Quality of Life Issues for Three Young Adults with Developmental Disabilities
Receiving Music Therapy During Transition from High School to Adult Life:
A Phenomenological Inquiry

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Master of Music

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This thesis titled
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ABSTRACT

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Quality of Life Issues for Three Young Adults with Developmental Disabilities

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Director of Thesis: Kamile Geist

The purpose of this research was to document the experiences of individuals with intellectual disabilities (ID), developmental disabilities (DD), and/or Autism Spectrum Disorder (ASD) and their families/caregivers who received music therapy services in order to observe its effect on their lives during their transition period from high school into young adulthood. Participants included three young adults between the ages of 18 to 23 with ID/DD/ASD, their family members, and the music therapists who worked with them. The research questions were: 1) What were the experiences, thoughts, and feelings for all participants regarding music therapy services during the transition from high school to young adulthood and how did it affect overall quality of life? and 2) How does music therapy help with transition, coping with the changes and quality of life for the individuals involved? The methodology was phenomenological with data sources being observations of music therapy sessions, interviews with the individuals and their family members, and interviews with the music therapists. Coded data consisted of transcribed interviews and observations of sessions to substantiate prominent themes or unusual phenomenon (Moustakes, 1994). Four themes emerged in the data analysis: 1) the client’s connection with music allowed for a connection with people (socialization);
2) the love of music encouraged focused attention (focus); 3) families will search for and
go to great lengths to provide services that benefit their child (effort); and 4) transition
through various life stages greatly increased quality of life through the participation of
music therapy (quality of life).

*Key words: intellectual disability, developmental disability, Autism Spectrum Disorder,
transition and music therapy.*
I would like to dedicate this work to my God and family without whom I could not have accomplished the completion of my degree.
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CHAPTER 1: INTRODUCTION

Transition from high school to young adulthood can be challenging for anyone. Independence, participation in community, and setting future goals are a few of the plans made during transition preparation with the high school team of teachers, the student with special needs, their family, and other therapists. Individuals with intellectual disabilities (ID), developmental disabilities (DD) or Autism Spectrum Disorder (ASD) and their families have additional challenges in making the transition from high school to young adulthood a smooth and seamless process. Their concerns may include the lack of employment opportunities for their child, whether independent living is feasible or whether their child will be able to communicate his or her needs to someone other than a family member. Music therapists can be members of this team to assist an individual with ID/DD/ASD and their families through this major change in their lives.

According to the American Music Therapy Association website, “Music therapy is the clinical and evidence-based use of music interventions to accomplish individualized goals within a therapeutic relationship by a credentialed professional who has completed an approved music therapy program” (American Music Therapy Association, 2011). If listed as a related service on his or her Individual Educational Program (IEP), this credentialed specialist would provide music therapy services to a young adult with ID/DD/ASD still in public school (Coleman & Brunk, 1999). These services are adapted to meet the individual needs of the young adult to reach the goals and objectives established for self-expression, learning, and personal growth (Davis, Gfeller, & Thaut, 2008). Music therapy services are available through various venues
such as clinics, private homes, or a sheltered workshop before or after the young adult graduates or leaves the public school system (Davis, et al., 2008). Although the young adult’s education in the public school ceases after graduation, music therapy services can continue and be a stabilizing factor in their changing lives.

Transition from high school into young adulthood for individuals receiving special education services begins in their teenage years (Betz, & Redcay, 2005; Chen, 2011; Marquette, 2007; McIntyre, Kraemer, Blacher, & Simmerman, 2004). The Individuals with Disabilities Act (IDEA, P. L. 101-476) mandates that schools provide transition services for individuals receiving special education services and documented in the student’s IEP. Schools are required to assist individuals in making the transition from high school to young adulthood; however, according to one study, social services in communities “…varies greatly across the nation” because states are responsible for how services are distributed (Rizzolo, Hemp, Braddock & Schindler, 2009, p. 152).

**Background**

Having a disability can separate one from the rest of society. This separation excludes many of these individuals from typical activities, which they cannot participate. They require additional family support and government assistance. Approximately 11.9% of the population has some form of disability diagnosis according to the United States 2010 Census (United States Census, 2010). The Center for Disease Control and Prevention estimates that there are 4.5 million diagnosed with developmental or intellectual disabilities in the United States (Center for Disease, n.d.). These conditions may include “…autism, Down syndrome, and congenital anomalies” (Braddock, 2007, p.
170), and can include labels such as “…mental retardation, …and brain injury” (Braddock, 2007, p. 171). Other definitions or conditions cited as developmental or intellectual disabilities include cerebral palsy and epilepsy (Farnan, 2007). For most of these individuals and their families, their disability will define how they live the rest of their lives.

Family and caregiver support is usually the stabilizing factor for individuals with ID/DD/ASD. Although many of these individuals still live in institutions, nursing homes or other community settings as adults, many more rely on family and caregivers for support into the adult years (Braddock, 2007; Fresher-Samways, Roush, Choi, Desrosiers & Steel, 2003; Rizzolo et al., 2009). The number of individuals with ID/DD/ASD living in their family home is growing in the United States. For many of these individuals, families are continuing to support them into their adult years since family support services, which may include provisions such as transportation, financial assistance and respite services, have increased more than 34% between 2000 and 2006 (Rizzolo et al., 2009). These caregivers are also aging and want their family member(s) to be taken care of when they are gone (Braddock, 2007; Braddock, Hemp, Rizzolo, 2004; Rizzolo et al, 2009). Braddock (2007) reports, “research and training support has declined significantly in comparison to the growing financial commitments for services and income maintenance” (p. 169). Services and supports for these families and caregivers are limited in many communities throughout the United States.

Government funding for services for individuals with ID/DD/ASD does not cover all the needs. Formed in the early 1960’s, the Kennedy Panel wanted states and local
governments to include individuals with ID in the communities, schools, and work places; nevertheless, funding for services is decreasing (Braddock, 2007; Braddock, et al., 2004; Rizzolo, et al., 2009). When government monies shrink, the burden shifts to the families and caregivers to provide the majority of financial support throughout their lives. According to a recent Harvard University study, costs to raise and care for an individual with ASD “… can add up to 3.2 million over his or her lifetime compared with the $222,360.00 it typically takes to raise a child to age 18” (Chen, 2011, p. 10). These figures can be daunting for families who are responsible for their child’s happiness, activities, quality of life, and meeting their needs.

Families and caregivers are often the ones who know the individual best and know their needs. For individuals with severe intellectual disabilities or Profound Multiple Disabilities (PMD), communication about needs and desires or anxiety about upcoming events can be challenging (Dillon & Carr, 2007; Hagopian & Jennett, 2008; McIntyre et al., 2004). An individual with PMD cannot verbally communicate his or her happiness or unhappiness or make choices about leisure activities similarly to an individual who can voice their opinions and desires (Dillon & Carr, 2007; Zijlstra and Vlaskamp, 2005). Families and caregivers are concerned about their children’s future and their quality of life (Chen, 2011; Howlin, Goode, Hutton & Rutter, 2004). Since an individual’s IQ (Intelligence Quotient) determines his or her future plans, an adult with ID/DD/ASD that is looking for direction in their life will rely heavily on family and caregivers to direct them since adult services are limited (Howlin, et al., 2004).
Many music therapists throughout the United States work with individuals with ID/DD/ASD (American Music Therapy Association, 2011). While music therapy with individuals with ID/DD/ASD began in the institutional setting, music therapists serve their clients in a number of different settings which may include residential facilities, schools, private clinics, day habilitation centers and/or home environments (Davis et al., 2008; Farnan, 2007). Music therapy may include group sessions, sensory stimulation, the playing of instruments, or choirs to work on social, physical or functional skills based on the individual or group needs (Farnan, 2007). Chen (2011) stated that young adults with ID/DD/ASD are “…like any other young adult” (p. 9) and explain that family, friends, hobbies, recreational activities, and meaningful contact with their community influence their quality of life (Kensinger, 2004; McIntyre, et al., 2004; McManus, 2007). I would presume that if an individual with ID/DD/ASD and their family are seeking services that would provide socialization and assist with other non-musical needs, then music therapy could be a service that would be beneficial.

The Research Purpose

The purpose of my research was to find out how participating in music therapy had or was assisting the individuals with ID/DD/ASD and their families in transitioning from high school to being a young adult and how it affected their quality of life. My overriding reason for investigating how music therapy assisted in transition from high school to young adulthood grew from personal experiences I had with my son with ASD. During his last two years in high school, he often verbalized his concern over what his life would be like after he graduated. He expressed anxiety over the potential inability to
see his friends or the teachers and staff at the school. He was concerned about the type of job he would obtain and what requirements it would have of him. His awareness of his disability caused anticipatory anxiety related to anything unknown. The transition team at his high school worked diligently to assist in an appropriate placement to try to elevate his concern. My role as his mother was to reassure him that everyone, including his family, teachers at school, and other members of the community were working to make his transition from the structured school environment to his role as an adult in the community a smooth one. Now enrolled in music therapy through a local community music school, my son enjoys his sessions and has recently learned to play the bass guitar. I wondered if he had been participating in music therapy during this transition time, if the music therapy would have assisted him and reduced the anxiety he was experiencing.

I tell my story as a prelude to the stories below. These three stories are examples of music therapy sessions from an observer’s point of view. Not every session is the same as these, but tailored to meet the needs of the client for that particular moment in time and guided by the goals and objectives set forth by the therapist, client and family. My reason in telling you these stories was to allow you a glimpse of the diversity found in a music therapy session and how participating in music allows the music maker to be more than they might be in another setting.

Wayne (pseudo name).

The first observed session was with Wayne who entered the session area via a hallway. He was a nice looking young African American with glasses with a big smile on his face. He did not look at me directly, but sat on the bench next to me. He had books with him and after his dad arrived, I stood up and introduced myself. When I looked towards Wayne and said hello, his dad prompted him to say hello back to me. The
smile remained and the hello was unnatural. He continued to ‘hug’ his books as we walked into the session room. His therapist gave him instructions and I faded into the background. After the session started, I lost track of time and my feelings of anxiety disappeared. I became immersed in the music, the activity, and the conversation.

Wayne wrote his session schedule on paper, and then he and his therapist began. She gave him opportunities to make choices, state his preferences in complete sentences, since that was one of the main goals, and direct the pace of the session. Wayne is an accomplished musician. He played the piano and drum set. He not only performed pieces he and his therapist had been working on, but he played other piano works he had found or been given from school. Each time he finished, he said, “I did good.” I assumed it was one of his ‘comfort’ sentences. His therapist encouraged him to expand his statements identifying what he had done “good” and to include comments about her part in the performance. Not only did this young man read standard piano score, which can be quite challenging, he kept a nice rock beat on the drum set, which for those of us with little coordination, is rather impressive. His therapist encouraged him on a second number to make his pattern ‘more complicated’ by adding eighth notes on the cymbal. He was able to accomplish this task while using both feet to play the bass drum and high-hat and his left hand was playing the snare drum. I was impressed!

After finishing this part of the session, the therapist and Wayne guided me to the ‘porch’. This area contained a number of computers and other electronic equipment. Wayne enjoys music computer games and the therapist uses the games as a reward for the accomplishments done earlier in the session as well as a chance to test his music theory knowledge. Despite the fact that Wayne has difficulty saying a complete sentence without prompting, and challenged to hold a conversation with anyone, he is intelligent. He can read and follow the instructions provided in the game, needing little assistance from his therapist, who was taking data. While the computer game was fun, some of the activities tested him, but he remained calm. At one point, he was selecting the wrong answers and he raised his voice, rubbed his head and began to rock back and forth. His therapist calmly reminded him that he was doing his best and to try again. He contained his excitement and finished the task.

When his session time was over, he stood to leave. With prompting from the therapist, he bid me goodbye and headed out the door. I was stunned. I had never witnessed anything like that in my life and thought I was going to explode from excitement. This music therapy session gave a young person like Wayne an opportunity to practice socialization skills and perform music beautifully.
Sam (pseudo name).

My next observation session was with Sam. This young adult did not seem to notice me from the time we started until the session was almost over. Upon arriving in the therapy room, he sat down next to his therapist and began to sing. They were working on a musical based on his love of video games and this song was a part of that project. He sang, she typed and she would often have to slow him down and ask him for clarification, but that did not stop the creativity exuding from this individual. At times, he snapped his fingers and moved to the music because he was the music. After they finished the typing, it was time to record. She wanted to hear him sing the song from start to finish so she would have some indication of the song as a whole.

She then got up from the computer and headed to the printer to insert more paper. Nothing seemed to work correctly. Despite setbacks with the computer software or the printer not wanting to cooperate, Sam remained focused on the task. When the therapist determined that she was not going to be able to print out the words, they moved over to the piano so they could begin the process of writing down the musical notes. She had him make choices regarding the kind of sound, beat and style he wanted the composition to include so she could program these features into the electronic keyboard. After several minutes had elapsed, his therapist took a moment to check the clock and stated it was time to go. She allowed him to choose a song from YouTube®, so he could sing along with the recording. I suspect this was his reward for all the hard work he had done during the session. As soon as the music started, he was out of his seat, snapping his fingers and moving to the music. He knew every word and ‘performed’ quite nicely.

After Sam finished his ‘reward’ song, he noticed me in the corner. He came over and asked what I was doing and what device was I using (referring to the camera). Once I told him it was a camera, a transformation took place. I was in the presence of an actor, reciting his lines, and using hand motions to get his point across. Had I been willing, he would have stayed another 45 minutes, I am sure.

In just the few minutes I was able to talk to Sam, one knew immediately that he was autistic. He did not use direct eye contact, his conversation jumbled and most of his statements were incomprehensible to the listener. However, here was a person who was a performer, a musician, a singer and a composer. If you compared Sam to Wayne, the differences were obvious. Wayne hardly talked; Sam talked too fast and his conversation did not make sense. Yet what they had in common was the reason I was visiting them – the music.
Abby (pseudo name).

My last observation session was with Abby. This young lady huddled next to her mom when they arrived and did not look towards me, but turned her head to the side. Her younger brother was with them also. He greeted me when it was appropriate for him to do so and moved restlessly in his seat, like any 10 to 12 year old would. Abby entered the session room, stood in the middle of the room and announced that there were going to be three of us. Trying to insure my comfort, her therapist followed us into the room, arranged some chairs, and then the session began.

For the first few minutes, it was obvious that she was nervous about me being there. She kept repeating to herself, under her breath, “She has a camera and she is taking pictures of us.” It seemed as though she just needed to express herself, then she could focus on her task, which was singing. She wanted to sing songs about the sun. Her therapist asked her why. Was it because it was sunny outside or was there some other reason? I do not remember her answer, but she stated she wanted to sing the entire session. Her therapist indicated that would be fine, but that would be a large amount of singing. The therapist also reminded her that if she changed her mind, that would be acceptable.

Before any singing could commence, Abby and her therapist wanted to progress through a vocal warm-up. They followed a specific set of tasks and Abby wanted to follow them in order. Despite her comfort with the routine of her session, she was very distracted during this process, often looking back to where I was standing with the camera and video recorder. Her therapist repeatedly manipulated her body and used musical cues to keep Abby on task. I did not know what to do, so I just remained in my designated spot. Eventually she got so engrossed in making music, that my presence became secondary. Even though someone was playing the drums nearby in a separate room, she remained focused on the music in her session.

After they finished the warm-up, Abby then selected the ‘sun’ songs she wanted to sing. Her therapist pointed out that they had not done some of these for quite some time, but that did not seem to fade her desire to continue. Although her back was to me at times, I could tell when Abby was singing and when she was not singing. Her therapist sang with her, but occasionally dropped out to hear Abby by herself. The amazing part of this process was how the music followed Abby. If she started to slow down because she could not remember certain words, then her therapist slowed down with her. After each selection, they hit fists. I assumed it was their personal congratulations to each other. Her therapist also complemented her on remembering the words, using good diction or some other positive statement. At one point, the therapist asked Abby to
point out something she had done well for that particular song. If she did not word it correctly, her therapist gently guided her statements so that it did not seem as if she were correcting her.

After all the ‘sun’ songs were complete, it was time to move on and to determine how much time remained. This developed into a task in and of itself. It became obvious that telling time was still a challenge to Abby even as a young adult. The therapist instructed her to look at the clock and talked her through the systematic process how to calculate the time. Patiently, the therapist cued Abby on how to read the clock and then use math to determine how many minutes remained in the session. It worked, but not without some struggles in between. At one point, Abby got frustrated, threw up her hands and raised her voice. Eventually, she determined the amount of time left in the session.

After verifying the time remaining, Abby and her therapist started a relaxation protocol. I learned later in the interview with the therapist and the family that this work had become a phenomenal revelation in Abby’s life. It had created a way for her to function in stressful situations. Abby chose to lie on the floor and the therapist began to play the piano, quietly, but purposefully. They started with breathing exercises, and then began imaging a place that Abby enjoyed. The music breathed with Abby and Abby breathed with the music, which was impressive to observe. While imaging the beach scene, the music represented the waves of the ocean. This improvised music, composed on the spot, matched the moment and it was lovely.

When the time came for the session to conclude, the therapist played repeating phrases intent on creating an ending for Abby. She also used verbal prompting to cue Abby to sit up and conclude the session. Abby stated she was done. The therapist quickly ‘checked in’ with her to make sure she was all right and then Abby left the room. I did not know what to say. Here was an individual that had come to the session anxious due to my presence, but had left totally relaxed and ready to leave. I knew at that point that I had truly witnessed music as therapy and it was beautiful.

**Problem & Addressing the Need**

Based on my literature review, one problem that I addressed in this study was to examine if music therapy services assisted individuals with ID/DD/ASD and their families and caregivers through the transition from high school into young adulthood. The other research question focused on if music therapy services assisted in increasing
quality of life for these individuals during this transition time and continuing into adulthood. This phenomenological study examined personal perspectives offered by individuals with ID/DD/ASD, the music therapists that worked with them, and their families, on how music therapy services affected the quality of life during their transition from high school to young adulthood.

As a practicing music therapist, I wanted to hear from these individuals and their families and caregivers how participation in music therapy services affected their lives through their transition from high school into young adulthood. I wanted to know if they saw this participation as being beneficial and increased their quality of life. I know there are many music therapists who work with individuals with ID/DD/ASD, yet did not find any studies, which detailed the thoughts and feelings of individuals with ID/DD/ASD and their families and therapists and how music therapy had affected their lives and quality of life.

This study included interviews with three young adults with ID/DD/ASD, their family members or caregivers, and the music therapists who work with them. I recorded, transcribed, and analyzed the interviews and music therapy sessions for three families from the mid-west area of the United States for this research. I used a content analysis procedure to determine themes that emerged in the data.

**Definitions**

Transition and/or Transition Services –

The term `transition services' means a coordinated set of activities for a child with a disability that- (A) is designed to be a results-oriented process, that is focused on improving the academic and functional achievement of the child with a
disability to facilitate the child's movement from school to post-school activities, including post-secondary education, vocational education, integrated employment (including supported employment), continuing and adult education, adult services, independent living, or community participation; (B) is based on the individual child’s needs, taking into account the child's strengths, preferences, and interests; (C) includes instruction, related services, community experiences, the development of employment and other post-school adult living objectives, and, when appropriate, acquisition of daily living skills and functional vocational evaluation (Wrightslaw, 2014, para. 3 - 4).

Quality of Life –

“…is a multi-dimensional concept” (Pain, Dunn, Anderson, Darrah, & Kratochvil, 1998, p. 5) which may include length of life, presence or lack of disabilities, status of physical, emotional or physical health, whether one considers him or herself at a disadvantage socially or culturally.

Intellectual Disabilities (ID)–

“…is a disorder with onset during the developmental period that includes both intellectual and adaptive functioning deficits in conceptual, social and practical domains” (American Psychiatric Association, 2013, p. 33).

Developmental Disabilities (DD)–

[An] umbrella term that includes intellectual disability but also includes other disabilities that are apparent during childhood. Developmental disabilities are severe chronic disabilities that can be cognitive or physical or both. The disabilities appear before the age of 22 and are likely to be lifelong. Some developmental disabilities are largely physical issues, such as cerebral palsy or epilepsy. Some individuals may have a condition that includes a physical and intellectual disability, for example Down syndrome or fetal alcohol syndrome” (AAIDD.org, 2013, para. 4 - 5).

Autism Spectrum Disorder (ASD) –

Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history…. Deficits in social-emotional reciprocity…. Deficits in nonverbal communicative behaviors…. Deficits in developing, maintaining and understanding relationships…. Restrictive, repetitive patterns of behavior, interests, or activities…. Symptoms must be present in early developmental period…. Symptoms cause clinically significant impairment in social, occupational, or other
important areas of current functioning (American Psychiatric Association, 2013, p. 50).

IDEA (Special Education Law) –

In 1970, Congress enacted the Education of the Handicapped Act (EHA), which funded state and local special education programs…. Section 504 of the Rehabilitation Act of 1973, a federal anti-discrimination law, was designed to prohibit any state, local or private organization…from discriminating against an otherwise qualified person solely on the basis of a disabling condition…. PL 94-142 (1975) …[is an] historic law, now currently enacted as the Individuals with Disabilities Education Act, or IDEA (Darrow, 2007, pp. 96-97).
CHAPTER 2: LITERATURE REVIEW

Individuals with intellectual disabilities (ID), developmental disabilities (DD), or Autism Spectrum Disorder (ASD) and their families and caregivers participate in developing a transition plan from high school into young adulthood through the student’s IEP (Individual Education Program). Topics of relevant studies of individuals with ID/DD/ASD addressed transitioning into adulthood and extracurricular activities, and discussed the views of the individuals themselves, family members and caregivers (Van Naarden Braun, Yeargin-Allsopp & Lollar, 2006; Forte, Jahoda & Dagnan, 2011; Marquette, 2007; Osgood, Foster & Courtney, 2010; Tobin, 2003). The newer concept of person-centered planning, physical health, happiness or unhappiness, how IQ in childhood determines what the person is like as an adult, and quality of leisure time were other topics of interest (Betz & Redcay, 2005; Dillon & Carr, 2007; Howlin, Goode, Hutton & Rutter, 2004; Orentlicher, 2008; Zijlstra & Vlaskamp, 2005). The lasting effects of music interventions on behaviors of individuals with ID/DD/ASD vary in the literature (Bhatara, Quintin, Heaton, Fombonne, Levitin, 2009; Boso, Emanuele, Minazzi, Abbamonte, & Politi, 2007; Ingber, 2003; Kaplan & Steele, 2005). However, literature on how music affects quality of life is limited (Coleman, 2002; Hash, 2010; Hays, 2006).

Music therapy is a related service for students who receive special education services in the public schools. According to Coleman & Brunk (1999), related services include “diverse interventions [such] as speech-language pathology, social work services, and rehabilitation counseling” and music (p. 10). Historically, “music educators were
pioneers in the practice of mainstreaming as the music classroom … served as an accepted placement for students with disabilities” (Darrow, 2007, p. 97). Since music therapy is a related service, it is required only for the individual to successfully meet their education goals. However, some school districts include music therapy as an enrichment service, which may include group sessions, teacher consultation or co-treatment with other school professionals (Coleman & Brunk, 1999). Children whose ages range from 3 to 21 can qualify for special education services with transition planning being a part of the IEP process when it is necessary to prepare for post-school activities such as independent living, work-related skills or post-secondary education (IDEA, n.d.; Wrightslaw, 2014).

Transition planning begins at age 16 nationally, but in Ohio, the requirement is age 14 (IDEA, n.d.; Ohio Department of Education, 2012). This planning process involves the IEP team and is written by school professionals, families/caregivers and the student themselves may be involved seeking out future employment opportunities, living arrangements and plans for leisure activities (Betz, & Redcay, 2005; Marquette, 2007; Smith, 2010; Tobin, 2003). Orentlicher (2008) states, “these transition services should be based on the students’ interests and preferences and … result in the achievement of meaningful post-school outcomes [such as] …leisure activities” (p. 3). The following is a review of the literature regarding the current state of music therapy with individuals with ID/DD/ASD, the issues surrounding transition to young adulthood, and how music influences the quality of life for these individuals.
Music with Individuals with ID/DD/ASD

Many researchers have shown that music is effective with individuals with ID/DD/ASD. The literature review conducted by Hooper, Wigram, Carson, & Lindsay (2008) organized descriptive, philosophical, and experimental writings from 1943 – 2006 to include music used with individuals with ID. The aim of this two-part search was to organize and publish an overview of the work accomplished in the field of music therapy and offer a historical account of how music can effect the cognitive, physical, emotional and psychological domains of those with intellectual disabilities. The experimental writings not only highlighted the need for evidence-based research in the field of music therapy, but also compared the musical aptitude of individuals with and without ID (Hooper et al., 2008).

Education and music skills.

According to Darrow (2007), many children with disabilities did not attend public school, but “…were educated in segregated institutions” (p. 94). Since music therapy had its beginnings in institutions, Hash (2010) investigated the historically important work done at the Illinois Asylum for Feeble-Minded Children from 1865 – 1920 (Farnan, 2007; Hash, 2010). Hash (2010) reported that this early attempt of including music education in an institution setting was to “…accompany physical exercise, develop speech, provide recreation, improve socialization, and enhance worship” (p. 37). Although, the overall goal of curing these individuals did not occur, the children benefited from the socialization and musical training (Hash, 2010).
Individuals with ID/DD/ASD have or can obtain musical skills. Music education has played a role in musical training for individuals with disabilities since the passage of PL 94-142 (Darrow, 2007). Darrow (2007) states, “in the early years of mainstreaming, music educators were given little or no training” (pp. 97-98); however, the law allowed schools to hire music therapists to service students in special education classrooms or assist those who for some reason, could not participate in the music education setting.

Programs such as Music and Minds centered on “…talent development [and focused] on strengths, interests and learning style preferences” (Reis, Schader, Milne and Stephens, 2003, p. 293). This study identified young adults with Williams Syndrome, a “…rare congenital disorder …that transcends traditional theories of intelligence and cognitive impairment” who were able to develop their music potential (Reis, et al., 2003, p. 294).

Music therapy sessions often focus on an individual’s strengths as opposed to their deficits since all have the potential for making music in some form or fashion.

**Music potential and leisure skills.**

Music potential includes creating music and listening to music which can often change or affect the listener as well as the performer. In an ethnodrama study by Snow, Snow and D’Amico (2008), attitudes of audience members were changed because the music and drama presented by individuals with ID/DD gave them an opportunity to communicate “…what it is like to live their lives” (p. 37). Snow et al., (2008) stated that the individuals with DD that participated in this production were able to assist in expressing themselves by composing and performing the musical portion of the drama. Self-expression is a primary focus in music making, especially in a music therapy
session. The Snow et al., (2008) study demonstrated that self-expression is vital to those with ID/DD and performance gives a chance for such expression.

For many, listening to music is a primary way to find enjoyment because not everyone is a performer. Listening to music can be a past time or leisure entertainment for anyone and an individual with ID/DD/ASD may find themselves listening to music because it has been pre-selected activity instead of a chosen one. When Magee and Bowen (2008) examined music as a leisure skill, they determined that it enhanced relationships because of its social nature and relatives and caregivers developed a meaningful way to communicate to their family member with multifaceted disabilities who were unable to enjoy music recreationally. Unfortunately, leisure for many with Profound Intellectual and Multiple Disabilities (PIMD) contained more empty hours than quality time and was planned and carried out by a professional instead of being the choice of the individual, according to a study done by Zijlstra and Vlaskamp (2005). Their investigation into the quality of leisure activity for individuals with PIMD highlighted the fact that these individuals were often incapable of planning their own leisure and relied on others for assistance (Zijlstra & Vlaskamp 2005). Their findings concur that individuals with ID/DD/ASD require support for life choices.

Socialization, communication and physical challenges.

Life skills such as socialization and communication are often the focus of music therapy with individuals with ID/DD/ASD. Several reports (Farnan, 2007; Kaplan & Steele, 2005; Boso, et al., 2007) highlighted deinstitutionalization in the 1970’s and 80’s and how the use of music in institutions with individuals with ID/DD/ASD decreased.
These accounts highlighted community programs, which showed that generalizing skills in the areas of socialization and communication occurred. The study by Boso et al. (2007) demonstrated that music therapy services could lessen autistic symptoms and increase the musical skills of eight students who received music therapy for a year. This study showed improved social and communications skills in addition to music skills (Boso, et al., 2007).

Even when physical limitations were present, evidence in two studies (Ingber, 2003; Ringenbach, Mulvey & Beachy, 2007) indicated how individuals with ID/DD/ASD learned through verbal instruction and participation in music making. Ingber (2003) used MIDI (Musical Instrument Digital Interface) with her Cerebral Palsy patients who had limited movement because it provided “…fun opportunities for working on motor skills, social interaction, and stimulating creativity” (p. 46). Ingber (2003) was blind and relied on verbal instruction since many of her clients were not capable of reading instructions. Motor skills, self-expression, social skills and increased self esteem were the benefits experienced by her clients use of music software and MIDI files (Ingber, 2003). Ringenbach et al. (2007) investigated individuals’, with and without Down syndrome (DS), ability to use different instruction methods when drumming. Verbal, visual and auditory instructions used with 30 individuals determined bimanual coordination between three groups (10 with DS; 10 mental age-matched (MA); 10 chronological age-matched (CA)). Results indicate that “…all groups moved the drumstick and wrist as one unit”, yet individuals with DS performed best when following visual instructions (Ringenbach et al., 2007, p. 959). These studies provide evidence that individuals with ID/DD/ASD
are capable of learning yet adaptations are necessary. As a music therapist, I often use adaptive techniques with my musical interventions to create a successful music-making environment for my client(s) even if physical limitations are not visually apparent.

While many view individuals with ID/DD/ASD as being vastly different from their non-disability peers, this is not always true. Bhatara, et al., (2009) demonstrated that individuals with ASD and non-ASD individuals interpreted soundtracks similarly when paired with animation. The results of this study showed that “…adolescents with ASD show[ed] no deficits in their ability to integrate music with moving visual displays or their ability to extract meaning from musical excerpts” (Bhatara et al., 2009, p. 390). When presented with music, this study also showed that all participants interpreted the animation differently when it “…altered the participant’s perception of the visual events” (Bhatara et al., 2009, p. 389).

**Transition from High School to Young Adulthood**

Transitioning from high school to the community and becoming a contributing member of society for people without disabilities can be challenging. Osgood et al., (2010) identified that services for vulnerable populations “…end abruptly as they transition to adulthood, even though the need for them continues” (p. 209). They also state, “…non-college-bound youth have much poorer prospects for successful and satisfying adults lives” (Osgood et al., 2010, p. 210). However, special education is one program that does provide a plan for transition. Transition planning, which involves teachers, families and the individual with a disability can be successful if support and education are a part of the process. Osgood et al., (2010) also attribute “…healthy
interpersonal relationships...certain personality traits, such as persistence and confidence, also enable some vulnerable youth to make a successful transition to adulthood” (p. 218).

**Adult roles and IQ.**

Another factor in the transition process is the acquisition of adult social roles as recognized by Van Naarden Braun et al., (2006). They acknowledged that parents of individuals with developmental disabilities have concern for their child obtaining employment, post-secondary schooling or becoming a caregiver themselves, but proved that “there is not a one-to-one relationship between impairment and the acquisition of adult social roles” (Van Naarden Braun et al., 2006, p. 921), except in the case of severe mental retardation. In such cases, Van Naarden Braun et al., (2006) stated, “supported employment, sheltered workshops and work or day activity centers may be more appropriate transition goals for young adults with severe developmental disabilities” (p. 916). Every parent, especially those with children who have a disability, are concerned about their child’s future and how they will function in their new adult role, navigate their community and contribute to society as they transition into adulthood (Van Naarden Braun, 2006).

An individual’s IQ may be a key factor in the development of their self-determination or ability to choose and successfully transition from high school to young adulthood. Howlin, et al., (2004) determined that if an individual has an IQ of 70 or greater, the likelihood of some independence is higher; however, these individuals remain “…very dependent on their families or other support services” (p. 212). Furthermore, while these individuals can still make progress as adults, their IQ remains stable and
independent living depends greatly on the support offered by families, employment and social services as well as the development of meaningful relationships (Howlin, et al., 2004). An individual with ID/DD/ASD and their family may be able to gauge their quality of life on the success of their transition from high school to young adulthood.

**Family responsibilities for support.**

Families and caregivers often act as spokespersons for their individual living with them; however, if the young adult with ID/DD/ASD has verbal skills and is able to express their wants and desires, Hall (2009) and Harnik (2010) revealed that independence, community involvement, and social interactions were important. In their mixed method study, Forte et al., (2011) compared the worries experienced by young people with mild to moderate ID as they make the transition to adulthood. This inquiry revealed:

…that the ID group’s most salient worries (being bullied, losing someone they are dependent upon, failing in life, followed by making and keeping friends)… [differed from]… their non-disabled peers (getting a job, followed by not having enough surplus money, failing, and having to make decisions about their future choices) at this stage of transition (p. 398).

 McIntyre et al. (2004) reiterated that an individual with severe ID has difficulty in communicating their needs and emphasized the importance of family involvement. Oschwald (2002) identified “family factors: close relationship with a caring parent figure, authoritative parenting: warmth, structure, high expectations, socioeconomic advantages and connections to extended supportive family network” (p. 43). Support can come from
outside sources such as teachers, other adult mentors and co-workers according to Oschwald (2002). Therefore, family members, caregivers, and others who support an individual with ID/DD/ASD bear a large responsibility for their loved one with a disability.

According to Chen (2011), finding a program that is effective often takes hours of intense planning on the part of family and/or caregivers. If independent living is accomplished, Marquette (2007) claimed that “the quality of supports and not the severity of the disability” (p. vi) was one aspect of making the transition successful. Families and caregivers were responsible for assisting these young adults in planning an effective transition and according to Marquette (2007), “creating networks of support” (p. v) for that transition. On the other hand, Marquette (2007) and Howlin et al. (2004) noted that if an individual is less dependent on their family, then family quality of life is greater.

Some have challenges that are more complicated due to their limitations in communication, socialization and physical impairments. Nurses Betz and Redcay (2005) sought to identify how organizing a transition team that examined all aspects of an individual with Special Health Care Needs (SHCN) was important to the individual and their families in making sure that the physical challenges be taken into consideration when developing a transition plan. Since most of these individuals continue to live with family into the adult years, Tobin (2003) reported that tension could occur among family members who have to assist in “filling in the gaps in the school and adult services systems” (p. iii). Tobin (2003) also noted that one specific strategy key to transition success is for the individual with ID/DD/ASD to state their preferences.
Music to Improve Quality of Life

Research indicating how music can address or enhance quality of life for individuals with ID/DD/ASD is emerging. Fresher-Samways, et al., (2003) and McIntyre et al., (2004) both contend that quality of life involves cultural differences and an individual’s unique perception of their personal circumstances. McIntyre et al., (2004) states, “most descriptions of quality of life include a delineation of dimensions at both individual (micro) and environmental (macro) levels” (p. 132). Since quality of life is so personalized, music therapists working with individuals with ID/DD/ASD and their families/caregivers must rely on the individuals and their families/caregivers for guidance in designing goals and objectives aimed at improving quality of life.

In addition, the American Music Therapy Association recognizes that music therapy is a profession whose mission is to improve quality of life for clients served by its credentialed therapists (American Music Therapy Association, 2011). Martinez (2009) stated, “music therapy may be applied as a method intervention contributing to the improvement of quality of life by reducing… anxiety, [and] depression…” (p. 330). Offered on an individual or group basis, and at any age, music therapy’s therapeutic benefits to an individual’s quality of life maybe many, however, little formal documentation exists identifying exactly how the music therapist should accomplish that feat.

When surveying the literature, I found only three studies that mentioned or paired music or music therapy and quality of life for individuals with ID/DD/ASD or other special population. First, Hash’s (2010) study investigated the children at the Illinois
Asylum discovered that the efforts made by the staff to include music into their daily routine showed improvement in their quality of life. Secondly, Coffman (2002) examined music and the quality of life with healthy older adults. He identified four factors (physical well-being, environment, psychological well-being and social relationships) as influential among older adult’s perception of their quality of life (Coffman, 2002). His article calls to music educators, music therapists and music researchers to recognize the growing need to examine the phenomenon of quality of life with this growing population and the need for more study. Lastly, Hays (2006) examined how music contributed to the quality of life for older individuals with special needs by giving “meaning in people’s lives” (p. 55). Hays (2010) also stated that these individuals felt socially connected and had a greater sense of well-being. This study recognized that the individuals interviewed considered music therapeutic and provided structure to their life (Hays, 2010).

However, not all individuals with ID/DD/ASD verbalize their perception and opinion of quality of life. Many of the studies noted obtained data from caregivers and/or family members of the individuals with developmental or intellectual delays (Betz & Redcay, 2005; Carr, 2008; Dillon & Carr, 2007; Hasselblad et al., 2007; Howlin et al., 2004; Kaplan & Steele, 2005; McIntyre et al., 2004; Reis et al., 2003; Ringenbach et al., 2007; Van Naarden Braun et al., 2006; Zijlstra & Vlaskamp, 2005). For individuals with ID/DD/ASD, input into their perception of the effects of music therapy outcomes or quality of life is minimal and covered only in the Hays (2010) study mentioned above.
Managing transition from high school to young adulthood and understanding how the multidimensional paradigm labeled quality of life is vulnerable to its success is challenging for young adults with ID/DD/ASD and their families. Inadequate community support restricts opportunities both for the individual with ID/DD/ASD and their families to make a successful transition from high school to young adulthood and improve their quality of life. In addition, limited personal input does not provide full disclosure on how the individual with ID/DD/ASD feels about their quality of life as it relates to their transition success.

Although Smith (2010) addressed the topic of transition from high school to young adulthood in her work with young adults with ASD and how music therapy assisted her clients, she did not conduct formal research to address this issue. This study will expand the knowledge gained by providing opinions of individuals with ID/DD/ASD and their families and caregivers who have experienced music therapy during their transition from high school to young adulthood. Their opinions and statements will give voice to the impact music therapy has made on their lives and their family members.

In summary, the research presented in this literature review has identified the phenomenon surrounding transition from high school to young adulthood for an individual with ID/DD/ASD and their family and/or caregivers. First, exposure to music for individuals with ID/DD/ASD describes how their involvement with music or music therapy for many years has experienced various benefits. These include increased socialization, improved musical skills and increased self-esteem (Bhatara, et al., 2009; Boso et al., 2007; Darrow, 2007; Farnan, 2007; Hash, 2008; Hooper et al., 2008; Ingber,
2003; Kaplan & Steele, 2005; Magee & Bowen, 2008; Reis, et al., 2003; Ringenbach et al., 2007; Snow et al., 2008; Zijlstra & Vlaskamp, 2005). Secondly, transition addressed issues such as a need for an inclusive transition team (Betz & Redcay, 2005; Osgood, et al., 2010), acquiring adult social roles (Van Naarden Braun, et al., 2006), and young adult and/or family anxiety (Tobin, 2003; Forte, et al., 2011). Other studies concentrated on communicating needs (Hall, 2009; Harnik, 2010; McIntyre et al., 2004; Orentlicher, 2008), family involvement (Chen, 2011; Marquette, 2007; Oschwald, 2002) and how IQ relates to the level of success in adult life (Howlin et al., 2004). Finally, music and quality of life was limited to three studies, which reported on improved quality of life for children in a late nineteenth/early twentieth-century insane asylum (Hash, 2010), Coffman’s (2002) study with healthy older adults, and Hays’ (2006) study of increased well-being for older individuals with special needs.

**Purpose and Research Questions**

The purpose of this qualitative study was to give voice to three individuals with intellectual disabilities (ID), developmental disabilities (DD), or Autism Spectrum Disorder (ASD) and their families who had experienced music therapy along with their music therapist during their transition period from high school to young adulthood. I wanted to identify the feelings and opinions of individuals with ID/DD/ASD, their families and their therapist to examine if music therapy service increased their quality of life and/or assisted them and their families in transitioning from high school to young adulthood. I posed the following questions:
1) What were your experiences, thoughts, and feelings (for all participants) regarding music therapy services during the transition from high school to young adulthood and how did it affect overall quality of life?

2) Did music therapy help with transition, coping with the changes and quality of life for the individuals involved?
CHAPTER 3: METHODS

I conducted this research study at a community music school in Ohio. The participants recruited for this study included three young adults with intellectual disabilities (ID), developmental disabilities (DD), or Autism Spectrum Disorder (ASD), between the ages of 18 to 23, their families/caregivers and their music therapists. I observed three music therapists and their young adult client with ID/DD/ASD, in a music therapy session. The sessions occurred at the community music school where the clients received music therapy services weekly. I also interviewed three music therapists, each young adult’s parents and family members, and in one instance, a sibling. To complete data collection, I also interviewed each of the three young adults, with an adult family member present.

I used a phenomenological qualitative design and approach. According to Moustakas (1994), “the aim [of phenomenological inquiry] is to determine what an experience means for the persons who have had the experience and are able to provide a comprehensive description of it” (p. 13). Procedures included collecting data from music therapy clinical observations, taking photographs during the music therapy sessions, and audio/video recording the music therapy sessions and interviews with all participants as well as my own journal notes. I transcribed all interview data from the music therapy sessions verbatim and included them as data sources. I applied a content analysis method designed by Moustakas (1994) to determine emergent themes in the data to the data sources of interviews and observations from the music therapy sessions.
Participants

Recruitment and informed consent.

Identifying participants for recruitment involved the following: 1) music therapists needed to be interested in participating in the study, 2) music therapists needed to be serving clients and families who met the required criteria (see below) for the study, and 3) clients and families needed to be willing to participate in the inquiry. I retrieved possible names of music therapists with their email contact information from the American Music Therapy Association individual directory site (http://www.musictherapy.org). A purposeful sample (Patton, 2002) of music therapists from Ohio currently working with young adults, ages 18 to 23 with ID/DD/ASD was the primary criteria for selection from this directory. The music therapist participants listed were board certified music therapists registered as being a professional member of AMTA and had a private practice or specifically listed that they worked with young adults with ID/DD/ASD. I emailed approximately 53 music therapists asking if they were willing to participate in this study (see Appendix A). Seven therapists responded. One individual stated that she was no longer working as a music therapist and five therapists stated they did not have clients that met the criteria. One therapist, the director of a community music school where several music therapists were employed and served clients who met the age requirement (18 to 23) in a large urban area, agreed to be a part of the study. I then worked closely with her to recruit therapists and families receiving services at her facility.
I implemented the requirements met before the recruitment plan, which included all Institutional Review Board (IRB) policies, ethical standards for human subject research, and confidentiality requirements. The director of the community music school contacted the therapists within her facility who worked with client(s) who met the criteria and asked if they were willing to meet me and possibly participate in the study. Four therapists, including the director of the community music school, agreed to a Skype (Skype™, 2014) meeting in order for me to meet each therapist and describe the study in detail. One of those therapists determined that she did not have clients that met the criteria needed for the study. By the end of the meeting, all agreed that the director of the community music school and two of her staff therapists had clients and families that they felt certain would be willing to participate in the research.

Once the music therapists determined that 1) they were willing to participate and 2) selected their client and family that met the criteria, they presented a letter (see Appendix B) to the families and the young adult with ID/DD/ASD introducing the research project with the time and commitment requirements. After all participants agreed to the terms set forth in the recruitment letter, the therapist, their client and family/caregiver agreed on a time to meet with me, the researcher, to obtain informed consent. The letter of consent (see Appendix C) explained the name and purpose of the study, an estimation of time commitment, when and where the interview(s) would take place and that all interviews would be audio/video recorded (Mack & Macqueen, 2005). All participants, including therapists, families and/or caregivers as well as the young adults with ID/DD/ASD were given the option to discontinue participation at any time if
they so desired, however, all participants participated through the completion of the study (Patton, 2002).

**Participant criteria.**

All participants met a certain criteria for this study, defined as a purposeful sampling model (Patton, 2002). The music therapist participant was responsible for determining if he/she had a client(s) and family/caregiver(s) that meet the criteria needed for participation in this study as well as verifying with the individual with ID/DD/ASD and their family/caregiver if they were willing to participate in the study. Other criteria required that their client be 18 to 23 years of age, have a diagnosis of ID/DD/ASD, as defined by the DSM V, and received music therapy services during the transition planning from high school to adult life (American Psychiatric Association, 2013). The client participant demographics are located in the table below (see Table 1). The additional participants for this study included the parents/caregivers of the young adults with ID/DD/ASD receiving music therapy as well as their music therapist. I informed all participants of my role as the researcher (Creswell, 2009).
Table 1:

*Client Demographics*

<table>
<thead>
<tr>
<th>Name</th>
<th>Age</th>
<th>Race</th>
<th>Gender</th>
<th>Disability</th>
<th>Family Type</th>
<th>Participant level of Education</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wayne</td>
<td>20</td>
<td>African American</td>
<td>Male</td>
<td>Autism</td>
<td>Traditional</td>
<td>Still in high school</td>
</tr>
<tr>
<td>Sam</td>
<td>19</td>
<td>Israeli</td>
<td>Male</td>
<td>Pervasive Developmental Disorder</td>
<td>Single parent home</td>
<td>Still in high school</td>
</tr>
<tr>
<td>Abby</td>
<td>20</td>
<td>Caucasian</td>
<td>Female</td>
<td>Autism</td>
<td>Traditional</td>
<td>Finished high school</td>
</tr>
</tbody>
</table>

**Researcher’s Role**

My role as researcher consisted of gathering field notes while observing and video/audio recording the three music therapy sessions. I also conducted all semi-structured interviews with the 10 participants and video/audio taped them (Creswell, 2009). I transcribed verbatim the music therapy sessions and all interviews. After transcribing each interview, I used member checking to determine the overall accuracy of the transcriptions.

**Data Collection**

Data collection occurred over a period of 12 weeks. The length of time was longer than expected because I travelled approximately 220 miles to and from the facility. Scheduling observations and interviews at the community music school was difficult at times when dealing with changing client/family schedules and extenuating circumstances. I arranged interviews and observations at times that the client and their family/caregiver...
were scheduled to be at the community music school for their music therapy session so they would not be required to make an extra trip to the facility. Due to unforeseen circumstances however, one family/caregiver interview, with two people in attendance, occurred over Skype (Skype™, 2014) since I was not able to return to the facility to conduct the interview in person. All other interviews, including those with the three music therapists, the three individuals with ID/DD/ASD & a family member and the four family members occurred at the facility.

I observed all of the music therapy sessions at the community music school. They lasted approximately 45 to 60 minutes, were audio/video recorded to document the reaction of the therapist and client with ID/DD/ASD and document their reactions to the experience. Acting solely as an observer, I also took photographs and field notes for the purpose of data collection (Creswell, 2009). I did not have preconceived ideas of what might occur in the sessions. Transcriptions included observations of the statements and actions of the music therapist, their client and what happened during the session including notes about the music performed.

I interviewed the three music therapists, the three individuals with ID/DD/ASD and four family/caregiver members. Their comments and thoughts on their music therapy experiences were audio/video recorded. Due to technical difficulties, one of the interviews was not audio recorded, however, all interviews were video recorded. I collected other documents such as client/therapist composed song sheets and music cue sheets for playing the drum set. In an effort to prevent personal bias and process my own connections to the families, I kept personal notes in a researcher’s journal.
Interviews with the three music therapists occurred at the facility site and lasted approximately 45 minutes to one hour. No second interviews with therapists were required for clarification of data. I used the proposed questions constructed for music therapists (see Appendix D) as a guide during the interview. Therapists were open and honest in their descriptions of their work with their client and the interviews progressed as expected. As each therapist described their work (past and present) with their client, their excitement grew as did mine. The stories and recollections enhanced my observations made during the music therapy sessions mentioned earlier.

Interviews with the parents/caregivers of the young adult with ID/DD/ASD took place at the community music school with the exception of one family interview, which took place over Skype™ (Skype™, 2014). These interviews lasted approximately 45 minutes while their child was in their music therapy session. I used the proposed questions constructed for families/caregivers (see Appendix D) as a guide during the interviews. Families seemed eager to share their experiences and their child’s successes in music therapy. As the interviewer, I found that I had to subconsciously remind myself to remain neutral and un-biased during these interviews. Many of the statements made by the families and caregivers reflected my own experiences as a parent of a child with ASD. The one exception interview that took place over Skype™ (Skype™, 2014) included a sibling of the client. While I did not expect his participation to be significant, I discovered that his statements were quite insightful regarding the music therapy experiences for his sister and his family.
All interviews with the young adults with ID/DD/ASD and a family member who assisted with understanding and clarification were audio/video taped and noted, and occurred at the facility site. These interviews lasted approximately 30 minutes in length (Creswell, 2009). I used the proposed questions constructed for young adults with ID/DD/ASD (see Appendix D) as a guide during the interviews. I began these interviews with open-ended questions, but soon discovered that close-ended questions were easier for the young adult to answer. Parent/caregiver participants assisted in these interviews by restating the question or answering for their child if the young adult did not know how to answer the question. I expected these interviews to be challenging for the young adult and myself since I was unfamiliar with the young adult’s communication style. The parent/caregiver being present allowed for a clearer understanding for all involved.

Data Organization

I transcribed each of the nine interviews and the three music therapy sessions verbatim. Once the transcriptions were complete, I coded the data. For the observations, I used different colored fonts to distinguish actual speech from action during the music therapy session. I saved the interviews as separate word processing documents on my computer and printed for filing. All videos of interviews and music therapy sessions were transformed into movies using IMovie® (“IMovie®, 2014), then burned onto a DVD disk for safekeeping.

For member checking (Creswell, 2009), I summarized each interview and gave it to the participant either in person or via email for verification and initials. I emailed one
Data Analysis

Data analysis involved identifying and coding emergent themes of both the observations and interviews. Due to the phenomenological nature of this project, this allowed for “the original description of experience in the context of a particular situation [to be] the primary target of phenomenological knowledge” as stated by Moustakas (1994, p. 14). Coding for content analysis, as defined by Moustakas (1994), allows for identification of the thoughts of the participants, typical settings for music therapy and the relationship between the music therapist and their client built in the therapeutic process.

Data sources included: 1) transcriptions from the audio/video taped sessions of the observations and interviews, 2) observation and interview notes taken by the myself, 3) notes from the researcher’s journal, and 4) photographs of therapy sessions taken by the researcher (Creswell, 2009). Four themes, which I discuss in Chapter 4: Results emerged from the data analysis. I then looked for commonalities across the data. This ultimately informed my analysis and conclusions on the value of music therapy for quality of life for adults with ID (intellectual disabilities), DD (developmental disabilities) and ASD (Autism Spectrum Disorder).

Credibility Checks

In qualitative research, reliability, generalizability, and validity are accounted for differently when compared to quantitative research (Shenton, 2004). Shenton (2004)
credits E. G. Guba for defining the trustworthiness of a qualitative study using the following terms: “a) credibility (in preference to internal validity); b) transferability (in preference to external validity/generalizability); c) dependability (in preference to reliability); d) conformability (in preference to reliability)” (p. 64). I used several credibility checks within my study to insure rigor for my research.

One strategy I used included a systematic use of specific questions for the different types of participants (see Appendix D) (Creswell, 2009). The prescribed questions allowed all participating in the interviews to stay on topic and focused. I crosschecked the transcripts to alleviate any mistakes and enlisted the assistance of another person as an inter-coder agreement (Creswell, 2009). Inter-coder cross-checking showed 54%. While this percentage was less than what I anticipated, my inter-coder stated that he was not a therapist and missed the voice inflection in the written pages. He also stated that the separate pages I supplied in order to give him a sample of various interviews and sessions caused some confusion.

Another form of credibility was to not disclose my bias as the parent of a young adult with ASD and my perspective of how music therapy has influenced his quality of life (Creswell, 2009). I kept a personal journal during the course of data collection and documented my thoughts and feelings of the information shared during the interviews and observations. This form of documentation allowed me to examine and possibly resolve any personal issues of the information shared by the participants.

As stated previously, each participant had an opportunity to examine and validate the information shared during the interview through member checking (Creswell, 2009).
Family/caregiver participants assisted their child with ID/DD/ASD in validating the information they shared by not only being present during the interview but also assisting with reading and validating the summary. No negative information was presented during the data collection process therefore the use of an external auditor was not needed (Creswell, 2009).


CHAPTER 4: RESULTS

The outcomes of this phenomenological inquiry resulted in four themes discussed individually below. These themes emerged in the data analysis of the interviews and observed music therapy sessions: socialization, focus, effort and quality of life (see Table 2). According to Moustakas (1994), horizonalization is viewing “every statement [as having] equal value”, (p. 180), however, for purposes of space, this summary will highlight only selected statements from participants. I gave my interpretation of the impact of music therapy and the implementations derived from the data in Chapter 5: Discussion.

Socialization

The theme of socialization was most prevalent in the music therapy sessions between the music therapist and the client, interviews with the music therapist and with the family members. It involved conversations between the music therapist and client about the music, choices that the music therapist gave the client during the session and recollections from the music therapists and family members of how socialization is a goal area for individuals with developmental disabilities (DD), intellectual disabilities (ID) and/or Autism Spectrum Disorders (ASD).

The subject of socialization did not arise frequently in the interviews with the client participants. Since a family member(s) accompanied clients, statements regarding socialization often came from them. For example, Abby’s mother pointed out during her interview that she enjoyed talking with her music therapist during their sessions together. Through prompting during the interview process, Sam did state that he enjoyed working
with his music therapist. Socialization for Wayne included sharing his varied accomplishments with the researcher during the interview with prompting by his father.

Illustrations of conversations between the music therapist and the client are the following, which occurred during Wayne’s session (see Figure 4.1). Notes and comments are from me:

Therapist: “OK, … you want me to play the song on the guitar or the piano?”
Wayne: “I want a song on guitar.”
Therapist: “That was a fabulous sentence.”

Notes: This conversation continues with the music therapist prompting him to use complete sentences and cuing him what he can say to keep the conversation going. She praises him for starting a nice conversation. Talking about the music also provides opportunities for socialization.

Figure 4.1. Wayne and his therapist are singing about having a conversation.

Focus

The theme of focus occurred in the music therapy sessions, the interviews with the client’s families and the music therapist. This theme emerged because of the client’s deep love of music making. Family members gave examples of their child’s focused attention during their interviews. Wayne’s father stated:
So music has brought him to the level that make[s] him ready to receive other information because you have to get a child’s attention someway so you can teach other things too. And if we never got his attention one way, we never could have taught him [the] other things in his life to me.

Sam’s mother stated, “[He] knows songs from camp when others [did not] think he [had] been listening”, but the focus that he displayed during his music therapy session was prevalent during the entire session. I observed the process of him singing while the therapist typed as he sang (see Figure 4.2). He was singing, snapping, clapping while writing the song, answering her questions in song. As they prepared to record his voice via GarageBand®, the therapist had some trouble with the computer, but that did not appear to upset him or distract him in any way. At the end of the session, the therapist rewarded him by allowing him to sing a song he liked on YouTube®. When the song began, he stood up, held his left hand over his ear, rocked back and forth, snapped his fingers occasionally with the music, and added in motions as he “performed” it with the computer.

Figure 4.2. Sam demonstrates focus in his music therapy session.
During the interview with Abby’s therapist, she recalled a session where her client was loosing focus and how she, the therapist, used music to regain the attention of her client and return to task. She described the incident in this way:

She was getting stuck in that conversation, I said, ‘Well, let’s just move to the piano…. I’ll play and maybe that’ll help us talk a little bit’, so with some of the tension and release in the music, she started getting back to getting thoughts out…. She’d play and then just stop, and listen…and [then] she would start again…she wasn’t sustaining attention…but once that improved and we’re doing better with that [in our sessions together].”

**Effort**

The theme of effort, how families will search for and go to great lengths to provide services for their child, occurred frequently in the interviews with the family members and the music therapist. The researcher did not observe this theme in any of the music therapy sessions. During their interviews, families shared a short history of the struggles incurred in receiving a diagnosis for their child and efforts made to provide services such as speech and occupational therapy and their search for music therapy. Wayne’s father stated, “people have tried to convince me not to involve him in all these activities and to get on with my life and do other things, but my child is a part of my life.” Wayne’s therapist stated that the family was supportive and came to all his performances at the community music school.

Depending on his group schedule, Sam’s mother said they drive an hour each way to come to his music therapy sessions. His therapist stated that he sometimes came to music two times a week. The therapist for Sam stated, “Mom is appreciative that he has music in his life… [and is] so supportive of anything he wants to do musically.”
Abby’s mother was relieved that they had found a special hobby, “doing something that normal kids do [music lessons].” She described her daughter’s challenges and the families’ difficulties when Abby gets upset if she [the mother] or another family member is talking to someone and Abby has a difficult time waiting. Since her daughter has learned some relaxation techniques in her music therapy sessions where she starts doing a number of different breathing exercises, it makes life much easier for everyone. The mother said, “I’d sell my house if I couldn’t have her come here [the community music school].”

The only time the theme of effort emerged in the interview with the client and their family member was when the family member mentioned how long they had attended music therapy sessions or of special efforts made in the home environment to support the work done in the music therapy sessions. For example, Wayne’s father mentioned that he works with Wayne at home on some of his activities, for example, encouraging him to run around the block a number of times to get ready for a race.

Quality of Life

The theme of quality of life, which is described as transitions through various life stages greatly increased quality of life through the participation of music therapy, occurred in all interviews with clients and their family members, family member interviews and interviews with the music therapist. I did not observe this theme in any of the music therapy sessions. Wayne’s father stated, “He just seemed to mellow out over the years; doing music therapy here is so good. Music has [had a] greater impact on his life than all of the education that he has had,” is an example of some statements made
supporting this theme. Wayne’s music therapist addressed transition specifically when she said:

He’s come a really long way…. Dad doesn’t necessarily just have him in these transition years focus on job skills, he wants him to have the cultural experiences… for the whole transition thing…we’re the constancy between the school, when somebody dies…the heavier things…we can be the constancy in those transitional periods.

Sam’s mother mentioned that as far as she knew, he was the only special needs child in the middle school chorus and band. She also mentioned that her son did not enjoy the transition meetings at school, but that he was getting vocational training and that she wanted to explore other programming available to him. Sam’s music therapist stated, “Mom hasn’t said much about their transition process [going on at school]…. He has some transitional songs that (the previous therapist) …developed for him.” She commented that although Sam had been receiving music therapy services for some time, she had only been working with him for several months. She did state, “Music has helped his self-confidence and he can use it for himself, [to] calm himself, [for] personal enjoyment, leisure, [because] he’s gifted and he can do it with other people.”

Abby did mention in the interview with her and her mother that her music therapist is one of her favorite people. In discussing quality of life, Abby’s mother stated:

Music has been wonderful for her…. I feel that music…has been a really good medium to help her communicate…. [Music has] 100% benefited her quality of life. She looks forward to it…she’s going every Wednesday …and this is her time…. We feel so good that she is doing something besides just being in the world of autism.
Figure 4.3. By learning relaxation techniques from her music therapist, Abby is able to use those techniques outside of the therapeutic environment.

Abby’s therapist reiterated that the transition process in school was not a topic broached in the session, however she shared that she and Abby did work on some of her IEP (Individual Education Program) goals when Abby was in school.
Table 2:

**Theme Definitions and Occurrences**

<table>
<thead>
<tr>
<th>Participant</th>
<th>Socialization (Client's connection with music allows for a connection with people.)</th>
<th>Focus (The love of making music encourages focused attention.)</th>
<th>Effort (Families will search for and go to great lengths to provide services that benefit their child.)</th>
<th>Quality of Life (Transition through various life stages greatly increases quality of life through the participation of music therapy.)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wayne’s Family (Father)</td>
<td>The father stated that Wayne loves all of the musical things he gets to do.</td>
<td>Father: “So music has brought him to the level that make[s] him ready to receive other information because you have to get a child’s attention someway so you can teach other things too. And if we never got his attention one way, we never could have taught him [the] other things in his life to me.”</td>
<td>Father: “…people have tried to convince me not to involve him in all these activities and to get on with my life and do other things, but my child is a part of my life.”</td>
<td>Father: “…he just seemed to mellow out over the years…doing music therapy here is so good. Music has [had a] greater impact on his life than all of the education that he has had.”</td>
</tr>
<tr>
<td>Wayne’s Therapist</td>
<td>“Communication [and] language (were) big goal area(s) in the beginning as well as social skills…taking turns, waiting for turns, asking for my turn… he use to do other things that were inappropriate socially… perseverate on things…he would ask for the same thing over and over again…if I wrote that [‘say it one time’] down on his schedule, then he got it.”</td>
<td>“So the music has become really intrinsically reinforcing, social reinforcers have worked really well…..” “He’s motivated to sing and play… it was motivating because he wanted to play all those instruments.”</td>
<td>“…Dad would come into the sessions when he was little. The family is so supportive and so invested in the program… they have a really big interest and they’re very responsible about making sure that he gets here and gets what he needs.”</td>
<td>“He’s come a really long way….” “Dad doesn’t necessarily just have him in these transition years focus on job skills, he wants him to have the cultural experiences… for the whole transition thing…we’re the constancy between the school, when somebody dies…the heavier things…we can be the constancy in those transitional periods.”</td>
</tr>
<tr>
<td>Wayne’s Session</td>
<td>Therapist: “OK, … you want me to play the song on the guitar or the piano?” Wayne: “I want a song on guitar.” Therapist: “That was a fabulous sentence.” They continue this conversation with her prompting him to use complete sentences and she praises him for starting a nice conversation. Talking about the music also gives an opportunity for socialization.</td>
<td>Not observed.</td>
<td>Not observed.</td>
<td>Not observed.</td>
</tr>
<tr>
<td>Sam’s Therapist</td>
<td>She shared that he participates in many group sessions, i.e., dancing and that he has to be able to communicate effectively for his ideas to be used in his songs. They also work on how to resolve communication breakdowns, stay calm etc., when they occur. She stated, “Your behavior has to modulate, depending on who you are with and that he can do music with other people.”</td>
<td>She stated that sometimes he needs redirection, but her main goal was to give him some 1:1 attention, allowing him to rehearse and practice because he is very gifted.</td>
<td>Sometimes he comes to MT 2X’s a week, depending on if the group he is in is meeting and “they come a pretty far distance…. Mom is appreciative that he has music in his life… [and is] so supportive of anything he wants to do musically.”</td>
<td>“Mom hasn’t said much about their transition process [going on at school]…. He has some transitional songs that (the previous therapist) …developed for him.” She stated, ”Music has helped his self-confidence and he can use it for himself, [to] calm himself, [for] personal enjoyment, leisure, [because] he’s gifted and he can do it with other people.”</td>
</tr>
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Table 2

Continued

<table>
<thead>
<tr>
<th>Sam</th>
<th>Stated he enjoys singing, playing the piano … and he likes his therapist.</th>
<th>Not discussed.</th>
<th>Not discussed.</th>
<th>Not discussed.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sam’s Session</td>
<td>Not observed</td>
<td>He is singing, snapping, clapping while writing the song, answering her questions in song. At the end of the session, she rewards him by allowing him to sing a song he likes on YouTube®. When the song begins, he stands up, holds his left hand over his ear, rocking back &amp; forth, snapping occasionally with the music, adding in motions, etc. as he “performs” it with the computer.</td>
<td>Not observed</td>
<td>Not observed</td>
</tr>
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Table 2
Continued

| Abby’s Family (Mother & brother) | Mom said, “I feel that music…has been a really good medium to help her communicate…. Music has made her more comfortable…to actually bring out words…she said one time that autism is ‘really hard’…. We saw her come out of her shell.” | Brother stated, “They have concerts…she’s always …a little nervous, …but then as soon as they start playing the music… she starts singing…. She [Abby’s therapist] made a CD for Abby …and every once in awhile when Abby is having a rough day…[she can] put this on and relax.” | The family is relieved that Abby has something to do, a hobby, doing something that normal kids do. The mother described the difficulty they face when Abby gets upset if she or another family member is talking to someone and Abby has a difficult time waiting, but if she starts doing the breathing exercises, it makes life much easier for everyone. The mother said, “I’d sell my house if I couldn’t have her come here.” | The mother said, “Music has been wonderful for her…. I feel that music…has been a really good medium to help her communicate…. [music has] 100% benefited her quality of life. …she looks forward to it…she’s going every Wednesday …and this is her time…. We feel so good that she is doing something besides just being the in the world of autism.” |
| Abby’s Therapist | “[We have] worked through communication a lot...expressing her frustrations ’cause she gets really frustrated sometimes with her difficulty in communicating.... She told me that autism is hard because it makes it hard to wait... she acknowledged that she doesn’t like it when she’s perseverating, that she knows she’s stuck and she can’t stop it, that it doesn’t feel good.... She’s a perfect example of ...autism isn’t a processing error, but a processor error...it’s a different operating system.” | “...when she was getting stuck in that conversation, I said well, let’s just move to the piano.... I’ll play and maybe that’ll help us talk a little bit, so with some of the tension and release in the music, she started getting back to getting thoughts out.... She’d play and then just stop, and listen...and [then] she would start again...she wasn’t sustaining attention...but once that improved and we’re doing better with that.” | Not discussed. |
| Abby’s Session | When they finish doing an exercise that has gone well, they hit fits. As they discuss what each person’s role is, the therapist gives Abby the choice to make the decisions. | When Abby points to the music, she seems to concentrate more on the music during this segment. Later in the session, during the conversation about the time, Abby appears completely absorbed in the process of problem solving the amount of time left in the session. | Not observed. |
| | | “Transition wasn’t really a topic we talked about...I didn’t know a lot about what was going on, partly because things seemed like they might be a little bit up in the air... I was working with some of her IEP goals which were related to telling a story so that it made sense to another person...so we did songwriting...and working on ...the appropriate pronoun use.” | Not observed. |
CHAPTER 5: DISCUSSION

This study became a personal crusade for me. As the parent of a child with ASD (Autism Spectrum Disorder), I witnessed first hand the anxiety associated with transitioning from high school to young adult life. I wanted to know if other families had or were experiencing the same anxieties and questions that my child had expressed during his transition years. Since my child did not receive music therapy services in those transition years, my research questions grew out of a need to know if music therapy really made a difference in the life of the young adult and their families.

It was important to me as a researcher, however, to remain objective in gathering the data and therefore my researcher’s journal became a means of expressing my thoughts and feelings related to the data collection. In Chapter 3: Methods, it was also critical to my data collection that my status as a parent of a child with ASD to remain anonymous so all participants could speak freely. I am aware that one of the music therapists was knowledgeable of my status, but assisted in keeping that information confidential for the duration of this project.

Due to the nature of this type of inquiry, Creswell (2009) states that “generalizability, the external validity of applying results to new settings, people or samples” is not appropriate for this research study (p. 190). However, the impact and implications for music therapy are evident in the data presented. In this chapter, I would like to offer my opinions on the impact of this inquiry by presenting my views of the findings, how the process was in some cases expected and at times unexpected, the limitations of the study, and propose how further research in this area of study is needed.
Impact on Quality of Life

First, the impact of music therapy was significant for the quality of life for the individuals with intellectual disabilities (ID), developmental disabilities (DD) or Autism Spectrum Disorder (ASD) and their families. Recurring statements from family members and therapists assisted in stressing this finding through comments made when asked about how music therapy had effected their child’s or client’s quality of life. Presented below are a variety of statements from clients, families and music therapists to further emphasize the frequency of quality of life statements.

Wayne.

Longevity of the client/therapist relationship permeated statements from Wayne’s father and his music therapist in regards to quality of life. Wayne’s father stated after Wayne had left the room when his interview was concluded that “He misses it [music therapy] when he goes without …. He knows when he’s suppose to be here.” During the family interview, Wayne’s father also stated that he was “the richest poor man alive because he’s [Wayne is] happy.” I stated in this same interview, “you’re wanting Wayne to have [the] kind of life that anybody else would have.” The father also commented during his interview that “music therapy has played a roll from the very beginning…and learning music whether you [are] singing it or whatever instrument you [are] playing, is a sign of intelligence.”

Wayne’s therapist commented on her perception of the families’ quality of life when she recalled that Wayne “…had made tremendous progress because when he was a little kid, he was aggressive.” She stated that the family is very supportive and
encouraged me to visit the American Music Therapy Association (AMTA) website to read a poem written by Wayne’s mother some years back about how music therapy has influenced his life. She felt that “[their] quality of life is good” and reiterated all the different activities that Wayne has participated in over the years at the community music school. Both Wayne’s father and therapist mentioned that length of involvement played a vital role in shaping the family and Wayne’s quality of life.

In my opinion, music therapy’s impact on Wayne’s quality of life is significant for a number of reasons. First, here is a young man who as a child had many challenging behaviors and playing instruments and making music became a reward for appropriate behavior very early in his life. As his father stated, “music taught him everything.” He learned appropriate social behaviors, gained academic knowledge and is an accomplished musician. Secondly, as a young adult, he is learning a new instrument, the baritone, and has performed numerous times on piano and drums. Lastly, his family is committed to making sure his exposure to different opportunities can enhance his cultural experiences in life. Wayne’s participation in music therapy has and will continue to be significant for his well-being and continued development as an adult.

Sam.

How music therapy had made an impact was the focus of the quality of life statements from Sam’s mother and music therapist. Sam’s mother stated that music therapy has given him “a beat for life; music for life; helping him slow down.” She was confident that music had “taught him sharing, turn taking, idea sharing, waiting [and] patience.” She stated she wanted him in a “lot of activities to keep him busy”, but that
she is sometimes frustrated that all these activities “ends up being ‘therapy’.” She also emphasized that anything he chooses to do after high school “he will get to choose,” but “being on the stage in the spotlight keeps him happy.”

Unlike Wayne and his therapist who had worked together for many years, Sam’s therapist had only been working with him for a few months. She still felt strongly that “he’s doing a better job of self regulating, picking up on non-verbal cues, such as facial gestures that say ‘You’re escalating, I need you to stop.’” In comparing the duration of Wayne’s relationship with his therapist and the shorter duration of Sam’s relationship with his therapist, I thought it was interesting when Sam’s therapist felt it was “good for him to switch therapists.” Her opinion was that since “your behavior has to modulate, depending on [whom] you are with, [that interacting] with many adults, [doing] adult things” was her primary focus with Sam at present. I would have to agree with her because in my short time with Sam, I sensed he was a young man who required a lot of energy from his therapist. For some therapists, that can be quite draining emotionally, yet for others is invigorating. Her opinion on change could also be derived from her knowledge of how individuals with ASD (Autism Spectrum Disorder) is defined by the DSM-5™ which states these individuals have “restrictive, repetitive patterns of behavior, interests, or activities…” (American Psychiatric Association, 2013, p. 50).

She also felt strongly that music “gives him a purpose internally, externally… [and helps him] feel good about himself.” She thinks that music allows him to “show off a cool aspect of himself.” For the family, Sam’s music therapist thought, “music gives
the family a bonding point… [something the mother] can relate to and be proud of and encourage him to do.”

Like Wayne, I feel music therapy has played a significant role in enhancing Sam’s quality of life. In my brief encounter with this young man, I witnessed how music permeates his thoughts and actions. Music seemed to ‘ooze’ out of him and has become a way he can relate to others and connect with people in a way that is almost unexplainable. I agree with his mother regarding music “giving him a beat for life” and providing him a way to “slow down.” I believe music therapy gives Sam the ability to be who he wants to be in a way that is acceptable and allows him to continue to practice appropriate ways to interact with his world and those around him.

**Abby.**

Statements from Abby’s family and music therapist also emphasized the impact of music therapy in their quality of life statements. Abby’s mother stated, “When I first [saw her in therapy]… it brought a tear to my eye, because she had never done that before… just to follow directions… turn taking… its just been amazing.” She also stated that, “…she’s (Abby is) really sad and upset if she doesn’t get to come to music therapy.” Abby’s mother shared that “[her music therapist] has taught her [Abby] the relaxing and all that stuff. We use that a lot at home.” Abby’s brother shared that, “she [Abby] knows what to do when she’s in that [stressful] situation.” Although the family shared that the relaxation techniques do not work every time Abby is in a stressful situation, the mother stated, “I’m so proud of everything she’s done.”
Although Abby’s music therapist had worked for her for eight and a half years at the time of the interview, the duration of their relationship was not the primary focus of the quality of life statements. Abby’s music therapist stated, “I think in a lot of different ways, it [music therapy] has affected her quality of life…for the better. It has given her opportunities to express herself in ways that she doesn’t have [in] other places.” She also commented that, “…it’s [Abby’s participation in music therapy] been beneficial [for the younger brother] to see his older [sister] succeed in an environment.” Abby’s music therapist mentioned that she got the idea of doing relaxation with Abby when the family filled out a form stating that Abby gets uptight and they could not get her to calm down. She shared that she had personally witnessed Abby getting upset in sessions, for example, biting her [the music therapist], but she said that, “since we started doing that [the relaxation techniques], I haven’t seen her get to the same level of complete out of control-ness.”

Like Sam and Wayne, I believe that Abby’s quality of life is significantly better because of her participation in music therapy. The relaxation techniques have allowed her and her family to cope in various difficult situations. Understanding first hand that difficult situations cause stress for everyone, creating a way to cope in those types of situations creates a sense of comfort for all involved. These statements confirm the depth of conviction that the families and music therapists felt that music therapy affected the lives of the individuals with ID/DD/ASD and their families.
Interviewing

Interviews with participants played a major role in the gathering of data for this study. Following the pre-determined questioning (see Appendix D) allowed me to maintain focus on the main topic of conversation, and provided a protocol for maintaining confidentiality. In preparing for the task of interviewing, I had foreseeable expectations for this process. I expected the interviews with the families and therapists to be straightforward, but was not certain of how the interviews would proceed with the young adults with ID/DD/ASD. I discuss these below.

Foreseeable expectations.

Statements from families, the music therapists and the observations for each therapy session created more meaningful data than the interviews conducted with the individuals with ID/DD/ASD. Hall (2009), Harnik (2010) and McIntyre et al. (2004) support this implication regarding independence, social interaction and communicating their (the individuals with ID/DD/ASD) needs. Families and therapists as well as the observations made during the music therapy sessions provided an in-depth look at the individual with ID/DD/ASD and how participating in music therapy made an impact on their lives.

In planning for the interview with each individual with ID/DD/ASD, I asked family members to participate in the interview with their child. This was done because, 1) I was not a known person to the individual with ID/DD/ASD, 2) the open-ended questions might have been difficult for the individual with ID/DD/ASD to answer and 3) the family member could prompt the individual with ID/DD/ASD to assist them with
answering the questions. I thought these steps would make interviewing the individuals easier, however, I found that there were some unanticipated and unrealistic expectations on my part regarding how the individuals with ID/DD/ASD were going to respond to the questions.

Unanticipated expectations.

I started each interview with open-ended questions, but as the interview progressed, I found myself asking yes/no questions to the individuals with ID/DD/ASD in an effort to gain information from them. I hoped that even though I had a child with ASD, that my comfort level in the interview process with these individuals would provide a sense of comfort to those participating. My child is able to express himself well and I have seen him do satisfactorily in an interview setting. However, each individual with ID/DD/ASD interviewed seemed uncomfortable in answering the questions and often looked at their parent for assistance. Even if I tried to rephrase the question or ask it again thinking that they had not heard me, I got either an unusual answer or a blank look from the individual with ID/DD/ASD.

At times, I tried to give each individual time to answer the question, but the silence that followed seemed awkward for the parent, who would either rephrase or answer the question for the child. I would then ask yes/no questions to the individual with ID/DD/ASD to gain information, but later realized I was suppose to be asking open-ended questions. I commented on my frustration in not realizing that the interviews were more difficult than expected in my researcher’s journal. I found that the open-ended
questions were too difficult for the individuals with ID/DD/ASD to fully comprehend and answer to provide the kind of meaningful data obtained from the other participants.

**Transition Lacked Prominence**

I discovered through this inquiry that there was little discussion regarding the transition period from high school to young adulthood. In the last two years of high school, my child frequently discussed his concern for what he would do after high school. I expressed my astonishment regarding this parameter in my researcher’s journal simply to 1) have a means of expressing my thoughts and 2) to maintain confidentiality regarding my alternate role as the parent of a child with ASD.

Several factors possibly played a role in this particular finding. First, two of the clients interviewed were currently in high school at the time of their interviews. Family members for both of the clients stated that they wished their child to remain in school as long as possible. According to Individuals with Disabilities Act (IDEA, P. L. 101-476), individuals specifically labeled as special education students can remain in public school until they are age 21 (IDEA, n.d.). However, the third participant had transitioned from the school environment to a day habilitation program in the area. The family did not speak specifically as to whether their child had ‘graduated’ from high school, but simply informed me that their child was no longer in school, but in the day habilitation program explicitly designed for individuals with autism.

Secondly, music therapy services for all three individuals with ID/DD/ASD received those services at a community music school and not within the confines of the public school environment. It is possible that since the individuals were removed from
the school environment during their music therapy session, the separation precluded any connection being made between the transition process being discussed at school and coming to music therapy services during non-school hours. In addition, during the music therapists’ interviews, I asked each therapist specifically about discussions of transition during the music therapy sessions. The music therapist for Wayne stated that she had not received an IEP in recent years, but had supported him in that way in the past. Sam’s music therapist stated that although his previous music therapist had worked on some transitional songs that were used within the school environment, she had not heard Sam’s mother speak specifically about their transition process at school. Abby’s music therapist also shared that she had worked on IEP goals in the past, for example, story telling to assist her with using the appropriate pronouns, but stated, “transition wasn’t really a topic we talked about…and I wasn’t sure what her awareness with the plan was either…."

In examining the literature, several studies (Forte, et al., 2011; Oschwald, 2002; Osgood, et al., 2010; Tobin, 2003) state that both the individuals with ID/DD/ASD and their families feel tension and stress regarding the transition to adulthood. Even Smith’s (2010) article asked the question of who could provide support to these young adults during this change occurring in their life. I also wondered if the individuals’ challenges in expressing their thoughts and feelings regarding changes in their lives were influencing this finding. Other studies (Dillon & Carr, 2007; Hall, 2009; Harnik, 2010; McIntyre et al., 2004; Marquette, 2007) support the difficulty in communication for individuals with ID/DD/ASD. After considering all these variables, I questioned whether the transition
period was not prominent because music therapy had been active in assisting these individuals and their families during other transitions in their lives.

Limitations

This study was limited in a number of ways, partially due to its qualitative characteristics. As stated earlier, a qualitative study is not one in which generalization is appropriate or expected. Creswell (2009) states, “in the entire qualitative research process, the researcher keeps a focus on learning the meaning that the participants hold about the problem or issue, not the meaning that the researchers bring to the research” (p. 175). One of my research questions was to learn what experiences, thoughts and feelings that all participates had regarding music therapy services during the transition from high school to young adulthood and how these affected overall quality of life. This study covers only three individuals with ID/DD/ASD, their families and their music therapists.

Because of the distance between my home and where the interviews took place, data collection seemed rushed. Since one of my goals was to interview individuals who did not know me personally, I traveled some distance to find clients that met the criteria for my study. Some interviews occurred right after the individual’s music therapy session and this process was challenging and unusual for them. One interview with family took place over Skype® (Skype®, 2014) since the family was unable to have the interview in person at the community music school. While technology advancements do allow for simulations of person-to-person contact, this process was not the same as doing the interview in person.
Further Research

Conducting further research regarding the quality of life for individuals with ID/DD/ASD who are participating in music therapy is vital for the field of music therapy. At the time of this inquiry, no studies could be located in the literature that documented the thoughts and feelings of individuals with ID/DD/ASD and their families and their music therapy experiences, and how music therapy has affected their quality of life or assisted in the transition from high school to adulthood. The American Music Therapy Association (AMTA) website lists many music therapists working with individuals with ID/DD/ASD (American Music Therapy Association, 2011). Music therapists can play a key role in the lives of individuals with ID/DD/ASD and their families since music therapy is not specifically limited to the educational setting. According to Osgood, et al. (2010), services “…end abruptly as they (vulnerable populations) transition to adulthood, even though the need for them continues” (p. 209). By publishing this study later, I hope more music therapists will see opportunities to document their work with young adults with ID/DD/ASD receiving music therapy and include comments about how music therapy has affected their quality of life.

Follow-up interviews with these same clients and music therapists could add to this initial body of knowledge concerning the impact of music therapy on the quality of life for individuals with ID/DD/ASD and their families. Since two of the individuals with ID/DD/ASD were currently attending high school at the time of the study, it would be interesting to follow up with these specific individuals and their families to examine the role of music therapy and how it has affected their quality of life after leaving high
school. The third individual with ID/DD/ASD was attending a day-habilitation program for individuals with autism at the time of the study. Further inquiry into any changes in her quality of life would warrant additional study.

Additional inquiry regarding strategies used in the music therapy sessions could also render added information for music therapists and how best to work with individuals with ID/DD/ASD during the transition period in their lives. Surveys inquiring on the different experiences used in music therapy sessions would provide vital information to the many music therapists working with individuals with ID/DD/ASD. Moreover, further examination into the specific strategies and experiences used in the observed sessions for this study could provide interesting investigation to how those experiences worked with these specific individuals.

Since I did not request the IQ level of my participants before this study, I feel a follow-up study on how IQ plays a roll in communicating likes and desires might be applicable. Howlin, et al., (2004) found an individual’s intellectual quotient (IQ) as a factor in transition success. Hall (2009) states, “conducting research with people who have disabilities can be difficult” (p. 39). In discussing the interview process above, I found that the interviews with the individuals with ID/DD/ASD lacked the richness of data found in the other interviews and individual therapy sessions.

**Conclusion**

The goal of this study was to examine the thoughts, experiences and feelings from participants regarding music therapy services during the transition years from high school to young adulthood. While all participants shared, families seemed keenly interested in
telling their stories, experiences and feelings about music therapy and how it affected their overall quality of life. Some families were especially interested in assisting others in similar situations. Abby’s mother stated, “I would do anything to help anybody going through … a child with autism.” Wayne’s father shared that seeing his son excel in music is ‘therapy’ for him. He also stated that he knows that he is not the only one with a special needs child and it therefore gives him the strength to do what he needs to do. I know I have felt the same way and participate in support groups and give presentations on explaining to others what it is like to live with someone with ID/DD/ASD. In my presentations, listeners have often expressed shock and surprise at the challenges faced by parents of individuals with ID/DD/ASD.

I also wanted to explore if music therapy helped with this transition process and with coping with the changes and quality of life of the individuals involved. While the specific transition between high school and adult life was not a primary focus of my participants’ statements, I sensed that music therapy had assisted with the transitions of life. The music therapists shared that while their clients were younger, IEP (Individual Education Program) goals were addressed in their therapy sessions, but recently, more emphasis seemed to be on non-educational goals such as socialization, increasing self-esteem and assisting their client in coping with life’s challenges. Families expressed their delight in their child’s joy in participating in music therapy and how meaningful it had been over the years. Sam’s mother says she wants her son to use music and the beat to “…focus on what he is currently working on.” However, Wayne’s father stated, “…one
year of music therapy does not change a person.” He believed that it takes years for someone like his son to learn and change. He also commented that, “You can’t give up.”

Finally, giving voice to those who often do not have an opportunity to share their stories was important to this study. It was exciting to hear what these families had to say and give them a chance to share their experiences. I know the challenges these families face and laud them for their tenacity in trying to improve the quality of life for their family member with ID/DD/ASD. As a music therapist, I commend the work of the music therapists who participated in this research to provide music therapy experiences designed to improve their client’s quality of life. They press on week after week, year after year, hoping for a small sign, and often find themselves rewarded beyond their expectations.
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APPENDIX

Appendix A

Recruitment Email to Music Therapists

Dear Music Therapist,
Hello, my name is Stephanie Morris and I am a graduate student at Ohio University. Currently, I am working on my master's thesis proposal and I am seeking participants for a qualitative study. I am contacting you because I found your name in the AMTA directory as someone who works with clients who have a diagnosis of Intellectual/Developmental or Autism Spectrum disorder.

I am writing to ask you if you have someone in your practice or know of an individual that would fit the following criteria:

a) Age 18 - 23
c) Received music therapy while transitioning from high school to young adult life.

My research would include conducting an interview with you as their therapist, and interviewing the individual and their families/caregivers to determine how music therapy has impacted their lives during this transition period.

I would like to begin this research this fall and I am willing to travel to your clinic/worksite, follow all IRB rules and regulations regarding research with human subjects and will exercise all means of confidentiality possible.

In return, if you and your client(s) participate, I will personally make sure you get a copy of my final work. The clients and their families will be reimbursed for any expenses related to meeting with me either at your clinic site or facility where they receive services. I do not intend at this moment to interview or visit them in their home. Other documents such as session plans, and/or school IEP documentation may be needed for data with approval of you, the client, and the family/caregiver, of course.

Thank you in advance for considering this partnership. I feel my study will add to the body of research in our field. Please feel free to call me or email me if you have any questions.

Stephanie H. Morris, MT-BC
Ohio University Graduate Assistant
Athens, OH
email: sm772510@ohio.edu
phone: 254-709-4331
Appendix B

Recruitment Letter to Families

Date

Dear Family,

Hello, my name is Stephanie Morris and I am a graduate student at Ohio University in the field of music therapy. Currently, I am working on my master's thesis proposal and I am seeking participants for a qualitative research study. You are receiving this letter because you and your family meet the criteria for my study and I was wondering if you would be willing to participate. The following are some details about the study.

My research is focusing on young adults with intellectual/developmental disabilities or Autism who have received music therapy during their transition period in high school moving them toward young adulthood. My research questions focus on your experiences with music therapy, how it has or has not assisted with transition, and if it has changed your quality of life.

Your responsibilities:
1. After I receive your permission, I will be observing and audio and video taping your child in his/her music therapy session as well as taking photographs to give richer meaning to my research data.
2. Your (the families/caregivers) involvement will include participating in an interview with me for approximately 30 – 45 minutes.
3. I will also interview your child, and ask that you be present to assist with understanding and clarification. This interview will last approximately 30 – 45 minutes also.
4. After our interviews, I will transcribe them and summarize what information you gave me. I’ll ask that you read these summaries and confirm that my summary is correct, for both the interview with you, and the interview with your child.
5. If I made an error, we may need to talk on the phone and that conversation will be recorded as well.
6. When you conclude that the summary is accurate, your contribution to my research will be complete.

I would like to begin this research soon and am willing to travel to the clinic where your child receives music therapy. I will follow all Internal Review Board rules and regulations regarding research with human subjects, and exercise all means of confidentiality possible. I am willing to reimburse you for your travel by providing a $10.00 gas card if you are traveling to the clinic by car.
Thank you in advance for considering this proposal. At any time you wish to withdraw from the project, you may do so. I look forward to meeting you in person and hope that we can work together.

Cordially,

Stephanie H. Morris, MT-BC
Athens, Ohio
Appendix C

Consent Letters (Therapist)

Ohio University Consent Form

Title of Research: A Phenomenological Inquiry on the Quality of Life for Young Adults with Developmental Disabilities Receiving Music Therapy to Assist with Transitioning from High School to Adult Life

Researcher: Stephanie H. Morris, MT-BC

You are being asked to participate in research. For you to be able to decide whether you want to participate in this project, you should understand what the project is about, as well as the possible risks and benefits in order to make an informed decision. This process is known as informed consent. This form describes the purpose, procedures, possible benefits, and risks. It also explains how your personal information will be used and protected. Once you have read this form and your questions about the study are answered, you will be asked to sign it. This will allow your participation in this study. You should receive a copy of this document to take with you.

EXPLANATION OF STUDY

This study is being done because of the importance of documenting the personal experiences of the music therapist, individual with intellectual/developmental disabilities/Autism Spectrum Disorder (ID/DD/ASD) and their families/caregivers giving and receiving music therapy services during the transition period from high school into young adulthood.

If you agree to participate, you will be asked to allow the researcher to audio and video tape a forty-five to an hour long interview with you so you may share your experiences of how dispersing music therapy has affected you and your perception of the life of your client with ID/DD/ASD.

You will also be asked to allow one of your music therapy sessions with your client to be audio and video taped.

You will also be asked to provide copies of your music therapy session plans covering the span of time your client was transitioning from high school to young adulthood.

You will also be asked to review the summary of the interviews that are conducted and confirm that they are in fact true. If clarification is needed after you receive the summary, you will agree to participate in another interview to make any corrections needed to the summary.
You should not participate in this study if you are not willing to be audio and video taped for the purposes of data collection for this project.
You should not participate in this study if you are not willing to give permission for your music therapy session to be audio and video recorded or provide any session plans spanning the time your client was transitioning from high school into young adulthood.

You will be asked to meet with the researcher no more than two times after you agree to participate in this research (a total possible time commitment of three hours). Obligations will include participating in this intake process, an interview with the researcher lasting approximately forty-five minutes to one hour, and a possible follow-up interview to make sure that everything you said in the first interview is correct.

Risks and Discomforts

No risks or discomforts are anticipated.

Benefits

This study is important to science/society because:
1) This research will add to the body of research available to the music therapists who are specifically working with the ID/DD/ASD population.
2) This research could potentially demonstrate the benefits of music therapy to the education community and how it can assist individuals with ID/DD/ASD who are transitioning out of high school into young adulthood.

Confidentiality and Records

You will be videotaped and audiotaped. The data will be kept in a locked cabinet in my home and destruction of identifiable data will occur around December, 2013. Your study information will be kept confidential by myself and no one outside of my research team (advisor and committee members) will be knowledgeable of your participation other than the family members of your client and your client.

Additionally, while every effort will be made to keep your study-related information confidential, there may be circumstances where this information must be shared with:
* Federal agencies, for example the Office of Human Research Protections, whose responsibility is to protect human subjects in research;
* Representatives of Ohio University (OU), including the Institutional Review Board, or the committee that oversees the research at OU.

Compensation

You will receive a $10.00 gas card.
Also, in agreeing to participate in this research project, you will be presented with a complete copy of my thesis upon its completion.

Contact Information

If you have any questions regarding this study, please contact myself, Stephanie H. Morris, MT-BC at sm772510@ohio.edu or 254-709-4331 or Kamile Geist, MA, MT-BC, Music Therapy Program Director at geistk@ohio.edu or (740) 593-4249.

If you have any questions regarding your rights as a research participant, please contact Jo Ellen Sherow, Director of Research Compliance, Ohio University, (740)593-0664.

By signing below, you are agreeing that:
- you have read this consent form (or it has been read to you) and have been given the opportunity to ask questions and have them answered
- you have been informed of potential risks and they have been explained to your satisfaction.
- you understand Ohio University has no funds set aside for any injuries you might receive as a result of participating in this study
- you are 18 years of age or older
- your participation in this research is completely voluntary
- you may leave the study at any time. If you decide to stop participating in the study, there will be no penalty to you and you will not lose any benefits to which you are otherwise entitled.

Signature__________________________________________ Date__________

Printed Name________________________________________

Version Date: September 1, 2012
Title of Research: A Phenomenological Inquiry on the Quality of Life for Young Adults with Developmental Disabilities Receiving Music Therapy to Assist with Transitioning from High School to Adult Life

Researcher: Stephanie H. Morris, MT-BC

You and your child are being asked to participate in research. For you and your child to be able to decide whether you and your child want to participate in this project, you and your child should understand what the project is about, as well as the possible risks and benefits in order to make an informed decision. This process is known as informed consent. This form describes the purpose, procedures, possible benefits, and risks. It also explains how your personal information will be used and protected. Once you have read this form and your questions about the study are answered, you will be asked to sign it. This will allow your participation in this study. You should receive a copy of this document to take with you.

EXPLANATION OF STUDY

This study is being done because of the importance of documenting the personal experiences of the music therapist, individual with intellectual/developmental disabilities/Autism Spectrum Disorder (ID/DD/ASD) and their families/caregivers giving and receiving music therapy services during the transition period from high school into young adulthood.

If you agree to participate, you will be asked to allow the researcher to audio and video tape a forty-five to an hour long interview with you so you may share your experiences of how music therapy has affected your family’s quality of life and the life of your child with ID/DD/ASD.

If you are the legal guardian of your adult child with ID/DD/ASD, you will be asked to sign a permission form on their behalf so that they may be audio and video taped during an observation session and any interviews that occur between them and the researcher.

You and your child will also be asked to participate in the interview where the researcher audio and video tapes your child while they are being interviewed and assist in answering questions regarding their experiences and feelings about how music therapy has affected their quality of life during the transition between high school and young adulthood.

You and your child will also be asked to review the summary of the interviews that are conducted and confirm that they are in fact true. If clarification is needed after you
receive the summary, you and your child will agree to participate in another interview to make any corrections needed to the summary.

You and your child should not participate in this study if you are not willing to be audio and video taped for the purposes of data collection for this project.

You and your child should not participate in this study if you are not willing to give permission for your child with ID/DD/ASD to be audio and video taped for the purpose of data collection or this project.

You and your child will be asked to meet with the researcher no more than two times after you agree to participate in this research (a total possible time commitment of three hours). Obligations will include participating in this intake process, an interview with the researcher lasting approximately forty-five minutes to one hour, an interview with the researcher and your child with ID/DD/ASD and a possible follow-up interview to make sure that everything you said in the first interview is correct.

Risks and Discomforts

No risks or discomforts are anticipated.

Benefits

This study is important to science/society because:
1) This research will add to the body of research available to the music therapists who are specifically working with the ID/DD/ASD population.
2) This research could potentially demonstrate the benefits of music therapy to the education community and how it can assist individuals with ID/DD/ASD who are transitioning out of high school into young adulthood.

Confidentiality and Records

You and your child will be videotaped and audiotaped. The data will be kept in a locked cabinet in my home and destruction of identifiable data will occur around December, 2013. Your study information will be kept confidential by myself and no one outside of my research team (advisor and committee members) will be knowledgeable of your participation other than your family members and ________________, your child’s therapist.

Additionally, while every effort will be made to keep your, as well as your child’s study-related information confidential, there may be circumstances where this information must be shared with:
* Federal agencies, for example the Office of Human Research Protections, whose responsibility is to protect human subjects in research;
* Representatives of Ohio University (OU), including the Institutional Review Board, or the committee that oversees the research at OU.

Compensation

You will receive a $10.00 gas card.

Contact Information

If you have any questions regarding this study, please contact myself, Stephanie H. Morris, MT-BC at sm772510@ohio.edu or 254-709-4331 or Kamile Geist, MA, MT-BC, Music Therapy Program Director at geistk@ohio.edu or (740) 593-4249.

If you have any questions regarding your rights as a research participant, please contact Jo Ellen Sherow, Director of Research Compliance, Ohio University, (740) 593-0664.

By signing below, you are agreeing that:

• you have read this consent form (or it has been read to you) and have been given the opportunity to ask questions and have them answered
• you have been informed of potential risks and they have been explained to your satisfaction.
• you understand Ohio University has no funds set aside for any injuries you might receive as a result of participating in this study
• you are 18 years of age or older
• your participation in this research is completely voluntary
• you may leave the study at any time. If you decide to stop participating in the study, there will be no penalty to you and you will not lose any benefits to which you are otherwise entitled.

Signature ____________________________________________ Date ____________

Printed Name_____________________________________________________

Version Date: September 1, 2012
Consent Letters (Parental Consent)

Ohio University Parental Consent Form

Title of Research: A Phenomenological Inquiry on the Quality of Life for Young Adults with Developmental Disabilities Receiving Music Therapy to Assist with Transitioning from High School to Adult Life

Researcher: Stephanie H. Morris, MT-BC

You are being asked permission for your child to participate in research. For you to be able to decide whether you want your child to participate in this project, you should understand what the project is about, as well as the possible risks and benefits in order to make an informed decision. This process is known as informed consent. This form describes the purpose, procedures, possible benefits, and risks. It also explains how your child’s personal information will be used and protected. Once you have read this form and your questions about the study are answered, you will be asked to sign it. This will allow your child’s participation in this study. You should receive a copy of this documentation to take with you.

EXPLANATION OF STUDY

This study is being done because of the importance of documenting the personal experiences of the music therapist, individual with intellectual/developmental disabilities/Autism Spectrum Disorder (ID/DD/ASD) and their families/caregivers giving and receiving music therapy services during the transition period from high school into young adulthood.

If you agree for your child to participate, your child will be asked to allow the researcher to audio and video tape a thirty minute long interview with you and your child so both of you may share your experiences of how music therapy has affected your family’s quality of life and the life of your child with ID/DD/ASD.

You and your child will also be asked to review the summary of the interviews that are conducted and confirm that they are in fact true. If clarification is needed after you receive the summary, you and your child will agree to participate in another interview to make any corrections needed to the summary.

You and your child should not participate in this study if you are not willing to be audio and video taped for the purposes of data collection for this project.

You and your child should not participate in this study if you are not willing to give permission for your child with ID/DD/ASD to be audio and video taped for the purpose of data collection or this project.
You and your child will be asked to meet with the researcher no more than two times after you agree to participate in this research (a total possible time commitment of two hours). Obligations will include participating in this intake process, an interview with the researcher and your child lasting approximately thirty minutes with ID/DD/ASD and a possible follow-up interview to make sure that everything you said in the first interview is correct.

**Risks and Discomforts**

No risks or discomforts are anticipated.

**Benefits**

This study is important to science/society because:

3) This research will add to the body of research available to the music therapists who are specifically working with the ID/DD/ASD population.

4) This research could potentially demonstrate the benefits of music therapy to the education community and how it can assist individuals with ID/DD/ASD who are transitioning out of high school into young adulthood.

**Confidentiality and Records**

You and your child will be videotaped and audiotaped. The data will be kept in a locked cabinet in my home and destruction of identifiable data will occur around December, 2013. Your study information will be kept confidential by myself and no one outside of my research team (advisor and committee members) will be knowledgeable of your participation other than your family members and _____________, your child’s therapist.

Additionally, while every effort will be made to keep your, as well as your child’s study-related information confidential, there may be circumstances where this information must be shared with:

* Federal agencies, for example the Office of Human Research Protections, whose responsibility is to protect human subjects in research;

* Representatives of Ohio University (OU), including the Institutional Review Board, or the committee that oversees the research at OU.

**Compensation**

You will receive a $10.00 gas card.

**Contact Information**

If you have any questions regarding this study, please contact myself, Stephanie H. Morris, MT-BC at sm772510@ohio.edu or 254-709-4331 or Kamile Geist, MA, MT-BC, Music Therapy Program Director at geistk@ohio.edu or (740) 593-4249.
If you have any questions regarding your rights as a research participant, please contact Jo Ellen Sherow, Director of Research Compliance, Ohio University, (740) 593-0664.

By signing below, you are agreeing that:
• you have read this consent form and have been given the opportunity to ask questions and have them answered
• you have been informed of potential risks for you and your child and they have been explained to your satisfaction.
• you understand Ohio University has no funds set aside for any injuries you or your child might receive as a result of participating in this study
• you are 18 years of age or older
• your participation as well as that of your child in this research is completely voluntary
• you and your child may leave the study at any time. If you and your child decide to stop participating in the study, there will be no penalty to you or your child and you nor your child will not lose any benefits to which you are otherwise entitled.

Signature ____________________________ Date ____________

Printed Name ____________________________

Version Date: September 1, 2012
Title of Study: A Phenomenological Inquiry on the Quality of Life for Young Adults with Developmental Disabilities Receiving Music Therapy to Assist with Transitioning from High School to Adult Life

My name is Stephanie Morris. I am trying to learn about what you and your family think about your music therapy. I also want to know if your music therapy has helped you when you left high school. I want to know this because I think a lot of people would be interested in knowing how you felt about your music therapy. If you would like, you can be in my study.

If you decide you want to be in my study, you will need to do the following:

• Meet with me and your family/guardian about being in my study. (We are doing that now.)
• Let me watch you and videotape and audiotape one of your music therapy sessions.
• Sit with me and answer some questions for about 30 minutes, with your parents help.

You will not have to answer all the questions if you don’t know the answer and your parents can help you. You will help a lot of people find out about music therapy. Your family will get a $10.00 gift card for helping me with my study.

Other people will not know if you are in my study. I will put things I learn about you together with things I learn about other young adults like you, so no one can tell what things came from you. When I tell other people about my research, I will not use your name, so no one can tell who I am talking about.

Your parents or guardian have to say it’s OK for you to be in the study. After they decide, you get to choose if you want to do it too. You will only have to meet with me about 2 times, maybe an hour total. If you don’t want to be in the study, no one will be mad at you. If you want to be in the study now and change your mind later, that’s OK. You can stop any time.

My telephone number is 254-709-4331. You can call me if you have questions about the study or if you decide you don’t want to be in the study any more.

If will give you a copy of this form in case you want to ask questions later.

Agreement
I have decided to be in the study even though I know that I don’t have to do it. Stephanie Morris has answered all my questions.

_____________________________  ______________________
Signature of Study Participant  Date

_____________________________  ______________________
Signature of Researcher  Date
Appendix D

Proposed Questions (Therapists)

Participant Questions

Potential questions used during the interview process with the music therapy participants:

1. Tell me about your experiences with ________ (your client), i.e., how long you have been working with him/her?
   - How was he/she referred to you?
   - What progress you have seen?

2. How do you think music therapy has affected your client’s quality of life?

3. How do you think music therapy has affected the family of your client?

4. Do you have special sessions that you can share how ________ discussed leaving high school and how you worked through that with the music?

5. Are there other times that ________ or his family has opened up with you about a special event happening in his/her life and asked if you could help him/her work through that in the session?
   - What were they?
   - If not, why do you think ________ does not talk to you about those kinds of things?
Proposed Questions (Parents/Caregivers)

Potential questions for families with young adults with ID/DD/ASD:
1. Tell me about __________ (daughter/son)?
   - What are some things that have been challenging for him/her?
2. What were __________ (son/daughter)’s high school years like?
   - When preparing for transition, what were the experiences of your son/daughter? What happened for them? (Did they talk about it?)
   - How did music therapy play a role in this transition for your son/daughter?
3. Did he/she have music therapy in high school? If yes, how? If no, why not?
4. Why did you choose for __________ (daughter/son) to have music therapy?
   - How did you find out about __________ (the therapist) and the work he/she does at __________ (facility/clinic)?
   - How do you view the relationship between your son/daughter and their therapist?
5. What do you think __________ (son/daughter) feels about his/her music therapy sessions?
6. How do you think music therapy has affected your son/daughter’s quality of life?
Proposed Questions (Individuals with ID/DD/ASD)

Potential questions for young adults with ID/DD/ASD:
1. Tell me about yourself and what you like to do.
2. When did you start with music therapy and what do you like about it the most?
3. What do you do in music?
3. Do you and __________ (therapist) talk about other things other than music? If so, what?
4. You’re getting ready to leave high school. How do you feel about that? What do you want to do when you finish high school?
5. Do you like music therapy? What is your favorite thing?