other music therapists learn how someone might tell them what they want from music therapy. Your interview will be recorded using a video camera or by writing your answers down. Your name will not be connected to your answers to the questions. You will be asked to answer some questions. You can choose not to answer questions. You can choose to be finished answering questions at any time. Take the time you need to make your choice. Ask us any questions you have. You can ask questions any time.

If you would like to answer the questions you can sign your name or make a mark on this page to show that you want to participate and share about what you do in music therapy.

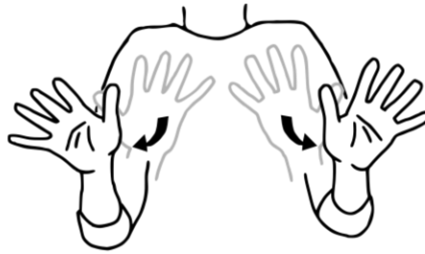
You are being asked to be part of an interview.



This interview may happen more than once and will last about 10 minutes.



You will be asked to answer some questions. You can choose not to answer questions.



You can choose to be finished answering questions at any time.

Appendix C
Interview Questions and Guide

1. What happened in music therapy sessions?

   Prompt: What kind of activities did we do? Did we play together or alone?

2. How did you feel playing instruments?

   Prompt: (can provide choices of confident, happy, sad, angry, alone, okay, excited, etc.)

3. What was your favorite instrument to play?

   Prompt: How did you feel when you played that instrument?

4. Do you make choices in music therapy?

   a. *Yes/No*

   Prompt: Do you choose songs? Instruments? Activities?

5. Did you like choosing what to do in music? (follow up to question 4)

   Prompt: (follow up question) How did it make you feel? Did you want to make more choices? Do you get to make choices/decisions outside of music therapy?

6. Did you like making music together or alone? (follow up to question)

   Prompt: How did it make you feel to play music together/alone?

7. Is there anything else you want to tell me about your music therapy that we haven't already talked about?

   a. *Yes/No*

   Prompt: Is there something you would change? What is your favorite thing to do with your music therapist? What is something you have learned (about yourself or just in general) in music therapy?

Appendix D
Therapeutic Principles Guidelines

Unique and Essential Therapeutic Principles

1. Focusing on the person's strengths and potentials
    1. The music therapist will promote abilities, tasks, and skills that are the client's strengths; encouraging areas of growth that the person shows interest in
    2. *What this is not*: continual praise or ignoring therapist's or client's boundaries.
2. Recognizing the person's competence related to their therapeutic process
    1. Similar to focusing on strengths, the music therapist will bring in instruments, songs, and activities that the client is interested in and does well with. According to the self-determination theory, this is related to the felt sense of confidence that the client may exhibit when they feel they do something well.
    2. *What this is not*: Only doing things that the person feels comfortable and confident with and not challenging the client
3. Collaborating with the client concerning goals, music experiences, and musical instruments
    1. The client will choose music experiences, instruments, and skills that they would like to work on.
    2. *What this is not*: Only doing what the client chooses to do and the therapist always never suggesting or providing choices.
4. Being emotionally involved in the music
    1. Encouraging emotional exploration and discussion through improvisation, singing, and music making; music therapist plays with dynamics and musical nuances to model emotions.
    2. *What this is not*: Only playing "happy" or "sad" songs; over-emoting or "performing" songs.
5. Acknowledging the person's musical identity and preferences
    1. Providing space for the client to choose musical instruments and songs; music therapist brings in a variety of styles to ensure preferences are accurate
    2. *What this is not*: Assuming the client's music preferences/cultural identity.

Essential but not Unique Therapeutic Principles

6. Engaging the person in music interplay (such as musical improvisation, creating songs, playing pre-composed music or listening to music)
    1. Playing songs together synchronously and through call-and-response play; recreative, compositional, and improvisational music making
    2. *What this is not*: the music therapist taking a primary role in all music making and only directed music making
7. Acknowledging and encouraging musical skills and potentials
    1. Verbally and extraverbally validating the client's musical skills, unconditionally with positive regard and providing opportunities for the client to expand upon musical skills
    2. *What this is not*: avoiding instruments that the client is unfamiliar with
8. Reflecting verbally on music and musical interplay

   1. Music therapist communicating with client about music through emotional expression and choice-making and providing opportunities for client to express preferences and perceptions in order to promote self-awareness
   2. *What this is not*: music therapist only commenting on their own perceptions of the music

9. Listening and interacting empathically
   1. The music therapist will provide space for the client to communicate and musically explore on instruments; The music therapist will also reflect and validate the client's emotions both musically, verbally, and extraverbally.
   2. *What this is not*: assuming client's emotions or perceptions at the moment

10. Tuning into the person's musical expressions
    1. The music therapist will listen to and acknowledge the client's music making using improvisation techniques (mirroring, reflecting, holding, etc.); noticing how the client plays instruments and music-making (emotions or dynamics)
    2. *What this is not*: always reflecting the client's musical expressions; only focusing on what the client plays

11. Establishing a strong and trusting rapport with the person
    1. The music therapist will use a warm affect and welcoming disposition with the client; finding common interests with the client; use an unconditional positive regard when interacting with the client
    2. *What this is not*: The music therapist failing to establish and maintain boundaries.

Acceptable but not Necessary Therapeutic Principles

12. Sharing one's own experiences
    1. If applicable, the therapist can divulge useful information that the client may find useful or that may promote a therapeutic relationship (i.e., sharing musical experiences or preferences)
    2. *What this is not*: sharing personal information often

13. Having music as the primary goal of therapy
    1. Focusing on playing music and a variety of music in the session; the interaction in the session primarily involves music
    2. *What this is not*: only interacting with music, ignoring or avoiding verbal discussion

14. Reflecting verbally and musically on problems
    1. If a problem comes up within a session, the client can choose whether or not to discuss and explore the situation with the music therapist musically and/or using an AAC device
    2. *What this is not*: The music therapists choosing to focus on the problem during the session without the client's consent; processing every problem that comes up

15. Teaching instruments/music
    1. The client chooses to focus on playing and learning music during sessions
    2. *What this is not*: music therapist only focuses on teaching music or instrument playing without discussion emotional content or awareness

Not Acceptable - Proscribed Therapeutic Principles

16. Neglecting the person's strengths and potentials
    1. Approaching therapy only focusing on need areas of potential growth or "improvement"
17. Having total control over the session's contents
    1. The music therapist chooses all of the music experiences, instruments, and songs
18. Avoiding emerging problems and negative emotions
    1. Only discussing positive emotions and insisting that only positive feelings are welcome in the session.
19. Directing in a non-collaborative style.
    1. The music therapist does not provide opportunities for the client to communicate preferences, choices, perceptions, or areas of growth during the music therapy process.
20. Disregarding or ignoring a person's preference or need
    1. The music therapist does not listen or use the client's preferences, needs, or choices when making clinical or musical decisions; the music therapist chooses all of the session's contents, song choices, and experiences.

Appendix E
Institutional Review Board Approval Letter

INSTITUTIONAL REVIEW BOARD
Office of Research Protections
ASU Box 32068
Boone, NC 28608
828.262.2692
Web site: http://researchprotections.appstate.edu
Email: irb@appstate.edu
Federalwide Assurance (FWA) #00001076

To: Anna McAfee
Music
CAMPUS EMAIL

From: Dr. Andrew Shanely, IRB Chairperson
Date:
RE: Notice of IRB Approval by Expedited Review (under 45 CFR 46.110)
Agrants #:
Grant Title:

STUDY #: 21-0255
STUDY TITLE: Music Therapy, Self-Advocacy, And Self-Determination.
Submission Type: Initial
Expedited Category: (7) Research on Group Characteristics or Behavior, or Surveys, Interviews, etc.
Approval Date: 5/07/2021

NOTE: This project, like all exempt and non-exempt research with human subjects at Appalachian State University, is subject to other requirements, laws, regulations, policies , and guidelines of the University and the state of North Carolina. As of August 24, 2020 and until further notice, this includes the requirement by the Office of Research to pause in-person research projects until it receives an additional review to ensure the existence of an adequate COVID-19 mitigation protocol. Please see the full requirement on theResearch Protections website, as well as answers to questions you may have

The Institutional Review Board (IRB) approved this study. The IRB found that the research procedures carry no more than minimal risk and meet the expedited category or categories cited above. This approval applies to the life of the study, and you do not need to submit an annual request for renewal. You are required to request approval for any changes you may make to the study in the future, as described below in the section on Modifications and Addendums.

IRB approval is limited to the activities described in the IRB approved materials, and extends to the performance of the described activities in the sites identified in the IRB application. In accordance with this approval, additional IRB findings and approval conditions for the conduct of this research may be listed below.

Study Regulatory and other findings:
The IRB has determined that this research is no more than minimal risk.

This research satisfies the criteria of category 45 CFR 46.404 for research with children, as the study is no more than minimal risk.

The IRB has determined that assent is appropriate for minor subjects in the research, and determined that the assent process is adequate in accordance with the criteria under 45 CFR 46.408(a).

The IRB determined that obtaining the permission of one parent is sufficient, as the study is no more than minimal risk.

All approved documents for this study, including consent forms, can be accessed by logging into IRBIS. Use the following directions to access approved study documents.

1. Log into IRBIS
2. Click "Home" on the top toolbar
3. Click "My Studies" under the heading "All My Studies"
4. Click on the IRB number for the study you wish to access
5. Click on the reference ID for your submission
6. Click "Attachments" on the left-hand side toolbar
7. Click on the appropriate documents you wish to download

Approval Conditions:

Appalachian State University Policies: All individuals engaged in research with human participants are responsible for compliance with the University policies and procedures, and IRB determinations.

Principal Investigator Responsibilities: The PI should review the IRB's list of PI responsibilities. The Principal Investigator (PI), or Faculty Advisor if the PI is a student, is ultimately responsible for ensuring the protection of research participants; conducting sound ethical research that complies with federal regulations, University policy and procedures; and maintaining study records.

Modifications and Addendums: IRB approval must be sought and obtained for any proposed modification or addendum (e.g., a change in procedure, personnel, study location, study instruments) to the IRB approved protocol, and informed consent form before changes may be implemented, unless changes are necessary to eliminate apparent immediate hazards to participants. Changes to eliminate apparent immediate hazards must be reported promptly to the IRB.

Post-Approval Monitoring (PAM): The PI is responsible for providing requested documentation and/or in-person review time of the study by the Office of Research Protections if this study is selected for a Post-Approval Monitoring Review.

Prompt Reporting of Events: Unanticipated Problems involving risks to participants or others; serious or continuing noncompliance with IRB requirements and determinations; and suspension or termination of IRB approval by an external entity, must be promptly reported to the IRB.

Closing a study: When research procedures with human subjects are completed, please log into our system at https://appstate.myresearchonline.org/irb/index_auth.cfm and complete the Request for Closure of IRB review form.

Websites:

1. PI responsibilities: http://researchprotections.appstate.edu/sites/researchprotections.appstate.edu/files/PI%20Responsibilities.pdf

2. IRB forms: http://researchprotections.appstate.edu/human-subjects/irb-forms

required

Vita

Anna Laura McAfee was born in Fort Smith, Arkansas. She attended the University of Central Arkansas, where she graduated with a Bachelor of Arts in music *summa cum laude*. Anna Laura then began studying music therapy at Appalachian State University through the combined Equivalency and Master of Music Therapy Program. She began her internship in June 2020 at Opportunities for Positive Growth in Marion, IN. After completing internship, Anna Laura passed her board certification exam in January 2021 and became a board-certified music therapist. Afterwards, Anna Laura returned to Appalachian State University for a Master of Music Therapy in January 2021. She will graduate from Appalachian State University with a master’s degree in music therapy in December 2021.