

PERCEPTIONS OF SELF-DETERMINATION IN MUSIC THERAPY FOR
INDIVIDUALS DIAGNOSED WITH INTELLECTUAL DISABILITIES: A SURVEY OF
MUSIC THERAPISTS

A Thesis
by
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Abstract

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Individuals diagnosed with intellectual and developmental disabilities (I/DD) experience positive outcomes and desire to participate in decision making but are often less likely to access this right than their peers without a diagnosis. These individuals may be able to increase their proficiency in self-determination through practice but it is unclear the extent to which they may be involved in healthcare related decisions, specifically while participating in music therapy. Through a survey of 8,539 board-certified music therapists, the purpose of this study was to identify aspects of self-determination being incorporated into music therapy treatment with individuals diagnosed with I/DD and to determine the extent to which self-determination is emphasized. In order to be eligible to participate in the online survey, the participants needed to be board-certified by the Certification Board of Music Therapists (CBMT). Participants were directed to the end of the study if they indicated they did not currently work with individuals diagnosed with intellectual and developmental disabilities. A total of 809 therapists consented to participate in the survey with 535 completed responses. A total of 327 participants indicated working with individuals diagnosed with intellectual and developmental disabilities and were

included in the results of this study. The survey consisted of 18 questions with both open- and closed-ended responses. Results of this study indicated elements perceived by music therapists to be essential to self-determination, benefits associated with access to self-determination, methods of incorporating self-determination into music therapy sessions, and relationships between work experience, attitudes about self-determination, and the frequency of self-determination being incorporated into sessions. Based on the results of this study, future research could explore potential implications of educational background and work setting on self-determination and should include perspectives from service users.

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Chapter 1

Introduction

Personal Significance

Self-determination and presumption of competence for individuals diagnosed with intellectual and developmental disabilities (I/DD) are particularly important to me. I grew up in a non-traditional family with experiences that shaped me in more ways than I ever thought possible. My parents served as therapeutic foster care providers for children and adults with (I/DD) in addition to various emotional and behavioral needs. I was surrounded by people who interacted with the world in various non-traditional ways and this impacted my view of what was “normal.”

I developed meaningful relationships with people who had been written off by so many others. I saw strength, courage, kindness, curiosity, intelligence and so much more in each of the individuals I had the pleasure of getting to know. I heard many teachers and other adults speak of how my foster siblings, whom I had come to know and appreciate for all of their unique abilities and strengths, would never accomplish anything and were incapable of learning or being taught. I was upset and did not understand how they could not see the same capabilities and strengths that I saw when I spoke to and spent time with my siblings.

I was glad to find support in the literature for values that I had held throughout my life up to this point. Being heard and noticed, having a voice, expressing feelings and emotions, and making choices are human rights. The literature in the fields of occupational therapy, special education and disability rights contained interesting publications about self-determination, but very few music therapy articles that explicitly discussed self-determination for individuals diagnosed with I/DD. This was surprising to me because I knew music therapists who promoted self-determination in their practice and it was so important to me as a music therapist to include in my work as well. At this point I knew that I wanted to explore the extent to which other music therapists promoted self-determination in their practice. More importantly, I wanted the opportunity to speak to individuals diagnosed with I/DD who had participated in music therapy about their experiences. It was important to me to not only know the perceptions of music therapists but also to learn and share the views and experiences of people who are directly impacted by the research.

Residence and I/DD

Work within this population, as in other populations, is shaped by factors that influence and impact the lives of individuals diagnosed with I/DD. Some of these influencing factors include individual strengths and needs, interests, family relationships, culture, societal impact, and living arrangement (Curryer et al., 2015; Curryer, Stancliffe, Dew, & Wiese, 2018; Kostikj-Ivanovikj & Chichevska-Jovanova, 2016; Nota, Ferrari, Soresi, & Wehmeyer, 2007; Rolvsjord, 2014; Shogren & Broussard, 2011). More specifically related to this thesis, living arrangement has particular impact on a person's access to self-determination and will be highlighted in this section.

Prior to the 1970s there were over 180,000 people living in large state facilities (National Council on Disabilities, n.d.). This trend changed with the implementation of deinstitutionalization and move away from large institutionalized residential facilities for individuals diagnosed with I/DD. The goal of deinstitutionalization was to move from living in segregated communities and institutions to integrating into the larger community and increasing engagement. The proposed benefits of community living include increased quality of life, improved social connections, and a decreased cost of care which could impact services offered (Kostikj-Ivanovikj, & Chichevska-Jovanova, 2016; National Council on Disabilities, n.d.; Nota et al., 2007).

A meta-analysis of international studies found that 4.94 adults for every 1,000 were diagnosed with I/DD (Maulik, Mascarenhas, Mathers, Dua, & Saxena, 2011). The National Council on Disabilities (n.d.) reported that living arrangements ranged from living independently in the community (least restrictive) to a skilled care facility with staff support 24 hours a day (most restrictive). Of the total 1,068,275 individuals diagnosed with I/DD receiving services in the United States, 469,123 resided in a residential or nursing facility. While 31% were reported as residing in a group living situation with seven or more residents and state institutions, the majority, 69%, of these individuals resided in a setting with six or less residents in the home. The remaining 599,152 individuals diagnosed with I/DD receiving services lived with family members and received support services.

There has been a decrease in the number of individuals residing in state institutions from previous years after deinstitutionalization was implemented to encourage individuals to be in the least restrictive living environment possible. States vary in terms of the number of individuals diagnosed with I/DD who reside in state facilities. The Midwest has the lowest percentage of

individuals residing in state facilities with states in the east and southeast reporting the highest numbers. Living in more restrictive environments affects the individual's access to self-determination and control over aspects of their daily lives. More independent and less restrictive living situations are directly associated with increased access to self-determination (Curryer, Stancliffe, & Dew, 2015; Kostikj-Ivanovikj, & Chichevska-Jovanova, 2016; Nota et al., 2007).

After the implementation of deinstitutionalization, more individuals may be residing and working in less isolated and exclusionary locations; however, it cannot be assumed that deinstitutionalization solves the social exclusion and access to self-determination of this group (Adkins, Summerville, Knox, Brown, & Dillon, 2012). When living in a home in a community setting, a person may or may not actually be fully integrated into a community with the people around them. This lack of social support and actualized independence could contribute to issues in accessing self-determination (Adkins et al., 2012; Murphy & McFerran, 2016). The individual may also find themselves overwhelmed by the freedoms associated with more independent living than what they were previously familiar with.

While residing in the more restrictive environment there are less opportunities to practice choice and decision-making skills and develop social relationships (Kostikj-Ivanovikj, & Chichevska-Jovanova, 2016; Murphy & McFerran, 2016; Nota et al., 2007). Because competence in self-determination increases with confidence, experience and social support, individuals who have had limited experience with self-determination may find themselves overwhelmed or without the necessary skills to make decisions once they are residing in a less restricted environment where they may have increased access to control over their lives (Garrels & Arvidsson, 2018; Murphy & McFerran, 2016). In order to discuss this idea of having choice

and control more deeply, terms frequently used will need to be further explored and defined. The following includes definitions of terms that will be used throughout this thesis.

Definition of Terms

Self-determination. Self-determination is broadly defined as a person's ability to express choice and control over aspects of their own life and course of action (Gadberry & Harrison, 2016; Garrels & Arvidsson, 2018; Shogren et al., 2015). Included in this definition is an individual's or group's right to exercise autonomy or act with purpose. To be self-determined, an individual must self-regulate behavior and autonomously act based on empowerment and self-realization to act as the primary causal agent of change in their life (Shogren et al., 2015). Access to self-determination changes over time and is impacted by research and understanding of the concept in addition to changing perceptions regarding disability and the individual's experience with making decisions and acting as a causal agent in their life. Self-determination is essential for independence and improves quality of life in individuals diagnosed with I/DD (Gadberry & Harrison, 2016; Shogren & Broussard, 2011). Making choices and maintaining control over aspects of one's life has been linked to positive outcomes in quality of life, life satisfaction and future prospects, such as independent living, employment, financial independence, and potential for social integration and community access (Gadberry & Harrison, 2016; Garrels & Arvidsson, 2018; Kostikj-Ivanovikj, & Chichevska-Jovanova, 2016; Shogren and Broussard 2011; Shogren et al., 2015).

Autonomy. Exercising autonomy, by definition, is accomplished through acting with purpose. Abrams (2018) stated "Persons- regardless of their state or level of "functionality"- act upon the opportunities existence affords, with autonomy and implicit or explicit purposefulness, that can also be studied and subsequently understood, appreciated, and/or expressed" (p. 140). It

can be understood that people do not merely behave without a sense of purpose, but that they act based on physiological and emotional motivations that may be conscious or unconscious. These motivations exist whether or not we can perceive what an individual's motivation for an action may have been.

Agency. Agency, rather than something a person can possess, serves as a descriptor that identifies a person or thing as acting and without the possibility of being acted upon (Abrams, 2018). Contrary to stimulus-response behaviors found in objects that can be acted upon producing a consistent response given a stimulus, humans by nature exhibit agency in their actions. Actions are motivated by biological and psychological need, aimed toward self-regulated goals, driven by understanding of cause and effect, impacted by context and supports or impediments that exist in that environment (Abrams, 2018; Shogren et al., 2015). Agency is wide in the range of behaviors and actions it covers and can be a cognitively complex process impacted by factors across many domains.

Choice versus preference. Expressing preference is different from choice and decision-making in that indicating preference involves presenting a like or dislike of a subject that the individual has previous experience with. Choice and decision-making, in comparison, are processes in which alternatives are identified and considered before a final selection is made (Mitchell, 2012). Choices and decisions range from simple to complex in terms of cognitive demands related to an individual's experience and familiarity with the subject matter. Both are complex cognitive processes requiring practice and development of skills to further develop an individual's ability to participate actively in choice and decision-making (Garrels & Arvidsson, 2018).

Music therapy. Music therapy is defined by Bruscia (2014) as a journey toward optimal health and functioning that takes place within a relationship between a client or group of clients, the music, and a credentialed therapist. The experiences in music themselves are informed by research and theory, and the direction of the profession is constantly adapting based on new findings and contextual changes. Growth is achieved with the assistance of the therapist and can be accomplished through the experiences or the relationship developed between client, therapist and music. Music therapy interventions can accomplish a wide variety of goals including, but not limited to, promoting wellness, expressing emotions, encouraging and improving communication, and managing stress. Treatment interventions for individuals diagnosed with I/DD are commonly focused towards improving communication, social skills, self-awareness, emotional expression, and community involvement (Adler & Samsonova-Jellison, 2017; Gadberry & Harrison, 2016; Graham, 2004; Lee, 2012).

Statement of Purpose

Music therapists are identifying and pursuing goal areas with their clients that may further develop self-determination skills; however, little is known about methods being used to give opportunities for self-determination within music therapy or about the extent to which self-determination is emphasized in current practice. There is also little published about the opinions and perspectives music therapists hold about self-determination within their work in this population. For these reasons, the purpose of this study is to identify aspects of self-determination being incorporated into music therapy treatment with individuals diagnosed with I/DD and the extent to which self-determination is emphasized. Research questions to be explored in this study include

1. What are music therapists' views regarding client self-determination?

2. What are music therapists' interpretations of skills and benefits associated with self-determination?
3. How is self-determination incorporated into music therapy sessions with individuals diagnosed with I/DD?
4. What is the relationship between music therapy experience, frequency of self-determination used in practice, and focus towards increased access for clients?

Chapter 2

Theories and Methods

Researchers approach the study of a topic with information from their own experiences, theories and lens, which clouds the objectivity of the research whether it is identified or not (Cameron, 2014). Emancipatory Research aligned with a Disability Studies perspective is advocated for by individuals in the disability community as a preferred means of generating new scientific information regarding work within this community. Part of emancipatory research is establishing the relationship between theories, models, and the research being done. For these purposes, the researcher has compiled and identified factors influencing this study to adopt a stance of transparency in the development of the research. The following chapter will comprise definitions of relevant theories and models for viewing disabilities and information regarding the impact each has had on this thesis. A description of the theory of the practitioner and definition of the methodology chosen for this thesis will be included at the end.

Medical Model. The medical model of disability believes that the individual with a disability needs to be fixed and that their deficiencies or abnormalities prevent them from participating in the community (Cameron, 2014; Rickson, 2014). The community is not seen as having any flaws that could prevent meaningful participation. Any impairment is the sole cause of difficulty with community involvement and should be corrected and erased if possible. A

common sentiment from this perspective is that a disability is a misfortune and that others should count themselves as lucky for not experiencing the same condition. This model also includes an opinion of the client/therapist binary relationship, which designates the client as the person in need and the therapist is the expert who will fix the client's problems (Cameron, 2014; Rolvsjord, 2014). The medical model negates the idea of self-determination by labeling the client as "less-than" and in need of the therapist to help "fix" their issues (Cameron, 2014; Hadley, 2014; Rickson, 2014; Rolvsjord, 2014).

Social Model. The social model of disability views current capitalistic society as the cause of disability. The impairment is acknowledged, but the attitudinal and environmental barriers present in the environment are credited with the prevention of participation and personal growth (Cameron, 2014; Goodley, 2014; Lubet, 2009; Rickson, 2014; Rolvsjord, 2014; Stokes, Turnbull, & Wyn 2013). Therefore, the emphasis is put on the oppressive forces that exist in the community and act against the individual with a disability. This stigma applies to both a focus on the negative impacts and inability of the individual with a disability and the view that these individuals are children in need of someone to make decisions for them (Rolvsjord, 2014). The social model of disability supports increasing choice and control for individuals with a disability through emphasizing person centered planning, involving the individual in decisions that could impact them, and has been advocated for by individuals diagnosed with I/DD (Mitchell, 2012).

Disability Studies. Disability studies emerged from the experiences of people with disabilities and offers a perspective on challenging ways in which society has excluded disabled people. Societally accepted language, person-first, is challenged from this perspective where some individuals may prefer to be referred to as "disabled" because their disability contributes to their identity and makes them uniquely who they are (Goodley, 2014). There are similar views

included in this perspective towards the societal impact on disability; however, there is a heightened focus on activism and social change (Cameron, 2014; Goodley, 2014). Operating from a disability studies perspective means raising awareness of troubling societal norms and oppressive structures that impact all marginalized people and challenging these beliefs and ways of being.

In research it is often impossible to claim true objectivity, because results are produced from implicit underlying assumptions present by the researchers (Cameron, 2014). After criticizing the objectivity of medical model based research, Disability Studies academics have proposed six core principles for emancipatory research. These principles include adopting a social model of disability as the basis for research, commitment to the desire of people with disabilities for self-emancipation, to only undertake research where it will further self-empowerment and/or remove societal barriers, to give voice to those impacted by the research, and to adopt multiple methods for data collection and analysis given the various needs of possible participants with disabilities. This research aligns with these principles in that a social model was adopted as the basis, the commitment of the research is to further access to self-determination in music therapy for individuals diagnosed with I/DD, the hope is to raise awareness and remove barriers that inhibit access to self-determination, and perspectives will be gathered directly from both individuals who identify as having a disability and those who do not.

Humanistic Therapy. Humanistic therapy is informed by a belief that all humans are capable of conceptualizing and moving towards their ideal health and wellness (Moore & Lagasse, 2018; Rolvsjord, 2014). This theoretical orientation aligns with disability studies in that the client is seen as an expert on themselves and is capable of making decisions regarding their treatment (Moore & Lagasse, 2018; Rolvsjord, 2014). Humanism should be combined with

social awareness to avoid a focus on the self that prohibits connection with other humans (Hadley & Thomas, 2018). Music therapy is informed by a relationship between the client, therapist, and the music (Abrams, 2018). The tenet of agency, when combined with relationality, creates a responsibility that each person has for the well-being of humanity. Humanism promotes respect for all humans regardless of differences. When combined with humanism, music can embody self-determination and agency. Music is participatory, requires action, and holds the intrinsic power of each person to act with purpose.

Personal Theory of Practice and View of Disability

I incorporate beliefs from the social model, disability studies, and humanistic therapy into my practice as a music therapist. I believe that societal and environmental factors contribute largely to “inabilities” and challenges faced with participation in the community. I also believe in the importance of presuming competence in every person I interact with. Because I do not have any way of knowing what an individual is capable of, it is important that I remain open to possibilities and operate under the assumption that the individual is capable of much more than meets the eye. I incorporate these views into my practice by inviting clients to participate in discussion regarding goal-setting and tracking goals, focusing on increasing skills necessary for self-determination, and respecting the rights of individuals to be involved in the treatment planning process by any means appropriate.

Methodology. A survey containing both closed and open-ended questions, to be further explored in chapter four, was selected given its ability to reach a large number of practitioners and gather multiple perspectives to incorporate into a picture of self-determination for individuals diagnosed with I/DD. This survey will provide opportunities for both open- and closed-ended responses regarding views of self-determination in current music therapy practice.

Using an online format allows the possibility to capture current practice in music therapy by reaching practicing music therapists who work in different geographic regions and gather responses given specific prompts and questions.

Chapter 3

Review of Literature

The following chapter will explore the role of self-determination with individuals diagnosed with I/DD in recent literature. Music therapists discussed self-determination and are aware of how it could be incorporated into music therapy sessions (Gadberry & Harrison, 2016); however, it is not as explicitly stated in publications as it may be incorporated into clinical practice by music therapists. Self-determination also may not influence the therapeutic relationship and process for all practitioners as frequently as those whose stance is from a social model of disability, especially those informed by disability studies. Given the overall length of time that individuals diagnosed with I/DD have been receiving support services, self-determination as a concept is also a relatively newer focus in research and clinical work with the emergence of guidelines from the United Nation's Convention on the Rights of Persons with Disabilities in 2006 (Curryer et al., 2018). Although it is associated with positive outcomes, individuals diagnosed with I/DD do not have the same access to self-determination as their peers without disabilities and have expressed barriers they have found to their own self-determination (Kostikj-Ivanovikj & Chichevska-Jovanova, 2016; Nota et al., 2007).

Given the various skills necessary to be self-determined, it can be assumed that self-determination has been implicitly included in some music therapy articles and can be improved

by isolating skills needed for self-determination and increasing access (Curryer et al., 2015; Garrels & Arvidsson, 2018; Shogren & Broussard 2011). The literature explored in this thesis draws from disability rights, music education, occupational therapy and special education literature in addition to music therapy literature. Topics in this chapter will include prior surveys of access to self-determination and literature covering work in areas of self-awareness, self-advocacy, confidence and self-esteem, communication and goal setting (Curryer et al., 2015; Gadberry & Harrison, 2016; Garrels & Arvidsson, 2018; Kostikj-Ivanovikj, & Chichevska-Jovanova, 2016; Shogren & Broussard 2011; Shogren et al., 2015). The identified areas included comprise skills necessary for self-determination. These skills can be isolated and targeted using various methods aimed at increasing an individual's ability to participate in aspects of self-determination more actively.

Overview of Self-determination

The impact of increased access to self-determination reaches beyond selecting an outfit to wear or what music is playing on the radio. It extends beyond acquiring the skills of making choices and setting goals to realizing the power of self-direction and having the confidence to use those skills to direct one's life towards a desired outcome. Researchers in special education and in transition services identified promoting self-determination as a best practice and recommended including it in the design and delivery of adult support services (Shogren & Broussard, 2011). Gaining control over aspects of one's life can increase self-esteem and life satisfaction while allowing the individual to improve their confidence in making future decisions (Gadberry & Harrison, 2016; Garrels & Arvidsson, 2018; Kostikj-Ivanovikj, & Chichevska-Jovanova, 2016; Shogren and Broussard 2011; Shogren et al., 2015). Participating in the decision-making process allows the individual to learn and further develop skills that can

improve their capacity for future decision-making (Curryer et al., 2015; Gadberry & Harrison, 2016; Garrels & Arvidsson, 2018; Kostikj-Ivanovikj, & Chichevska-Jovanova, 2016; Shogren & Broussard 2011; Shogren et al., 2015). Even though self-determination has been identified as important to future success in schools and transitioning into adult life, it has not been researched very much in how it impacts health care decision making and goal setting.

While the ability to exercise choice and control over one's life has been reported to be beneficial, individuals diagnosed with I/DD often have less opportunities for self-determination than their nondisabled peers (Garrels & Arvidsson, 2018; Curryer et al., 2015) with those residing in residential care facilities reported as having lower self-determination than individuals living in the community (Kostikj-Ivanovikj, & Chichevska-Jovanova, 2016; Nota et al., 2007). Reported barriers to self-determination include overprotective parents, the constant battle to prove competence, and supports that are not responsive to the present need, among others (Curryer et al., 2015).

Article three of the United Nation's convention on the Rights of Persons with Disabilities (UNCRPD) upheld the right to self-determination of individuals diagnosed with I/DD in promoting the importance of autonomy, choice-making, and independence (Curryer et al., 2018). The National Disability Insurance Scheme (NDIS) in Australia defined long-term services to be provided to individuals with I/DD, which include mental health services, employment assistance, and assistance for families and caregivers among other supports (Cameron, 2017). The operational guidelines of the NDIS encourage increased access to autonomy for people with disabilities and use of a strengths-based approach for client goal setting. It is also noted that people with disabilities are experts on themselves and should make decisions regarding services provided to them (Cameron, 2017; Goodley, 2014; Rolvsjord, 2014).

Baker, Mixner, and Harris (n.d.) echoed these sentiments stating that the United States is currently undergoing a movement towards self-determination for individuals diagnosed with I/DD. Regardless of the various treatment approaches taken, these beliefs are also present in music therapy practice as evidenced by the most recent *Code of Ethics* adopted by the American Music Therapy Association (2019) which also identifies client self-determination as essential to ethical practice. Section 1.3 of the *Code of Ethics* protects the rights of all clients to self-determination while Section 2.4 highlights the importance of empowering clients to make the desired changes in their lives. The tenets of ethical practice are not limited to only the clients who have an obvious ability to direct their own healthcare. These suggestions for ethical practice were made regardless of the perceived functional ability of the client.

Many people are impacted by research and perceptions of self-determination for individuals diagnosed with I/DD (Gadberry & Harrison, 2016; Garrels & Arvidsson, 2018; Kostikj-Ivanovikj, & Chichevska-Jovanova, 2016; Shogren and Broussard 2011; Shogren et al., 2015). Societal norms could be transformed by supporting and advocating for the human rights for all people, not only those diagnosed with I/DD. Previous researchers have explored and reported on the impact and relevance of self-determination within the disability community and on current practice in music therapy and other disciplines (Curryer et al., 2018; Gadberry & Harrison, 2016; Murphy & McFerran, 2016; Shogren & Broussard, 2011).

Prior Surveys. Several surveys investigating the extent to which individuals diagnosed with I/DD were included in decision-making were compiled in a literature review by Stokes, Turnbull, and Wyn (2013). A British survey with more than 250 young people with disabilities and their families as participants indicated that 40% of the respondents reported having little, if any involvement in the decision-making process and 25% having none (Heslop et al., 2002).

Another survey from the United Kingdom found that of the respondents included, 72 indicated preference of living situation and described their needs and possible supports, but felt powerless in the decision-making process and were often not included (McGlaughlin, Gorfin & Saul, 2004).

Individuals diagnosed with I/DD may experience being excluded from participating in the decision-making process due to several reasons. These may include but are not limited to a perceived lack of time to allow the individual to participate in decisions, the impact and significance of the decision being made, supports not matching the need, difficulties providing enough staff to allow for the support needed, and an increased need for support in the decision-making process by individuals who reside in more restrictive environments (Mitchell, 2012; Stokes et al., 2013). In this regard, a person's access to choice and involvement in the decision-making process is determined by perceptions of the person's competence, availability and appropriateness of supports, attitudes and beliefs of others, and a desire to protect from danger. The voice of the individual with a disability is often lost, even if the reasoning sometimes comes from a genuine place of care for the individual.

Self-awareness. A limited awareness of self is associated with an inability to differentiate between self and other, which inhibits a person's ability to initiate action and exercise control within their environment (Adkins et al., 2012; Adler & Samsonova-Jellison, 2017). Gadberry and Harrison (2016) stated that through participation in music therapy clients with autism spectrum disorder (ASD) were able to establish a sense of self. This sense of self can translate into better understanding their needs, wants, and ideas that may then be communicated to others. Understanding of self has been found in songwriting interventions exploring physical and emotional changes following a traumatic event (Baker et al., 2017) and

connection between self and others has been witnessed in improvisations (Adkins et al., 2012; Graham, 2004).

Baker et al. (2017) used a four-phase process that included exploring pre-injury identity, accepting the injury, understanding the injury, and integrating this into their lives. Participants' increased self-esteem was the result which received more attention in the publication; however, this songwriting process likely allowed participants to experience increased self-awareness through involvement in the exploration of these self-concept domains and integrating information into a new view of self. Given the design of the study, which was about exploring views of self before and after a traumatic event, participants had to be directly involved in a process of becoming more self-aware. The increased self-awareness accomplished through the procedure selected for the study contributed to participants' self-worth, which was identified as the primary outcome of the study. Songwriting allows for the development of self-awareness through a primarily verbal processing with musical support, but some participants may receive greater benefit from self-awareness achieved through methods that require less or no verbal processing. Improvisation is one commonly used intervention that can address self-awareness without a definite need for verbal processing.

Geretsegger et. al (2015) surveyed music therapists and compiled common characteristics of improvisatory work with children diagnosed with autism spectrum disorder. Points brought up by the expert panel of participants included, among others, the importance of body and self-awareness as a targeted outcome in improvisation. The final treatment guidelines included facilitating musical and emotional attunement, of which increased self-awareness was determined to belong, as unique and essential to the clinical improvisation process. A heightened awareness of the importance of addressing musical and emotional attunement in

improvisation with clients diagnosed with I/DD supports the idea that self-awareness can be addressed and increased through improvisatory work. Graham (2004) used a vocal improvisation approach in which she vocally supported client cries, supported vocal improvisation on piano, and incorporated humming motives heard from clients into their shared music. There was an increased responsiveness found from the participants after being involved in this shared music making and hearing their sounds repeated back to them. This warm and responsive environment may have allowed the clients to practice differentiating themselves from others and what responses they may receive from their cries.

Differentiating oneself from the environment and increasing awareness of self improves overall functioning and wellbeing and can increase the client's ability to exercise control over his or her environment and use it expressively (Adler & Samsonova-Jellison, 2017). In exploring how digital technology impacted participation of adolescents diagnosed with I/DD, Adkins, Summerville, Knox, Brown, and Dillon (2012) found further support for Paul Ricouer's (2005) 'course of recognition' stating that recognizing oneself and differentiating oneself from others aligns with requirements for agency in participation. They also found mutual recognition, recognizing of oneself by others, to be a key element in developing a sense of agency. By being heard and understood, a person experiences self-confidence, self-respect, and social esteem in addition to developing an understanding of the causal relationship between making decisions and seeing the outcome.

Communication. Communication is commonly addressed in work with adults diagnosed with I/DD and key to expressing opinions (Baker, Wigram, Stott, & McFerran, 2009; Graham, 2004; Lee, 2012; Pavilcevic et al., 2013). Without the ability to clearly convey thoughts, feelings, and needs, a person may be misinterpreted or labeled as not having relevant

input on a topic or decision. It is important to be clearly understood when making decisions and exercising control over aspects of a person's environment. Choosing songs has been used as a motivator to increase effective and meaningful communication attempts (Lee, 2012), while improvisation has been used to encourage interactive vocalization and therefore improve communicative attempts of participants (Graham, 2004) and songwriting has created opportunities to hear communication attempts sung back to the client (Baker et al., 2009). Gadberry and Harrison (2016) stated that reciprocal interactions naturally increase when in the setting of music therapy given the non-verbal communication that occurs within music making. Communication is developed and supported through participation in music therapy to encourage the exchange of ideas with others in addition to requests for needs and wants (Pavilcevic et al., 2013).

Improvisation is used to facilitate spontaneous self-expression and social engagement through music making, which can serve as an environment to experience reciprocal interaction with others. Graham (2004) found that clients improved communication attempts when engaging in improvisation. The therapist first adopted and repeated back the vocalizations of the client participants. Participants then recognized another person as hearing and responding to sounds that had been ignored or discouraged by others as these sounds had been previously interpreted as behavioral rather than communicative. Increased reciprocal interactions followed once the responsive environment and relationship was established. In a similar manner, Lee (2012) found that participants improved communication attempts when provided with reinforcement and a responsive environment. Participants selected songs which were subsequently performed for the participant. Communication attempts were encouraged and

responded to with the appropriate consequence that paired with the stimulus of the song that was selected.

In addition to improvisation and song selection, songwriting is an intervention that can be directed at improving communication. A survey of music therapists by Baker et al. (2009) found that songwriting was being used with individuals diagnosed with ASD and I/DD within their sessions to address clinical goals. When participating in the lyrical creation process, clients diagnosed with ASD or I/DD contributed content to the songs in various ways including fill-in-the-blank songwriting, answering open-ended and closed questions, brainstorming, and sharing stories within sessions. These procedures addressed communication goals in the process of the participant sharing ideas or choices with the therapist. The therapist then incorporated these into the song and the client would hear their contribution sung back to them. Incorporating ideas shared by the clients in the songwriting process provided validation, reinforced that their communication attempt was heard and understood, in addition to possibly contributing to increased confidence to share thoughts and ideas in the future.

While communication attempts were improved, these publications do not discuss implications of these skills transferring to future progress toward more independent participation in self-determination. It is also important to note the difference between expressing choice and preference as previously stated (Mitchell, 2012). Some individuals benefit from limiting choices to lessen the probability of becoming overwhelmed by the process of making a choice, but that also limits their ability to practice considering a greater number of alternatives before making their selection. Expressing preference over which instrument or song they would like to hear played is a different concept than making a choice in which alternatives are identified and considered prior to making the decision. Choice making can be a difficult concept to consider

within this context, especially when the individual is overwhelmed by multiple options or has trouble communicating exactly what they are thinking (Mitchell, 2012).

Confidence and self-esteem. Confidence and self-esteem are common areas of growth noted in music therapy literature and both contribute to an individual's ability to determine their future (Adkins et al., 2012; Galdo, 2014; Stickley, Crosbie, & Hui, 2011). Participatory and performance based music interventions have produced results of increased confidence and self-esteem when a person-centered approach was used (Adkins et al., 2012; Baker, 2013; Baker et al., 2017; Galdo, 2014; Pavilcevic et al., 2013; Stickley et al., 2011). Performances of original compositions were found to increase self-worth and confidence when received positively by the audience (Baker, 2013; Galdo, 2014). In the performance context, audiences see the person highlighted by their creativity and musical abilities that transcend the presence of a disability (Baker, 2013).

Stickley, Crosbie, and Hui (2011) found improved confidence and self-esteem as themes in discussions of outcomes from participation in the Stage Life program. This program invited participants diagnosed with I/DD to take part in various music and theater workshops and performances. Activities used included improvisation, singing, rhythm, songwriting, and acting. Increased confidence was seen in a previously shy and reserved man taking the place of a peer who was unable to be there rather than refusing to be on the stage at all. Reflections from parents and care givers also highlighted increased relaxation and contentment in participants of the program.

Self-esteem was also improved when using songwriting as a means of processing physical and emotional changes following a traumatic event that caused physical and cognitive change and difficulties (Baker et al., 2017). As previously stated, these songs were used to

consider life circumstances of the past, present and future and how the participants were impacted by those circumstances. The participants processed changes in themselves and integrated aspects of their new identities in song form that could be used to share and discuss insights gained from the process. Songwriting and sharing of originally composed music can allow for improved self-esteem through developing social connections and recognition of mutual circumstances, in addition to positive reception by the audience (Adkins et al., 2012; Baker, 2013; Baker et al., 2017; Galdo, 2014).

Self-advocacy. Self-advocacy is a vital element to self-determination in that the ability to make known and advocate for one's wants and needs comprises a huge part of acting as a causal agent. Literature in this section is comprised of research from disciplines outside of music therapy as examples were not as prevalent in music therapy literature for individuals diagnosed with I/DD. Shogren and Broussard (2011) found in interviews of individuals diagnosed with I/DD that the ability to speak up and make a choice or need known was identified as a vital step in the process of expressing self-determination. McPherson, Ware, Carrington, and Lennox (2017) implemented health journals to document health information and use as a communication tool while at doctor's appointments to encourage individuals diagnosed with I/DD to participate more actively in decisions regarding their health. Using these journals, the participants were able to communicate with their doctors about their health and some reported increased confidence in participating in this process without the help of their parents/guardians. Participants also reported improved relationships with medical practitioners after being able to more effectively advocate their needs and experiences. Some parents and guardians noticed increased confidence and were less likely to speak on behalf of the individual diagnosed with I/DD in this context.

In a rock band program facilitated by a music educator (Galdo, 2014), the student participants self-advocated their choice to participate in the group. One student, who had been playing on the football team during the time that the group met, continually advocated to participate in the rock band group instead of the football team by practicing his instrument and bringing it to school every day (Galdo, 2014). He used the communication means he had available to him and demonstrated perseverance in making his choice known and understood by parents and teachers involved with the group.

Choice and decision making. Communicating choice and making decisions is one of the most concrete measurements of self-determination. Through making decisions, an individual exercises power and control over their life. As previously stated, making a decision is a much more cognitively complex process than expressing preference due to the various alternatives which are identified and considered prior to a decision being made (Mitchell, 2012). Supported decision making is a process that has been gaining popularity as a method of including individuals diagnosed with I/DD in exercising self-determination and enhancing legal agency (Shogren, Wehmeyer, Lassmann, & Forber-Pratt, 2017). This process is both an alternative to appointing a legal guardian and a framework for accessing the supports needed to most meaningfully participate in making decisions that impact the individual.

Supported decision making can, in similar fashion, be incorporated into therapeutic work with individuals diagnosed with I/DD. In considering the personal significance and goals when developing treatment plans, the interests of the client are further supported and validated (Moore & LaGasse, 2018). While respecting the decisions of the service user is important, Hillman et al. (2012) highlighted the implicit risks of violating human rights by simply adopting a “one size fits all” mentality toward supporting decisions made. These one-size policies teach the individual

that they are in need of permission to act as a causal agent in their life while also enabling neglect to occur as a consequence of respecting the decision of the individual without discussion of the possible outcomes. If the individual decides to constantly wear dirty and torn clothes without washing them or to act in a way which could endanger their life, then it was simply their decision which was being respected by the service provider. It is important to ensure that supports match the unique needs of the individual to enable the most meaningful and active involvement possible while providing protection from possible manipulation.

Hassan (2016) found that choices being made by individuals diagnosed with I/DD may not be made with as much agency and control as it may seem to support staff without proper training and consideration of environmental factors. Participants may have enjoyed listening to music or watching television as leisure activities, but they were also mostly reliant on the staff to operate the devices and could not necessarily decide to participate in those activities without staff support. Staff interpreted one participant's desire to participate in preferred leisure activities by his facial expression and stated that they would often turn the music up louder as it typically produced a smile. This example, while demonstrating social connection between the staff and the participant, is not an example of freely made choice, with or without supports. It also demonstrated that choice-making was contingent on the presence of staff and that this process cannot effectively be discussed outside of the social context. Relationships impact a person's choice-making and the same choice might not be expressed when in the presence of a different support person, whether because of the staff's ability to interpret it or because of some other realized social connection between the choice, the person, and the staff.

Goal setting. Setting goals and developing a vision for the future that is achievable impacts an individual's ability to direct their life in terms of where they will be or what they may

be able to do in the future. Incorporating client perspective into goal formation whenever possible is a powerful method for encouraging further motivation to address that goal, allows the client to feel heard and valued, and provides experience in identifying areas of desired growth (Rolvjord, 2014). Garrells and Arvidsson (2018) used the self determined learning model (SDLMI), to explore how skills were practiced through mentorship and reflection. Participants were active in the various steps of selecting goals, becoming aware of barriers and resources, identifying and moving through the steps toward goal achievement, self-assessment, and reappraisal of goals. Mentors were available to offer support for various needs that arose on an individualized basis. Through this process, participants gained experience in the process of identifying need areas, creating an action plan, monitoring progress, and making adaptations as needed. It was also evident that goals were selected based on skills that were personally important for the participants to learn and master. One participant selected sight words as an area to work on, not only because she wanted to improve her reading skills, but so she could communicate with her peers via text message.

Similar mentorship and support was found for student participants in the Rock Penguins rock band from their teachers and parents. Students had goals of learning the various instruments and practiced both in the group and outside of the band to achieve their goals and perform at various venues (Galdo, 2014). Skills targeted and learned in this group also included reading skills, communication skills, and social interactions. Parents and teachers supported the participants in reaching the desired skill level on musical goals, but other gains were noted as an added bonus of involvement in the group.

Views of self-determination. It is most common to see the perspectives and hear the voices of parents and professionals when reading research impacting individuals diagnosed with

I/DD (Cameron, 2014). Shogren and Broussard (2011) conducted interviews of 17 individuals diagnosed with I/DD while attending a statewide self-advocacy conference regarding their views of self-determination. Participants discussed the meaning of self-determination in their lives and mentioned the role of the environment and its impact on opportunities for choice and control. As had been found in other studies, participants who resided in less independent settings reported having less access to self-determination. However, these participants commented on the fact that their decreased access came from a place of love and care from guardians and parents. The connection between advocacy and self-determination was emphasized in addition to goal setting and identifying personal goals being a large part of the process.

Curryer et al. (2018) found similar results in their interviews of families and individuals diagnosed with I/DD. Participants reported how they learned from experience and that their access to choice and control increased over time. Participants accepted assistance from their family and important advisors around practical issues which required choice and decision making, such as financial management. There were limitations to choice and control reported; however, some of these limitations were self-imposed given the individual's anxiety about their ability to make the decision.

Self-determination is a multi-faceted concept that evolves as an individual's ability increases or decreases within various domains and based on society's view and understanding of the concept (Shogren et al., 2015). It does not need to be a process that an individual engages in alone in order to be an authentic exercise of control and autonomy. Appropriate support from someone who is trusted helps to move through barriers to self-determination and allow the person to exercise this right with support from another. This support can come from a family member, trusted peer mentor, or a professional with knowledge of aspects surrounding the

choice (Curryer et al., 2018). Whether exercising choice alone or with support, the individual is learning and gaining experience in skills necessary for increased self-determination in the future. Incorporating agency into therapeutic work, particularly including the participant's voice throughout the therapeutic process, can be accomplished by incorporating personal goals into therapeutic goals (Moore & LaGasse, 2018). Self-determination may also be targeted through highlighting skills in need of development and improving them with a long-term goal of impacting a person's ability to direct their life. Working on skills that are needed for successful self-determination have positive impacts that contribute to overall improvements in quality of life and are important for therapeutic work with individuals diagnosed with I/DD.

Conclusion. Previous literature has indicated that self-determination is a concept that music therapists working in this population are aware of (Gadberry & Harrison, 2016) but it is not frequently discussed explicitly in how it appears in or interacts with music therapy. There have been interviews conducted with individuals diagnosed with I/DD and their families to collect information about their families' and their own perceptions self-determination outside of music therapy (Curryer et al., 2018; Shogren & Broussard, 2011). These interviews have provided information regarding barriers, frequency, significance, and included some perspective from individuals diagnosed with I/DD. However, none of this research directly related to music therapy or healthcare decision making. The aim of the current study is to explore self-determination as it explicitly relates to music therapy practice.

Chapter 4

Method

This chapter will include information regarding the process utilized for conducting this study. Participants, the survey and its design, the study design, procedures and data collection and analysis will be described. An online survey approach was used to enable the researcher to include information collected from music therapists who work in a wide variety of settings and geographic regions.

Methodology

An online survey was implemented as the design of this study to provide a broader picture of the impact of this topic on the lives of individuals diagnosed with I/DD. This approach allowed information to be collected from music therapists who work in different settings and regions. As mentioned previously, this research was intended to be emancipatory in nature, which prompted a social model lens to be taken as the theoretical orientation of the research (Cameron, 2014). Data were collected through both closed and open-ended questions to enable assessment of perceptions beyond selecting choices offered.

Participants

An email containing an invitation to take part in a survey was sent to 8,539 music therapists who were currently board-certified by the Certification Board for Music Therapists.

Email addresses for all board-certified music therapists were purchased from the Certification Board for Music Therapists. At the time this study was conducted there was no feasible method for separating out music therapists who currently worked with individuals diagnosed with I/DD from music therapists who were retired or who primarily worked in other populations. A question in the demographic portion of the survey directed participants to the end of the survey if they responded that they did not work with individuals diagnosed with intellectual and developmental disabilities.

Fifty-eight emails were undeliverable and seven individuals replied to the initial email stating that they were no longer working in the field and would not be participating in the survey for those reasons. A total of 809 music therapists consented to take the survey, which resulted in a response rate of 9.54% with 535 completing the survey, for a completion rate of 69.84%. Of the 535 who completed the survey, 327 of them reported working with people diagnosed with I/DD.

A total of 8.6% of participants identified as having a disability (n=28) while 89.2% identified as not having a disability (n=290) and 2.2% preferred not to answer (n=7). The participants were from a variety of locations across the United States and outside of the country. The majority of participants, 27.1%, were from the Great Lakes Region with 21.2% working in the Mid-Atlantic region. Table 1 includes responses of participant geographic regions.

Table 1

Geographic Regions of Participants

Region	Percentage of Respondents	<i>n</i>
Great Lakes Region	27.1%	88
Mid-Atlantic Region	21.2%	69

Midwestern Region	9.2%	30
New England Region	3.4%	11
Southeastern Region	8%	26
Western Region	13.5%	44
Outside of the United States	3.7%	12

All respondents were board-certified music therapists; however, there were a variety of educational backgrounds and additional trainings and certifications reported by participants. Some received a bachelor's degree in a field other than music therapy, music performance, for example. Reported educational backgrounds outside of the provided options included neonatal intensive care unit music therapy, Nordoff-Robbins music therapy, Bonny Method of guided imagery in music, among others. Table 2 provides information about participant educational background.

Table 2

Participant Educational Background

Educational Background	Percentage	<i>n</i>
MT-BC	79.8%	261
Master's	44.3%	145
Doctorate	4.9%	16
Neurologic music therapy	20.2%	66
Applied behavioral analysis	3.1%	10
Other	15.6%	51

Music therapy is provided to clients in a variety of formats and locations. Music therapists reported the settings in which they most frequently worked. Work settings reported beyond the provided options included hospitals, university clinics, outpatient sites, and various funding sources to provide services in private or group home settings. Table 3 provides the percentages of music therapists' work settings.

Table 3

Participant Work Setting

Work Setting	Percentage	<i>n</i>
Private Practice	34.2%	111
School System	15.7%	51
Day Program	5.8%	19
Group Home, Nursing Home or Residential Facility	12%	39
Other	32.3%	105

The majority of participants, 44.6%, reported having worked as a music therapist for 10 or more years. Music therapists having worked for between one and three years were the second most common response at 28% while working for between four and six years was reported at 19.4%. The least common amount of time to have worked as a music therapist was between six and ten years. Table 4 provides the number of years participants had worked as a music therapist.

Table 4

Participant Experience in Music Therapy

Number of Years	Percentage	<i>n</i>
1-3	28%	91

4-6	19.4%	63
6-10	8%	26
10+	44.6%	145

Setting

The survey was hosted online and completed in the setting of the music therapists' choice. Qualtrics was used to format, distribute, and record data from the survey (Qualtrics, 2020).

Procedure

An application to Institutional Review Board at Appalachian State University was submitted and approval was gained for the project (see Appendix C). The survey was sent out by email to Board Certified music therapists with information about the study in the body of the email (see Appendix A). Three emails were sent, the first was the original email with a two-week due date, the second with a reminder with the questionnaire link and a one-week due date, and the final was an extension due to technical difficulties with a two-week due date.

Measures

Due to a lack of preexisting measurement tools, the researcher developed the survey used in this study. The purpose of the survey was to gather demographic information about the respondent, information about their understanding of self-determination, and to compile information about incorporation of self-determination in their music therapy practice. This survey was piloted by professionals who work with individuals diagnosed with I/DD and music therapists who work in other populations to gather feedback on the clarity of the questions.

The survey included a series of 18 questions divided into three sections (see Appendix B). Section one included demographic information, section two included information about the respondents' views of self-determination for individuals diagnosed with I/DD, section three included information about how self-determination is incorporated into music therapy sessions.

Materials. Qualtrics and the survey itself comprised the materials necessary for the survey of music therapists.

Data Collection and Analysis

Data was collected through the Qualtrics online survey (Qualtrics, 2020) and analyzed by the researcher. Descriptive statistics were analyzed using SPSS to provide an overview of the respondents. Comparisons of responses to closed-ended questions were run to explore any correlations that may have been present in the data. Key themes present within open-ended questions were identified and coded by reviewing the data for similarities and extrapolating significant thoughts brought up by participants within or outside of the themes. Once themes were identified, the data was divided into categories and subcategories. Categories included essential skills and traits of self-determination for both clients and therapists, necessary environmental factors, benefits for both clients and therapists/caregivers, and benefits related to independent community living. Essential skills for the client was then further divided into three subcategories including cognitive skills, relational skills, and intrapersonal skills.

Chapter 5

Survey Results

The following chapter includes results from a survey of music therapists on self-determination in music therapy with individuals diagnosed with I/DD. Views of self-determination, interpretations of skills and benefits associated with self-determination, reports of the incorporation of self-determination in sessions, and relationships between music therapy experience, frequency of self-determination used in practice, and focus towards increased access for clients will be reported. The information will be presented in four sections consistent with the research questions: music therapists' views regarding client self-determination, music therapists' interpretations of skills and benefits associated with self-determination, how self-determination is incorporated into music therapy sessions with individuals diagnosed with I/DD, and relationships between music therapy experience, frequency of self-determination used in practice, and focus towards increased access for clients.

Section 1: Music Therapists' Views Regarding Client Self-determination

Music therapists reported views held about the importance of self-determination within sessions for individuals diagnosed with I/DD and to what extent these individuals had the ability to increase their abilities in self-determination. A definition of self-determination was provided and participants indicated their views on how self-determination is expressed, if it was important

to incorporate into music therapy sessions, and whether it could be improved over time. The majority of participants agreed that there were degrees to which self-determination could be expressed and that it is important to incorporate into music therapy sessions; however, there was less agreement regarding the level of independence required to label an action as self-determined and whether it could be improved over time. Table 5 provides the percentages of music therapists' reports of level of agreement with statements offered in the survey.

Table 5

Music Therapists' Perceptions of Self-Determination

Survey Question	Strongly Disagree		Somewhat Disagree		Neutral		Somewhat agree		Strongly agree	
	Disagree	<i>n</i>	Disagree	<i>n</i>	Neutral	<i>n</i>	agree	<i>n</i>	agree	<i>n</i>
1. There are degrees to which self-determination can be expressed by an individual	4%	13	1.8%	6	5.2%	17	35.5%	116	50.5%	165
2. In order to be considered self-determination, an action or decision must be made completely independently of assistance or influence by another person	11%	36	36.4%	119	11.3%	37	29.4%	96	10.7%	35
3. It is important to incorporate self-determination in music	1.8%	6	1.5%	5	3.4%	11	18.3%	60	72.8%	238

therapy work with clients

diagnosed with I/DD

4. Self-determination can be improved over time with practice and experience making choices and expressing control over aspects of daily living	12.5%	41	2.1%	7	3.1%	10	29.7%	97	51.7%	169
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Section 2: Music Therapists' Perceptions of Associated Skills and Benefits

Participants listed the elements essential to practice self-determination within eight provided free-response spaces. Similarly, participants listed potential benefits for access to self-determination within an additional provided free-response boxes. Although the survey questions inquired specifically about the skills and benefits directly associated with self-determination for the client, many participants listed other essential elements that were not skills based and included benefits for the therapist or caregiver in addition to the client. Elements outside of skills that were reported included personal traits of the client, elements essential for the therapist to provide, and environmental factors outside of the client's control.

A total of 172 different skills, personal traits, or environmental factors were listed. Skills were coded into four categories: skills essential for client, personal traits essential for client, elements essential for therapist, and essential elements outside of the client's control. The category of essential skills for the client was then separated into three subcategories, essential relational skills, essential cognitive skills perceived by others, and essential intrapersonal skills. The total number of responses, including single elements mentioned multiple times, was 1,233. When separated into the four categories, 74.9% of the listed items were assigned as essential skills for the client, 14.9% were essential personality traits for the client, 7% of these were essential skills and traits for the therapist, and 3% were essential elements outside of the client's control. Table 6 provides the top 25 most reported essential elements for clients separated into categories and subcategories. Additionally, table seven provides the top 20 essential elements for therapists and elements beyond the client's control.

Table 6

Essential Elements of Self-Determination for Clients

	Skills Essential for Client		Personal Traits for Client
Relational Skills	Cognitive Skills	Intrapersonal Skills	
Communication	Cognition	Self-Awareness	Confidence
Choice Making	Problem solving	Self-Regulation	Creativity
Environmental Awareness	Identify Preferences	Motivation	Patience
Advocacy	Discern Choices	Awareness of needs	Perseverance
Understand Social Cues	Critical Thinking	Follow-through	Assertiveness
Self-Expression	Planning	Independence	Willingness
Initiate Conversation	Goal Awareness	Daily Living Skills	Resilience
Respond to Environment	Identify pro's and con's	Try New Things	Passion
Follow Directions	Situational Understanding	Determination	Responsibility
Empathy	Causal Understanding	Interest	Flexibility
Medication Compliance	Organization	Autonomy	Adaptability
Leadership	Attention	Motor Ability	Persistence

Cooperation	Comprehension of Consequences	Impulse Control	Self-Discipline
Tolerance of Other Opinions	Understand Time	Cope with Mistakes	Grit
Forgiveness	Conceptual Understanding	Be Alive	Strong will
Active Participation	Prioritization	Self-Respect	Compassion
Observation	Short-term Memory	Initiative	Humility
Tolerance of Ambiguity	Self-Assessment	Self-efficacy	Hope
Competition	Objectivity	Aware of Skills	Good Attitude
Accept feedback	Skill Generalization	Aware of Limits	Dedication
Acceptance of self and others	Judgement	Self-Actualization	Energy
religion/spiritual growth	Frame of Reference	Aware of Motivations	Endurance
	Understand Yes/No	Self-Reflection	Resolve
	Predict outcome	Delayed Gratification	Optimism
	Talent	Intuition	Charisma
	Physical/Mental Maturity	Dignity to Fail	Inspiration

Table 7

Elements Essential to the Therapist and Outside of the Client's Control

Essential Elements for the Therapist	Elements Outside of the Client's Control
Unbiased Support System	Safety
Belief in Client	Control
Presume Competence	Money Management
Repetitive Opportunities	Safe and Acceptable Options
Appropriate Resources	Leisure Options
Research	Enough Time
Consider Needs of Others	Non-triggered Nervous System
Open Mindedness	Access to Basic Needs
Provide Access to Choice	Food/Drink Options
Mentorship	Clothes
Encouragement	Housing Options
Trust	Job Options
Empowerment	Vocational Skills
Experience	Transportation
Choice is Honored	Lack Victimization
Growth Strategies	Freedom
Listen	
Attuned to Needs	

Emotional Support

Education

Participants identified 144 different benefits associated with self-determination within provided free-response spaces. Benefits were coded into three categories: benefits to the client, benefits to the therapist/caregiver, and benefits in independent living. One identified benefit, improved relationships, crossed over into both benefits to therapist/caregiver and to the client. The majority of reported benefits were assigned as benefits to the client with benefits to the therapist/caregiver and independent living benefits being mentioned a similar number of times. Table 8 provides the percentages of benefits reported in each category.

Table 8

Percentages of Perceived Benefits Associated with Self-Determination by Category

Benefit Category	Percentage	<i>n</i>
Benefits to Client	89.5%	1071
Benefits to Therapist/Caregiver	5.1%	61
Benefits Associated with Independent Community Living	5.3%	64

While less benefits than essential elements were identified overall, there was slightly greater consistency among responses in this area. The total number of responses, including duplicates, was 1,196 benefits. The number of benefits reported was 140 once duplicates were removed from consideration. Table 9 includes the top 25 benefits divided into each category. Other benefits not listed in the top 25 include 76 benefits to clients with responses appearing on 13 or less occasions in the data.

Table 9

Benefits Associated with Self-Determination

Benefits to Client	Benefits for Independent Living	Benefits to Therapist/Caregiver
Independence	Job Opportunities	Improved Relationships
Self-esteem	Greater Community Access	Decreased Strain on Responsible Parties
Life Satisfaction	Meaningful Life Experiences	Educate Others About Abilities
Quality of Life	Job Performance	Increased Quality of Care
Autonomy	Independent Living Opportunities	Help Others
Control	Increased Wealth	More Effective Therapist
Improved Relationships	Productivity	Listening/Responding to Others
Increased Self-Worth	Accolades	Decreased Cost of Care
Motivation	Clarify Role in Society	Increased Caregiver Job Satisfaction
Self-Awareness	Wider Variety of Programs	Increased Evidence Based Practice
Decreased Frustration/Anxiety/Stress	Spiritual Development	Increased Understanding of Client Need
Increased Access to Needs/Wants	Education	Greater Impact
Increased Social Opportunities	Success in Various Settings	Accept All Forms of Communication
Communicate Goals/Needs	Networking	Decreased Learned Helplessness
Accomplishment	Better Work Habits	Increased Emotional Support
Healthier Lifestyle	Involvement in Politics	Funding Based on Client Needs
Self-advocacy	Daily Living Skills	Ability to be Others Focused
Pride		
Choice Making (access and skill)		
Cognitive Skills		
Decreased Maladaptive Behaviors		
Empowerment		
Coping Skills		
Authentic Identity Expression		

Section Three: Appearance of Self-determination in Music Therapy Sessions

Survey participants listed ways in which self-determination appeared in their sessions with clients diagnosed with I/DD. Nine options for possible ways self-determination may appear in a session were offered and the participant selected all that applied to their practice. Three additional free-response boxes were available for participants to offer other methods of incorporating self-determination in their sessions. Options included creating a responsive environment, providing choices of instruments and interventions, client involvement in tracking data and determining goals, and addressing skills needed for increased self-determination abilities. Responses are displayed by frequency in the graph (see figure 1).

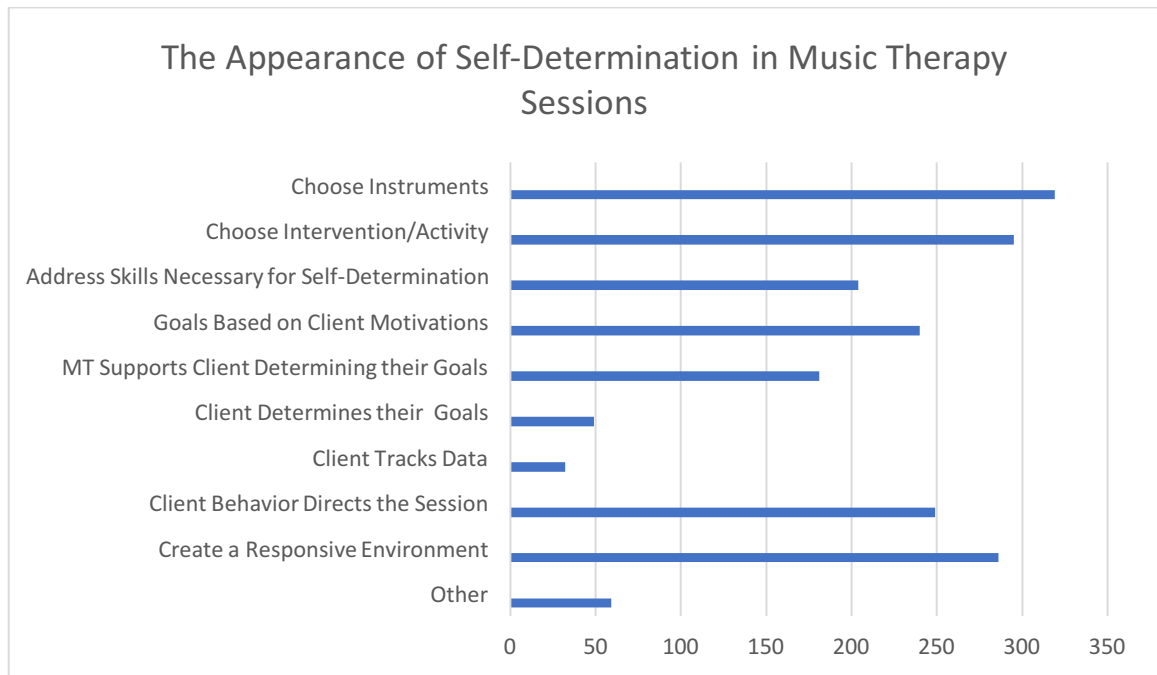


Figure 1. Frequency for Methods of Incorporating Self-Determination in Music Therapy.

The most frequently reported methods for incorporating self-determination in music therapy sessions were offering clients choices of instruments and interventions within the session. Other frequently reported methods were consistent with creating an environment that was responsive and empowered clients to actively engage with the session. This participation then could impact the direction of the session. Least often reported were occasions when the client would determine their own goals and track their own data. There were no repeated responses in the “other” category that could be grouped together to display on the graph. Examples included engaging in client-led improvisations that may or may not relate to events in other areas of the client’s life, engaging with social media, using strengths-based language, and making adaptations to maximize client independence.

Section Four: Relationships Between Work Experience, Ways of Practicing, and Self-Determination

Participants reported demographic information at the beginning of the survey including the number of years they had been working as a music therapist. Other questions addressed the importance of incorporating self-determination into music therapy sessions, how frequently goals were aimed at increasing access to self-determination, and how often self-determination was incorporated into music therapy sessions. A Spearman’s rank-order correlation was run to determine any correlations between these elements. The following results were found through comparing each of these factors to determine any possible relationships. Table 10 provides the Spearman’s rank-order correlations between years of experience, the importance of incorporating self-determination into music therapy sessions with individuals diagnosed with I/DD, the

frequency of goals in music therapy sessions aimed at increasing access to self-determination, and how often self-determination is incorporated into music therapy sessions. Eight correlations were found to be significant at the 0.01 level and two correlations were found to be significant at the 0.05 level.

Table 10

Correlations Between Years of Experience, the Importance of Incorporating Self-Determination, Frequency of Goals Addressing Increased Access, and Frequency Self-Determination is Incorporated

	Years of Experience	Importance of Incorporating	Frequency of Goals Directed at Increasing Access	Frequency Self-Determination is incorporated
1. Years of Experience	-	-.062	.162**	.117*
2. Importance of Incorporating	-.062	-	-.421**	-.217**
3. Frequency of Goals Directed at Increasing Access	.162**	-.421**	-	.485**
4. Frequency Self-Determination is incorporated	.117*	-.217**	.485**	-

*Correlation is significant at the 0.05 level (2-tailed)

**Correlation is significant at the 0.01 level (2-tailed)

Chapter 6

Discussion

This chapter presents findings from a survey of music therapists in connection to the literature and research questions. This information addresses music therapists' perceptions of self-determination for individuals diagnosed with I/DD, interpretations of associated skills and benefits, how self-determination is incorporated into music therapy practice, and any relationships between music therapy experience, frequency of self-determination used in practice, and focus towards increased access for clients. Discussion of each research question will be presented followed by recommendations for clinical practice, limitations of the study, and implications for further research.

What are music therapists' views regarding client self-determination?

Results of this study indicated that music therapists have varying levels of alignment in their perceptions of aspects of self-determination. There was a higher level of agreement about the existence of degrees or levels to self-determination being expressed and the importance of incorporating it into music therapy practice than the level of independence required for an action or decision to be considered self-determined. Slightly more participants believed that an action or decision could still be labeled as self-determined when a third party was consulted. The idea that self-determination is not

mutually exclusive from seeking advice from a trusted mentor aligns with literature that promotes skill building and active participation in the goal setting process through mentorship (Garrells & Arvidsson, 2018). The individual still has power to be directly involved in directing the course of their life and are being informed of what circumstances impact them at that moment even when seeking advice from a trusted mentor.

While most strongly agreed (51.7%) that self-determination could be improved over time with practice and experience, there was still a larger percentage than expected, 12.5%, that strongly disagreed with that statement. This discrepancy could be due, in part, to the theoretical orientation of the therapists participating in this survey. A belief that environmental and cultural factors contribute largely to a person's access to self-determination may impart a belief that practice and experience has little to do with improved access (Cameron, 2014; Goodley, 2014; Lubet, 2009; Rickson, 2014; Rolvsjord, 2014; Stokes, Turnbull, & Wyn 2013). This belief aligns with specific models of disability, social model and disability studies, and these views may have impacted some responses in the survey.

Two respondents highlighted this bias in their response to a free-response question in the survey by stating that skills necessary for self-determination were based on the individual and their needs for increased access within the community and system they lived. While not explicitly stated, this belief is present in literature discussing the relationship between residence and a person's access to self-determination (Curryer et al., 2015; Kostikj-Ivanovikj, & Chichevska-Jovanova, 2016; Nota et al., 2007). Living in a more restricted environment is directly associated with decreased access to self-

determination and is certainly a factor that influences a person's ability to improve access to choice and control over their life.

What are music therapists' interpretations of skills and benefits associated with self-determination?

As previously mentioned, skills necessary for self-determination may be unique in that people may need to address different skills in their development of self-determination within various settings. As a result of this survey, a large number of associated skills were identified and divided into categories based on what area of the client's life the skill most fit. The largest category of skills were essential skills and personal traits for the client. In alignment with beliefs that the environment and persons working with the individual also impact their access to self-determination, some skills were essential for the therapist to provide or part of the environment and outside of the client's control.

Skills essential for the client were able to be divided further into three sub-categories, relational skills, cognitive skills, and intrapersonal skills. The most frequently reported skills in each category (confidence, communication, choice-making, self-awareness, self-regulation, cognition and identifying preferences) aligned with skills identified as essential in the literature (Curryer et al., 2015; Gadberry & Harrison, 2016). Less frequently mentioned skills (competitiveness, delayed gratification, motor control) were not mentioned in the literature demonstrate a gap between what is known about self-determination for individual people and what is reported in the literature. Given that there were over 170 different features reported as essential to self-determination, it can be

assumed that this is a concept influenced by a variety of factors and that level of access is individualized to each person.

Essential elements provided by the therapist included functioning as an unbiased support system, believing in the ability of the client, and providing repetitive opportunities and appropriate resources. One of the highlighted barriers to self-determination in the literature was the concept that supports offered to individuals diagnosed with I/DD do not always match the need being presented (Curryer et al., 2015; Mitchell, 2012; Stokes et al., 2013). Additionally, the idea that presumption of competence plays a role in a person's access to self-determination is also supported by interviews where individuals reported a consistent need to prove their abilities to other people who played some role in determining their ability to participate in that decision (Curryer et al., 2015). The need for repetitive opportunities is related to an individual's ability to practice and become comfortable with skills necessary for self-determination. It can be assumed from these results that improving skills needed to actively participate in self-determination is impacted by the opportunities available and that therapists and caregivers play a role in providing space for individuals to practice and improve these skills.

Overall, there were slightly less benefits listed than skills. Benefits were divided into three categories: benefits to the client, benefits to the therapist/caregiver, and benefits in independent living. Independent living was determined to be its own category because of how the responses did not align with the majority of responses given. There were some respondents who interpreted self-determination as synonymous with independent community living and therefore the associated benefits included mainly job opportunities

and greater community access. Independent living is related to self-determination in that living in a less restrictive environment is associated with greater access (Curryer et al., 2015; Kostikj-Ivanovikj, & Chichevska-Jovanova, 2016; Nota et al., 2007); however, the literature supports a claim that self-determination is more broad than this one aspect of autonomy (Gadberry & Harrison, 2016; Garrels & Arvidsson, 2018; Shogren et al., 2015). There was also a lower amount of agreement in responses than what was expected with a large number of responses that could not be grouped together given the distinctness of the language used. For example, improved life satisfaction and quality of life were both reported as benefits and were unable to be combined. Life satisfaction aligned more with the individual's perception of their experiences, while quality of life referred to the variety and caliber of supports and services offered and accessible to the individual.

The majority of benefits reported were benefits to the client and included increased independence, self-esteem, confidence, life satisfaction, and quality of life among others. Many of the associated benefits aligned with improvement of skills listed in the previous section (communication, self-advocacy, decrease maladaptive behaviors, etc.), in addition to an increased likelihood of reaching goals as a reported benefit. Increased life satisfaction, self-esteem, and improved confidence in future decisions are all benefits found in previous literature that were frequently reported in the survey (Gadberry & Harrison, 2016; Garrels & Arvidsson, 2018; Kostikj-Ivanovikj, & Chichevska-Jovanova, 2016; Shogren and Broussard 2011; Shogren et al., 2015). In both previous literature and in this survey, most of the benefits reported were for the client. Some music therapists also reported benefits beyond those received by the client.

Benefits to the therapist and caregiver were reported by a small number of respondents. These benefits had not been discussed in the literature prior to this study. Improved relationships were mentioned as benefits to both the client and the therapist while decreased strain on the responsible parties, increased quality of care, increased understanding of client needs, and increased use of evidence based practices were mentioned as some of the benefits to the therapist. This new information adds to the knowledge base that the benefits of incorporating self-determination extend to clients, therapists, and caregivers, whereas previously benefits were only discussed in terms of the benefits to the individual diagnosed with I/DD.

How is self-determination incorporated into music therapy sessions with individuals diagnosed with I/DD?

The most frequently reported methods of incorporating self-determination into music therapy sessions included offering choices within the session. Choice-making as the most frequent method of incorporating self-determination within sessions further supports literature that offering choices within the session can be used as a method of offering a degree of control to the client (Gadberry & Harrison, 2016; Lee, 2012). Creating a responsive environment and following the musical and nonmusical cues of the client were also frequently reported as methods of incorporating self-determination into music therapy. Music therapy literature has supported each of these methods (Adkins et al., 2012; Gadberry & Harrison, 2016; Graham, 2004); however, the connection between these therapeutic techniques and incorporating self-determination in music therapy sessions has not been explicitly stated in previous literature. In improvisation and in sequencing music therapy experiences, the responses of the client can lead the therapist

and inform clinical decisions during the session. The client then has some degree of influence over the direction of the therapy session when working with a responsive therapist who is attuned to their needs and communication.

Respondents reported additional methods for incorporating self-determination in music therapy sessions within free-response spaces. The responses provided varied in content and demonstrated a range of methods being incorporated. Client-led improvisations was a natural extension of creating a responsive environment where therapy can be directed by musical and nonmusical behaviors. Additionally, making adaptations and using strengths-based language were highlighted as they relate to self-determination. Appropriate supports and adaptations, as mentioned previously, is an identified barrier to self-determination (Curryer et al., 2015; Mitchell, 2012; Stokes et al., 2013) and has now been addressed in two areas of this survey of music therapists. While these responses were not included in the most commonly reported, it does demonstrate that some music therapists are aware of the impact that these supports have on a person's access to self-determination.

The two least frequently reported options involved the client selecting their own goals and tracking their own data. It is unclear why these methods are the least frequently reported. One possibility is that the systems that music therapists work within and are trained in may not be as effectively set up to support incorporating self-determination (Cameron, 2014; Hadley, 2014; Rickson, 2014; Rolvsjord, 2014). Depending on the needs and availability of supports, it may be less reasonable for a therapist to offer this. Additionally, referrals are sometimes made for development in a very specific area and in some settings, like school systems, there is a set of objectives

that were determined as priority above all else for that individual. In these cases, the therapist may be expected to address pre-determined goal areas in their music therapy work.

What is the relationship between music therapy experience, frequency of self-determination used in practice, and focus towards increased access for clients?

While there was no reported significant relationship between how long a music therapist had been working and their perception of the importance of incorporating self-determination in music therapy practice, relationships were found connecting years of experience, the frequency self-determination is incorporated into sessions, the importance of incorporating self-determination in music therapy, and the frequency of goals being directed at increasing access to self-determination. There was a somewhat significant positive relationship between the number of years a music therapist had been practicing and how often self-determination was incorporated in music therapy sessions. This result could have been impacted by the demographics of the participants. The majority of respondents had 10 or more years of experience in music therapy and the second largest category was music therapists with one to three years of experience. Because of the largest two categories were the most and least experienced practitioners, the responses provided were from music therapists who had significantly different amounts of experience. It is possible that music therapists became more familiar with this concept and how to incorporate it into music therapy sessions over the course of their careers. One participant emailed the researcher with questions about self-determination and expressed concern that their clients were unable to speak and therefore could not engage in self-directed action. Another admitted not understanding the concept and how it

applied to her work after completing the survey. These factors imply that there is a need for information in the literature about where and how self-determination fits into music therapy practice with individuals diagnosed with I/DD.

There was a significant positive correlation between the frequency of goals being directed at increasing access to self-determination and how often it was incorporated into sessions. As therapists worked towards increasing access to self-determination globally, there was also an increase in how often it was incorporated into sessions. This finding seems to support the idea that access to self-determination is improved by increased practice and experience, in addition to perceptions of others about the ability of the person to actively participate in the decision-making process (Garrels & Arvidsson, 2018; Shogren et al., 2015). By having increased opportunities to engage in self-determination during the session, the therapist is demonstrating a belief that the person is capable. Goals directed at increasing access to self-determination allow the individual repetitive opportunities to practice skills with the intent of improving future self-determination.

There was a significant negative relationship found between music therapists' perception of the importance of incorporating self-determination in music therapy and the frequency of goals in therapy directed at increasing access to self-determination. The answer choices for frequency of self-determination were listed from never to always and the answer choices for the importance of incorporating self-determination in music therapy were listed from strongly agree to strongly disagree. Because of the ordering of the answer choices in the survey, the relationship indicates that increased importance of incorporating self-determination was associated with higher frequency of goals being directed at increasing access. There was also a significant negative relationship found

between the frequency of self-determination being incorporated into music therapy sessions and the perceived importance of incorporating self-determination into music therapy. Similarly, these results indicate that increased perceived importance of incorporating self-determination in music therapy was associated with a higher frequency of self-determination being incorporated into music therapy sessions.

Recommendations for Clinical Practice

Self-determination is a complex concept that can be incorporated into music therapy in a variety of ways (Curryer et al., 2015; Gadberry & Harrison, 2016; Garrels & Arvidsson, 2018; Kostikj-Ivanovikj, & Chichevska-Jovanova, 2016; Shogren & Broussard 2011; Shogren et al., 2015). Music therapists believe that it is important to incorporate into music therapy sessions and that there are associated benefits for therapists, caregivers, and clients. Self-determination should continue to be incorporated in music therapy as is supported by previous literature (Adkins et al., 2012; Gadberry & Harrison, 2016; Graham, 2004; Lee, 2012). Additionally, further advocacy and incorporation of client directed therapy services may be beneficial to clients and the profession. Advocacy and sharing of successes and methods of incorporating self-determination for clients, in addition to the benefits, may assist in systems adapting to allow for more authentic participation from service users.

The development of these new methods for incorporating self-determination and adapting to fit the individual needs of clients will call for creativity from music therapists. Analyzing the problem, seeking input from others, and engaging in complex problem solving will become part of the steps to incorporate self-determination within systems that were not designed to support this way of working with individuals diagnosed with

I/DD. An additional method of advocating for increased access for clients is translating musical self-initiation from sessions into language understood by caregivers and treatment team members who are not music therapists. In clinical improvisation, for example, a client may exhibit musical and nonmusical behaviors that demonstrate self-initiation that are not frequently observed in other areas. Highlighting these events and teaching the significance can encourage staff supporting the individual to challenge their perspective of what the person is capable of.

Another way of advocating for self-determination in music therapy is to highlight it explicitly in music therapy research and education. While confusion about this topic was reported by a relatively few number of music therapists who participated in the survey, it did come up for several people and it can be assumed that there may have been more who did not make this known. By highlighting self-determination with its definition, methods of incorporating, benefits, and descriptive examples, music therapists can increase their knowledge and ability to further advocate for and incorporate this with individuals diagnosed with I/DD.

Limitations of the Study

There were several limitations of this study. One limitation of this study were the technical difficulties that were experienced with the online survey distribution. The original email containing the survey link and description of the study did not reach all of the participants it was intended for and some who had expressed a desire in participating in the survey were unable to because of unknown technical glitches. Another limitation was the requirement to purchase email addresses for all board certified music therapists from the Certification Board for Music Therapists rather than being able to acquire email

addresses for only those who identified working with individuals diagnosed with I/DD. It is unclear if the number of responses received is significant because a total number of music therapists working with individuals diagnosed with I/DD is unknown.

Another limitation is the lack of participation by service users in giving their perspective of self-determination in music therapy. This study provides a description of what music therapists believe about self-determination in music therapy, but does not include the voice of individuals diagnosed with I/DD. Additionally, some information that may have been important to discuss, potential harms associated with self-determination for example, were not included as topics addressed by survey questions. Because of the design of the survey, having free-response spaces available for reporting educational background and work setting, there were also correlations that could not be tested for that may have provided additional insight into possible relationships between educational training and work setting and incorporation of self-determination. This study functions as an initial investigation of music therapists' awareness and perceptions about self-determination and further investigation would need to be done to gather additional information on the topic.

Implications for Future Research

A theme that emerged from this research was the knowledge that music therapists view self-determination as important and recognize benefits for clients, therapists, and caregivers, but may not feel that they are able to incorporate self-determination beyond providing choices and making clinical decisions based on client responses to interventions. Exploring advocacy and how music therapists are expected to function within systems that serve clients diagnosed with I/DD. There has been little research

exploring self-determination as it relates to music therapy and even less exploring advocacy for increased access for clients.

There was a significant relationship between the number of years someone had been practicing music therapy and how frequently self-determination was being incorporated into music therapy sessions. Future research could further investigate why this relationship is present and what could be done to narrow the gap between less experienced professionals and those who have been serving as music therapists for 10 or more years. Further investigation could also address whether work setting or educational background and training has an impact on the incorporation of self-determination in music therapy.

Finally, the perspectives of service users who are directly impacted by access to self-determination in music therapy should be further explored. Previous literature outside of music therapy (Curryer et al., 2015; Curryer et al., 2018; Heslop et al., 2002; McGlaughlin, et al., 2004) has included the voices of individuals diagnosed with I/DD; however, the participants had relatively limited barriers to self-determination and most lived fairly independently within community settings. Future studies should strive to provide accommodations and recruit participation from individuals who have a wider range of perspectives regarding access to self-determination. This access should also be explicitly explored as it relates to music therapy.

Conclusion

This study provides some insight into music therapists' perspectives of self-determination in music therapy for individuals diagnosed with I/DD. It explores beliefs held about self-determination and associated benefits for clients and therapists alike.

Additionally, relationships were found between years of experience, the importance of incorporating self-determination, and the frequency that goals were aimed at increasing access to self-determination. The findings of this study support music therapists' awareness of self-determination and provide information about how frequently it is reported as being incorporated into sessions with individuals diagnosed with I/DD. Even though much of the literature supporting this research came from areas outside of music therapy, there was alignment in the reporting of essential skills and associated benefits of self-determination.

An initial view of self-determination in music therapy with individuals diagnosed with I/DD is provided by this study and there is a need for further research to expand the available information in music therapy literature. Additionally, the perspectives of services users should be sought and included as research about self-determination directly relates to them and their access to choice and control.

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Appendices

Appendix A

Consent Email for Music Therapists Invited to Participate in the Survey

Dear Music Therapist,

As a music therapist who provides services to individual(s) diagnosed with intellectual and developmental disabilities, you are invited to participate in a survey to gather information about your views of self-determination within music therapy practice with this population and how it may appear in your clinical work. This survey is part of my thesis research, which I am conducting at Appalachian State University.

Your contact information is being used with permission from the Certification Board of Music Therapists, but the information you provide will remain completely anonymous. The survey is hosted by Qualtrics, which is a secure site, and email addresses will not be stored or distributed by the researcher. The anonymous data will be included in the researcher's master's thesis, and the study may be submitted for publication and presentation at AMTA conferences. There is an opportunity at the end of the survey to provide contact information for further involvement in the research. This would be entirely voluntary and is not a requirement for participation in the survey.

Your participation in completing this survey is voluntary, and there are no consequences if you decline to participate or decide to discontinue participation at any time. No risks are associated with completing this survey, and you will receive no compensation. You will be asked to complete 18 questions regarding the use of music therapy in this capacity; this process should not take more than 10-15 minutes. If you are willing to participate, please continue to access the online survey. By submitting responses to the survey you are consenting to participate. You can choose to respond to all, some, or none of the items.

Please complete the survey by December 15, 2019.

Questions may be directed to:

Katelyn Beebe, Principal Investigator, johnsonkp2@appstate.edu

Melody Schwantes (Reid), Faculty Supervisor, ms18994@appstate.edu

By continuing to the survey, I acknowledge that I am at least 18 years old, have read the above information, and provide my consent to participate under the terms above.

Thank you for your participation.

Warm Regards,

Katelyn Beebe, MT-BC
Principal Investigator
Candidate for Master of Music Therapy degree

Appendix B

Music Therapist Survey Questions

Section 1 of 4

Demographic Information

1. What population do you work with?
 - a. Children with I/DD (0-12 years)
 - b. Adolescent with I/DD (13-18 years)
 - c. Adults with I/DD (19-50 years)
 - d. Older adults with I/DD (51 + years)
2. What setting do you work in?
 - a. Private practice
 - b. School system
 - c. Day program
 - d. Group home, nursing home or residential facility
 - e. Other
3. What is your level of education? (Check all that apply)
 - a. MT-BC/Bachelors/Equivalency
 - b. MMT/MM/MA
 - c. Ph. D., DMA, etc.
 - d. NMT
 - e. ABA
 - f. Other (Please list)
4. What is your geographic location?
 - a. Great Lakes region
 - b. Mid-Atlantic region
 - c. Midwestern region
 - d. New England region
 - e. Southeastern region
 - f. Southwestern region
 - g. Western region
 - h. Outside the United States
5. How many years have you been working as a music therapist with individuals diagnosed with intellectual and developmental disabilities?
 - a. 1-3
 - b. 4-6
 - c. 6-10
 - d. 10+
6. Do you identify as having a disability?
 - a. Yes
 - b. No
 - c. Prefer not to answer

Section 2 of 4

Perceptions of Self-Determination

Self-determination is broadly defined as a person's ability to act autonomously and express choice and control over aspects of their own life

7. Self-determination can be improved over time with practice and experience making choices and expressing control over aspects of daily living
 - a. Strongly disagree
 - b. Disagree
 - c. Neutral
 - d. Agree
 - e. Strongly agree
8. In order to be considered self-determination, an action or decision must be made completely independently of assistance or influence by another person
 - a. Strongly disagree
 - b. Disagree
 - c. Neutral
 - d. Agree
 - e. Strongly agree
9. What skills are required for self-determination? List as many as you would identify as essential skills for self-determination
 - a. _____
 - b. _____
 - c. _____
 - d. _____
 - e. _____
 - f. _____
 - g. _____
 - h. _____
 - i. _____
10. What are some possible benefits from increased access to self-determination? List as many as you would identify as possible benefits
 - a. _____
 - b. _____
 - c. _____
 - d. _____
 - e. _____
 - f. _____

- g. _____
 - h. _____
 - i. _____
11. There are degrees to which self-determination can be expressed by an individual
- a. Strongly disagree
 - b. Disagree
 - c. Neutral
 - d. Agree
 - e. Strongly agree
12. All clients are able to work towards increased access to self-determination
- a. Strongly disagree
 - b. Disagree
 - c. Neutral
 - d. Agree
 - e. Strongly agree
13. Self-determination is important to incorporate in music therapy work with clients diagnosed with intellectual and developmental disabilities
- a. Strongly disagree
 - b. Disagree
 - c. Neutral
 - d. Agree
 - e. Strongly agree
14. How frequently is self-determination emphasized in your music therapy sessions?
- a. Never
 - b. Rarely
 - c. Sometimes
 - d. Often
 - e. Always

Section 3 of 4

How Self-Determination May Appear Within a session

15. How does self-determination look in your music therapy sessions? Check all that apply
- a. Making choices (songs/instruments)
 - b. Selecting or requesting interventions/activities
 - c. Working on specific skills needed for self-determination
 - d. Goals selected based on assessment of client interests/areas of motivation
 - e. Music therapist facilitates client helping to determine goals
 - f. Solely Client determined goals
 - g. Client helps track data
 - h. Client affect and musical/non-musical behavior directs the course of the session
 - i. Creating a responsive environment that supports and encourages self-expression
 - j. Other (Please list) _____
 - k. Other (Please list) _____
 - l. Other (Please list) _____
16. How often are goals in therapy aimed at increasing access to self-determination?
- a. Never
 - b. Rarely
 - c. Sometimes
 - d. Often
 - e. Always
17. What are some possible reasons you as a therapist might take on a stronger leadership role?
- Check all that apply
- a. Specific goal(s) requested by the treatment team
 - b. Unsafe behaviors that need to be addressed
 - c. Facilitating a meaningful experience that may be new or unfamiliar
 - d. Increased support requested or warranted
 - e. Encouraging development in a very specific area
 - f. Other (Please list) _____
 - g. Other (Please list) _____

Section 4 of 4

Opportunity for Client Participation

18. Do you have a client who may be interested to participate in an interview? This 5-question semi-structured interview will be used to provide insight on the perspective of individuals diagnosed with intellectual and developmental disabilities who have participated in music therapy and their experiences with self-determination in music therapy. To be eligible to participate in the interview participants must have a diagnosis of I/DD, participation experience in music therapy, a familiar communication partner present for the interview, a method of communication that is understood by the communication partner (aided or unaided), consent from a guardian and assent to participation in the study. Please provide your email address if you agree to being contacted about client participation in the interview.

Thank you for completing the survey!

If you have any questions regarding the survey, please contact:

Katelyn Beebe, Principal Investigator, johnsonkp2@appstate.edu

Melody Schwantes (Reid), Faculty Supervisor, ms18994@appstate.edu

Appendix C

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: Katelyn Beebe
 Music
 CAMPUS EMAIL

From: Dr. Andrew Shanely, IRB Chairperson

Date:

RE: Notice of IRB Approval by Expedited Review (under 45 CFR 46.110)

STUDY #: 20-0075

STUDY TITLE: Perceptions of Self-determination in Music Therapy for individuals Diagnosed with Intellectual Disabilities: A Mixed Methods Study of Music Therapists and Service Users

Submission Type: Initial

Expedited Category: (7) Research on Group Characteristics or Behavior, or Surveys, Interviews, etc.

Approval Date: 12/12/2019

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 determined that this study involves minimal risk to participants.

This review was conducted under the 2018 Requirements of 45 CFR 46 and the IRB determined that Continuing Review is not required in accordance with section 109(f)(1), under one of the following criterion:

(i) Research eligible for expedited review in accordance with §46.110;

You may see an "expiration date" in IRBIS which is years in the future--this is to allow for no annual review until the IRBIS system can be updated to remove a date requirement for this field.

Please note: After a discussion with the PI, the IRB Administration determined that a letter of support/approval was only necessary for the research activities with the client subjects from the regional treatment facility, not for the Music Therapists from the registry. The PI agreed to supply the approval from the regional treatment facility when it became available and prior to research activities in this facility. Thus the current approval is only for research with the music therapists; please submit a modification when the approval letter from the facility becomes available and the IRB will grant you full approval.

All approved documents for this study, including consent forms, can be accessed by logging into IRBIS. **Note the IRB Administration edited the consent form to remove the expiration date as this study will not expire.**

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:

Vita

Katelyn Beebe was born in Asheville, North Carolina. She attended Western Carolina University, where she earned a Bachelor of Music in music performance magna cum laude. Katelyn then attended Appalachian State University to study music therapy as a student of the combined Equivalency and Master of Music Therapy Program. She began her internship at J. Iverson Riddle Developmental Center in June 2018 and after completing her internship, Katelyn passed her board certification exam and became a board-certified music therapist (MT-BC) in January 2019. Katelyn was offered and accepted a position as a creative expressive arts therapist at J. Iverson Riddle Developmental Center and returned to Appalachian State University for the Master of Music Therapy in January 2019. While pursuing this degree, Katelyn worked full-time as a music therapist at a facility for adults diagnosed with intellectual and developmental disabilities and supervised pre-internship music therapy students in clinical practicum placements. Katelyn will graduate with a master's degree in music therapy in August 2020. After graduating from Appalachian State University, Katelyn will continue to work as a music therapist at the same facility for adults diagnosed with I/DD.