

THE EFFECT OF MUSIC THERAPY ON THE MALADAPTIVE EMOTIONALLY  
REGULATIVE BEHAVIORS OF ADULTS WITH DEVELOPMENTAL DISABILITIES

By

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Submitted to the graduate degree program in Music Education and Music Therapy and the  
Graduate Faculty of the University of Kansas in partial fulfillment of the requirements for the  
degree of Master of Music Education (Music Therapy).

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Date approved: August 25, 2011

## ABSTRACT

The purpose of this study was to examine the effectiveness of individualized music therapy protocols in decreasing the duration of instances of elevated levels of maladaptive emotionally regulative behaviors in adults with developmental disabilities. The participants were four adults with developmental disabilities, recommended for the study based on the presence of severe and/or frequent instances of maladaptive emotionally regulative behaviors. ABAB reversal design was used to examine the effectiveness of the usual staff techniques (A) and the individualized music therapy protocols (B) in decreasing the duration of instances of maladaptive emotionally regulative behaviors. The independent variables were the following two conditions: interacting with each participant while he or she was exhibiting the targeted maladaptive emotionally regulative behaviors at a rate per minute that exceeded the participant's usual rate per minute, using (A) non-music interventions recommended by staff, or (B) individualized music therapy protocols. The dependent variable was the time that elapsed from the onset to the conclusion of each instance of elevated levels of maladaptive emotionally regulative behaviors. Results from the four case studies indicated that music therapy protocols can be used to decrease the duration of instances of elevated levels of maladaptive emotionally regulative behaviors in adults with developmental disabilities, and that music therapy protocols can decrease these behaviors more quickly than the usual staff techniques in most cases. Three out of four participants responded better to the music therapy protocols than the usual staff techniques. The final participant responded to music therapy protocols and staff techniques exactly the same in terms of average duration of instances of elevated levels of maladaptive emotionally regulative behaviors.

## ACKNOWLEDGEMENTS

First, I must thank Dr. Cynthia Colwell for her invaluable help and guidance through many months of work on this study. Her clearly communicated feedback and timely advice were the light that led me through what sometimes seemed like an endless tunnel. I very much appreciated her willingness to meet with me in person despite her busy schedule. I also wish to thank Dr. Alicia Ann Clair and Dr. Christopher Johnson who served as my committee members. I appreciated their feedback, which helped me to see critical aspects of my study through a different and savvy pair of eyes.

What I learned previously through taking classes from Dr. Colwell, Dr. Clair, Dr. Johnson, and Dr. Dena Register was the foundation for this study. I learned about the history and various techniques of music therapy, as well as practical clinical skills and different approaches to music therapy from Dr. Colwell, Dr. Clair and Dr. Register. I learned all the essentials for conducting research in music therapy, as well as practical life insights, from Dr. Johnson. These classes helped me toward my career goal, encouraging my creativity, curiosity and critical thinking along the way.

I owe many thanks to the Work Enrichment Director at my experimental site. I could not have completed this study without the support and guidance she gave me at every turn.

I want to thank my parents, Don and Mary Ann Enns, for helping me throughout my life to follow a good path, and for loving me every step of the way. I am also very grateful to my dear husband, Jim, for all of his love and support throughout this process. Thank you, Jim. Lastly, I thank God for His love and grace given through Christ, without which, I don't know where I would be.

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## CHAPTER I

### INTRODUCTION

Developmental disability is one of the more widely accepted terms currently used to describe individuals with significant impairments both in intellectual and adaptive functioning (American Association on Intellectual and Developmental Disability, 2010). Coming to a unified definition and detailing the boundaries of developmental disability (DD) has been a challenge for professionals in the social sciences, though the inherent worth and capacity for learning possessed by these individuals has not been in question in recent history, as it was in centuries past. The purpose of this study was to examine the effectiveness of music therapy interventions in decreasing the duration of instances of elevated levels of maladaptive emotionally regulative behaviors of adults with developmental disabilities. Previous research has demonstrated the effectiveness of music therapy interventions in reducing stress and in improving the emotions, as evidenced by an increase in adaptive behaviors and/or improved affect, of adults with DD (Alvin, 1975; Brewer, 1955; Bruscia, 1998; Hooper, 2001; Hooper, Wigram, Carson, & Lindsay, 2008).

A limited number of experimental studies have been conducted on the use of music therapy interventions to address emotional goals in adults with DD, while no studies focused on reducing maladaptive emotionally regulative behaviors in adults with DD using music therapy was found by the researcher. Although the present study is qualitative (case study), it may serve as a starting point for possible future quantitative experimental research on this topic. This thesis may support the validity of music therapy as an effective treatment for reducing maladaptive emotionally regulative behaviors in adults with DD. This chapter will give a brief explanation of



developmental disability, emotion, maladaptive emotion regulation, and interventions currently used with adults with developmental disabilities who experience maladaptive emotion regulation, followed by a separate section on music therapy interventions.

### *History of Developmental Disability*

In centuries past, many cultures and societies misunderstood the potential and value of people with developmental disabilities, and the treatment they received reflected this misunderstanding. Historically speaking, people with DD have experienced everything from abandonment and being made a public spectacle of, to abuse and squalid living conditions (Adamek & Darrow, 2005; The Minnesota Governor's Council on Developmental Disabilities, 2010). In the history of the United States, individuals with DD have experienced neglect and physical abuse while living in over-crowded institutions. As public awareness has improved, so has the treatment of these individuals.

The parents' movement gained momentum in the 1950s and was significant in raising awareness of the needs and abilities of individuals with DD. Parents and congress worked together to improve the living conditions and educational opportunities afforded to these individuals (Adamek & Darrow, 2005; San Francisco State University Disability Programs and Resource Center, 1997). The rising awareness that individuals with DD have potential for learning was put into practice with the passage of public law 94-142 in 1975. This law ensured that no child could be denied a free and appropriate public education because of disability (Adamek & Darrow, 2005; Drew, Hardman, & Logan, 1996; SFSU Disability Programs and Resource Center, 1997). The positive changes that have been made in recent history, including the amendments made to Public Law 94-142, reflect an understanding of the gifts and abilities

possessed by each person, and the respect every human being deserves, regardless of his or her level of ability (Adamek & Darrow, 2005).

### *Definition and Diagnosis of Developmental Disability*

Over the past 40 years, the definition of and terminology used to describe individuals with developmental disability has changed many times, making it difficult for the average person to stay current (Adamek & Darrow, 2005; Drew, Hardman, & Logan, 1996; SFSU Disability Programs and Resource Center, 1997). According to the American Association on Intellectual and Developmental Disability (formerly the American Association on Mental Retardation), developmental disability is an umbrella term that encompasses intellectual disability, but also includes physical disability. Developmental disability and intellectual disability (ID) are commonly used interchangeably, but for the present study, developmental disability will be used to refer to individuals characterized by significant limitations, both in intellectual functioning and in adaptive behavior, that originate before the age of 18 (American Association on Intellectual and Developmental Disabilities, 2010).

Individuals with developmental disabilities are diagnosed as such in infancy, childhood, or adolescence. The current DSM-IV criteria for diagnosing intellectual disabilities are: significantly sub-average intellectual functioning (an IQ of approximately 70 or below on an individually administered IQ test), concurrent deficits in present adaptive functioning in at least two of the identified skill areas (communication, self-care and home living, social skills, use of community resources, self-direction, functional academic skills, work, leisure, health issues and safety), and an onset before the age of 18. The descriptors mild, moderate, severe, and profound are also used to elucidate the overall severity of the disability (American Psychiatric Association, 2000). Often the diagnosis is made when a parent or caretaker suspects

developmental delay in his or her child and makes an appointment with a specialist such as a pediatrician. Parents then work together with a multidisciplinary team of early intervention specialists to arrive at the diagnosis (Abrams & Goodman, 1998).

### *Incidence and Characteristics of Developmental Disability*

A wide variety of diagnoses fall under the larger heading of “developmental disability.” Individuals with DD may have a genetic or chromosomal disorder such as Down syndrome or fragile X syndrome, or they may have cerebral palsy, an Autism Spectrum Disorder, significant vision impairments or hearing loss, or they may have intellectual disability resulting from an injury, disease, or from unknown origins. It is not unusual for an individual to have more than one type of disability, such as cerebral palsy and intellectual disability. It is also not uncommon for an individual with a certain type of disability, such as cerebral palsy or an Autism Spectrum Disorder, to not fit the label of “developmentally disabled” because of the mildness of the symptoms associated with his or her disorder (Centers for Disease Control, 2010). Recent statistics indicate that between one and two percent of the population has a developmental disability (Merck Source, 2007).

The characteristics of individuals with DD are unique to each individual. However, there are certain characteristics other than the over-arching limitations in both intellectual and adaptive functioning that apply to individuals in the different categories of DD. For example, while individuals with Down syndrome share a similar facial profile, often experience intellectual disability and may suffer from poor heart function, individuals with Autism Spectrum Disorders experience significant social, communication and behavioral challenges, sometimes with a comorbid intellectual disability. Individuals with an Autism Spectrum Disorder who do not have an intellectual disability and who can function in society with little or no assistance may not be

significantly impacted by their developmental disability. Individuals with cerebral palsy experience an impaired ability to move and to maintain balance and posture, but if they do not have a comorbid intellectual disability and can function in society with little or no assistance, they may be considered as having only a physical disability. The life expectancy of individuals with DD is estimated to be 20 years below average, and mental health issues have been found to be more prevalent in this population as well (Centers for Disease Control, 2010).

### *Defining Emotions*

Throughout centuries past, from Plato to Darwin to William James, the conception of the nature and purpose of emotions has undergone many changes. It is unfortunate that many ancient philosophies, such as those of the Stoics, have viewed emotions as completely irrational. Similarly, Plato distinguished emotions from the reasoning components of the human mind (Stanford Encyclopedia of Philosophy, 2010). This conception of the nature of emotions has become commonplace, and remains predominant in the minds of many even today. However, the view that emotions and reason are in stark contrast to one another has been increasingly challenged in the last 50 years in the fields of psychology, philosophy, and neuroscience (Power & Dalgleish 2008; Zelazo & Cunningham, 2007). If, indeed, they are not entirely irrational, despite the fact that they sometimes lead us to do things we would not do under different circumstances, then what are they, and why do they affect us so powerfully?

Much of the past 20 years of research on the topic of emotions has pointed towards the functional nature of emotions, as well as the inseparability of the human brain, body, and the emotions that animate them (Fosha, Siegel, & Solomon, 2009; Levenson, 1999; Power & Dalgleish, 2008; Vandekerckhove, von Scheve, Ismer, Jung, & Kronast, 2008). Power and Dalgleish (2008) propose two main routes for the generation of emotion; the appraisal route,

which involves effortful processing and interpretation of an event as goal relevant, and a direct access or automatic route that is more instinctual. Damasio (1994) conceives of two separate mechanisms of emotions. One mechanism he refers to as primary emotions. These emotions occur mainly in the more primitive brain structures, such as the hypothalamus, basal nuclei, and amygdala. Secondary emotions, he argues, occur once a person begins experiencing feelings and formatting systematic connections between categories of objects and situations and primary emotions. Secondary emotions rely heavily on the higher, more complex brain structures, such as the prefrontal cortex. Both Power and Dalglish, and Damasio argue that emotions are adaptive and useful. It is clear that current research supports the idea that, under ideal circumstances, emotions are a useful and integral part of the mechanisms of survival and adaptation.

Zelazo and Cunningham (2007) suggest that emotions, despite how they have been viewed historically, correspond to an aspect of cognition – its motivational aspect. In a somewhat more thorough explanation, Damasio (1994) concludes, “emotion is the combination of a mental evaluative process, simple or complex, with dispositional responses to that process, mostly toward the body proper, resulting in an emotional body state, but also toward the brain itself, resulting in additional mental changes...” (1994, p.139). And finally, Vandekerckhove, et al. (2008) conclude that emotions are not merely reflexes, but are more like an alarm bell that prompts for action or further investigation. They also note that emotions are subject to change and revision. If emotions are as suggested, connected with motivation, able to impact physiology and cognitive processes, and subject to change, they would seem a viable starting point for many kinds of therapeutic interventions.

### *Defining Maladaptive Emotion Regulation*

In defining *maladaptive* emotion regulation, we must first define emotion regulation. Some researchers, especially those concerned with emotion regulation in adults, consider the concept of emotion regulation as inseparable from the core concept of emotion. These researchers focus on the automatic and intrinsic regulation that happens in the brain directly after an emotion occurs, but before any behaviors can be seen (Campos, Frankel, & Camras, 2004; Gross & Thompson, 2007). In contrast, developmental researchers tend to focus on the extrinsic processes of emotion regulation, such as singing a lullaby to soothe a crying infant, or distracting a young child with a toy in order to avoid a temper tantrum (Gross & Thompson, 2007).

Emotion regulation can occur undetectably in the brain at any point after an emotion has been generated, or it can occur after an emotion has been generated and a resulting outward behavior has occurred. Emotion regulation may involve intervention from an outside source, such as a parent, friend or caretaker, or it may be self-initiated through a variety of mediums, such as drugs, alcohol, and exercise. It also may be achieved through altering one's circumstances, for instance, by leaving a particular environment, or by directing one's attention away from emotionally aversive stimuli (Campos et al., 2004; Gross & Thompson, 2007). According to Thompson (1990), an individual's ability to regulate emotions is a result of the individual's innate capacity for regulating his or her own emotions, which can change with age and experience, and also socioemotional experiences that have shaped the individual over the course of his or her life.

Sroufe (1996) explains that assessing maladaptive emotion regulation does not consist of analyzing the results of any single test. Instead, it involves many emotion indicators and

determining whether the demonstrated emotion regulation pattern promotes or precludes the individual's competence in his or her interactions with the environment. It also involves assessing whether the demonstrated emotion regulation pattern promotes or precludes the development of adaptive skills, such as the skills associated with everyday living. Therefore, the process of assessing maladaptive emotion regulation involves answering the following questions: Are the exhibited behaviors hindering the individual's attainment of a regulated emotional state in the current environment? And are the behaviors hindering the attainment of social and/or other functional skills?

*Interventions for Adults with Developmental Disabilities Experiencing Maladaptive Emotion Regulation*

A higher rate of depression and anxiety disorders, and thus, maladaptive patterns of emotion regulation, among individuals with DD than in the typically developing population is a well-documented fact (Cooper, Smiley, Morrison, Williamson, & Allan, 2007; Dekker, Koot, van der End, & Verhulst, 2002; Einfeld, et al., 2006; Emerson, 2003; Hartley & MacLean, 2009). An over-reliance on medication in the treatment of individuals with developmental disability is also widely documented, as is the fact that sometimes these individuals are given medications without first being properly diagnosed by a professional. Additionally, alternatives to medications are rarely considered, and evaluations of effectiveness and side effects are often the exception (Antonacci & Attiah, 2008; Holden & Gittlesen, 2004; M. Lewis, Lewis, Leake, King, & Lindemann, 2002).

While interventions that involve multiple treatment components including behavioral, psychosocial and pharmacological are recommended in the treatment of mood and anxiety disorders among the typically developing populace, an over-reliance on medication alone persists

among adults with DD (Antonacci & Attiah, 2008; Bogacki, Newmark, & Gogineni, 2006). A few studies involving the use of modified psychotherapy and modified cognitive behavioral therapy with individuals with DD have been conducted, though most have been case studies and lacking in detail when describing interventions used (Bogacki, et al., 2006; McCabe, McGillivray, & Newton, 2006). Still, these few studies have shown some promising results, pointing toward the need for more research in this area.

Among the literature on the use of psychotherapy and behavioral interventions for addressing mood and anxiety disorders, some have argued that behavioral interventions work better, especially for individuals with severe DD (Antonacci & Attiah, 2008). One study on treatment effectiveness for problem behaviors found that response-contingent treatments were more effective than response non-contingent, antecedent-contingent and pharmacological treatments for reducing internal maladaptive (such as self injurious) and socially disruptive behaviors, both of which are indicative of maladaptive emotion regulation (Didden, Duker, & Korzilius, 1997). The need for response-contingent interventions to address maladaptive emotion regulation, such as that which is associated with depression and anxiety, and can lead to internal maladaptive, and socially disruptive behaviors in adults with DD is becoming increasingly evident. While the debate over the use of psychotherapeutic or behavioral techniques continues, another successful treatment approach is used with adults with DD that can incorporate the benefits of both.

### *Music Therapy Interventions for Adults with Developmental Disabilities Experiencing Maladaptive Emotion Regulation*

Music therapy is the clinical and evidence-based use of music interventions to accomplish individualized goals within a therapeutic relationship by a credentialed professional.



An estimated 1.2 million people received music therapy services in 2008. Also in 2008, a reported 596 music therapists served individuals with disabilities in a variety of settings (American Music Therapy Association, 2009). Music therapy has been used to address the needs of children and adults with developmental disabilities ever since the pioneering work of Juliette Alvin, who wrote a book about her experiences that was published in 1975. Music therapy is a treatment approach that is backed by a growing body of research and has the advantage of being a noninvasive, safe, and flexible medium that is able to incorporate a wide variety of treatment techniques (Alvin, 1975; El-Hassan, McKeown, & Muller 2009). Additionally, as Dykens, Rosner, Ly, and Sagun (2005) describe, some individuals with developmental disabilities seem to use music instinctively in a therapeutic manner to reduce anxiety and to increase positive affect.

Some of the goals most commonly addressed through music therapy for this population are: fulfilling basic needs, developing a sense of self, establishing or re-establishing interpersonal relationships, dispelling pathological behavior, and developing an awareness and sensitivity to the beauty of music (Meadows, 1997). A number of approaches to music therapy are currently used with children with developmental disabilities, such as the Orff approach, and the Kodaly approach, but only a few approaches are reported as being used to address goals pertaining to emotional needs for children in this population. Even fewer approaches are reported as being used to address emotional goals for adults with developmental disabilities (Darrow, 2004).

The behavioral approach to music therapy can be used to address emotional goals with adults with developmental disabilities, though a strict behavioral approach tends to steer away from emotional goals because these can be harder to define and track. Behaviorists try to quantify and measure behaviors as closely as possible, and emotions, though they often result in

outward behaviors, tend to be somewhat elusive. Cognitive-Behavioral Techniques are used in Behavioral Music Therapy to decrease depression symptoms in adolescents and elderly persons with dementia, among many other similar goals in a variety of populations, but minimal research has been done on the use of these techniques to address emotional goals in adults with developmental disabilities. Similarly, the psychodynamic approach to music therapy is not usually used with adults with developmental disabilities, although emotional goals are commonly addressed within this approach. This approach focuses on questions of meaning and requires the clients to engage with the therapist in abstract thought, and this is difficult for adults with developmental disabilities (Darrow, 2004).

Emotional goals are reported as being successfully addressed in both children and adults with developmental disabilities in the Nordoff-Robbins approach to music therapy. This approach uses improvisational techniques to achieve long term goals that aim at developing the client's individual potential, and this process involves addressing and working closely with the client's emotions (Andsell, 1995; Clarkson, 1991; Darrow, 2004; C. M. Robbins & Robbins, 1991). It would seem that an ideal approach for working with adults with developmental disabilities who experience maladaptive emotion regulation would involve elements of both the Behavioral and the Nordoff-Robbins approach to music therapy. The behavioral approach would encourage the therapists to define and track outward behaviors and would encourage designing response-contingent interventions, while the Nordoff-Robbins approach would especially encourage the use of improvisation techniques, which can lead to positive emotional outcomes.

The purpose of this study was to examine the effectiveness of individualized music therapy protocols in decreasing the duration of instances of elevated levels of maladaptive emotionally regulative behaviors in adults with developmental disabilities. The independent

variable was the treatment that included two conditions: (1) interacting with participants after they began exhibiting maladaptive emotionally regulative behaviors, using non-music interventions recommended by staff, (2) interacting with participants after they began exhibiting maladaptive emotionally regulative behaviors, using individualized music protocols. The dependent variable was the time that elapsed from the onset to the conclusion of each instance of a heightened emotional state, as evidenced by the presence and then absence of targeted maladaptive emotionally regulative behaviors at a rate per minute verified by staff members as indicative of a heightened emotional state.

This study was designed to answer the following research questions:

- 1. Can individualized music therapy protocols be used to decrease the duration of instances of elevated levels of maladaptive emotionally regulative behaviors in adults with developmental disabilities?*
- 2. Can such music therapy protocols decrease the duration of these instances of elevated levels of maladaptive emotionally regulative behaviors more effectively, resulting in shorter instances of elevated behavior levels, than the techniques normally used by staff members?*

## CHAPTER II

### LITERATURE REVIEW

This chapter provides a review of clinical and research literature relevant to the present study on the effectiveness of music therapy interventions in decreasing the maladaptive emotionally regulative behaviors of adults with developmental disabilities. The review begins with a discussion on different strategies for regulating emotion, followed by a section on emotion as it relates to brain structures and functions. The second half of the review summarizes implications of current research and clinical studies on music and emotion regulation, as well as how all of this information points toward music therapy as a uniquely effective treatment strategy for reducing the maladaptive emotionally regulative behaviors of adults with developmental disabilities. The purpose statement for this study concludes this chapter.

#### Emotion Regulation Strategies

As was previously discussed, emotions correspond to the motivational aspect of cognition, are able to impact physiology and cognitive processes, and are subject to change (Damasio, 1994; Vandekerckhove, et al., 2008; Zelazo & Cunningham, 2007). Emotion regulation is the process by which individuals influence which emotions they have, when they have them, and how they experience and express these emotions (Gross, 1998). Fredrickson and Losada (2005) elucidate the connection between positive affect and mental health. They found a significantly higher ratio of positive to negative affect in individuals whose mental health was deemed as flourishing than in those who were classified as not flourishing. This points toward effective emotion regulation as an important component of mental health, because sustained positive affect is also strongly associated with adaptive emotion regulation (Sroufe, 1996).

In the study of emotion regulation, a number of psychologists have taken up the task of describing different emotion regulation strategies. Gross and Thompson (2007) described five strategies, the first four of which address controlling various factors in order to avoid the experience of negative emotions. These strategies included being selective about the situations one places oneself in and attending to certain aspects of a situation and not to others. The strategy that is most applicable to this study is termed “response modulation.” Response modulation refers to attempts at influencing physiological, experiential, or behavioral responding as directly as possible. These attempts include exercising, taking deep breaths, taking drugs that target physiological responses, drinking alcohol, smoking cigarettes, eating, and listening to music, all done in an effort to modify emotion experience.

Gross, Richards and John (2006) describe a form of response modulation that involves regulating emotion-expressive behavior such as smiling, laughing or crying. Similarly, Panskepp and Gordon (2003) describe how simulating emotional actions such as facial expressions can induce desired emotions. Panskepp (2009) describes a form of response modulation when he explains how playfulness is an underutilized means of rerouting adults who have long been in maladaptive emotional patterns onto positive affective tracks. Fredrickson and Losada (2005) argue for the importance of emotion regulation in order to avoid negative affects when they state that positive affects are the essential components of physical and mental health, resilience, and well-being.

Damasio (1994) argues for multiple routes for regulating emotions when he describes the mechanisms for what he terms “primary” and “secondary emotions.” Primary emotions are the more instinctual emotional reactions that are present from birth, and secondary emotions begin developing when an individual starts making systematic connections between categories of

objects and situations and primary emotions. Damasio's primary and secondary emotions bear resemblance to the terminology of recent psychologists who refer to the bottom-up and top-down approaches to emotion.

The bottom-up approach describes emotion as a response to stimuli that has intrinsic or learned reinforcing properties in and of itself, such as a loud noise that causes fear (Rolls, 1999). The top-down approach is used in appraisal theories of emotion and characterizes emotion as the product of cognitive processes that interpret the meaning of stimuli in the context of an individual's current goals, wants and needs (Schere, Schorr, & Johnson, 2001). Similar to Damasio's secondary emotions, top-down emotion processing would involve higher order brain structures such as the prefrontal cortex. Based on these insights we can surmise that emotion regulation may occur by directly accessing the instinctual, subcortical (below the cerebral cortex, or gray matter) regions of the brain, such as the cerebellum or amygdala, or it may occur by accessing the reasoning and decision-making abilities of brain structures located in the cerebral cortex. Might it involve both cortical *and* subcortical brain structures simultaneously? Understanding more about the specific brain structures involved in emotion regulation will help to answer this question.

## Emotion and the Brain

### *Hindbrain, Midbrain and Interbrain*

The deepest brain structure involved in the processing of emotion is the cerebellum, which is the largest component of the hindbrain (rhombencephalon). More than half of all brain neurons are located in the cerebellum. This large structure is devoted mostly to the integration of visual, auditory and vestibular information into motor coordination, but it is also involved in

emotion processing, emotion regulation, and a surprising amount of cognitive functioning (Saladin, 2008; Schmahmann, 2010; Strick, 2009).

Moving upward inside the brain, just above the hindbrain structure, called the pons, and just below the interbrain (diencephalon), we reach the midbrain (mesencephalon). The midbrain, which is the smallest division of the brain, is the location of the periaqueductal gray (PAG), which modulates awareness of pain. The PAG has been shown in previous studies to be involved in emotional responses (Juslin & Västfjäll, 2008). The inferior colliculi, which relay auditory signals upward to the thalamus, are also located in the midbrain. Other functions the midbrain is involved with are vision, eye movement and body movement.

Just above the midbrain (mesencephalon) we reach the interbrain (diencephalon), which contains the hypothalamus and thalamus. The hypothalamus is a key player in the generation of emotional responses such as anger, fear and pleasure, and is also involved in the sense of reward and punishment. Essential autonomic effects such as heart rate, blood pressure, and hunger are also mediated here. The hypothalamus relays signals from the limbic system to the thalamus. The thalamus is involved in sensory processing and acts as the gateway to the cerebral cortex. Nearly all sensory input and other information going to the cerebrum pass through the thalamus (Saladin, 2008).

### *Limbic System*

The limbic system is composed of a number of brain structures, both cortical (part of the cerebral cortex, or gray matter) and subcortical (below the cerebral cortex), and has important roles in the processing of emotion and in the establishment of memories. The structures of the limbic system include the amygdala, hippocampus, nucleus accumbens, cingulate gyrus, and parts of the prefrontal cortex (PFC), where complex thought occurs. The amygdala is located

deep in the brain, in the temporal lobe, and the hippocampus is located not far from the amygdala, in the medial-temporal lobe. The nucleus accumbens, which is a part of the basal nuclei, is a collection of neurons buried deep in the brain, lateral to the thalamus. The cingulate gyrus arches over the corpus callosum, which is the structure that connects the left and right cerebral hemispheres. Parts of the medial prefrontal and orbitofrontal cortex, which are involved in higher order cognitive skills such as conscious control and decision-making, are also usually considered to be part of the limbic system. These parts, though spread apart, are all connected to form a sort of inner border of the cerebrum (Saladin, 2008).

The amygdala is one of the most significant structures in the processing of emotion. It receives processed information from the senses of vision, hearing, taste, smell, and from general visceral stimuli. It is involved in reacting to a wide range of stimuli, such as a disgusting odor, a beautiful image, pleasant music, or a stomachache. Aversion centers are the dominant feature of the amygdala. Not surprisingly, it has been found to be especially important for the sense of fear. Some output from the amygdala projects to the hypothalamus and lower brainstem. Other output projects to areas of the prefrontal cortex that mediate conscious control and expression of emotion (Saladin, 2008).

The hippocampus is important for the creation of new memories, and is also involved in emotional responses. It appears to “teach” the cerebral cortex certain important memories over time, where they are then stored. The nucleus accumbens is dominated by gratification centers, and is thus thought to play an important role in reward, pleasure, laughter and addiction (Juslin & Västfjäll, 2008; Saladin, 2008).

In the study of the brain and emotions, researchers have found the anterior portion of the cingulate gyrus to be especially interesting. Some have proposed that the anterior cingulate



gyrus acts as a bridge between attention and emotion (Devinsky, Morrell, & Vogt, 1995). Beer and Lombardo (2007) surmised that it might also be involved in directing individuals away from punishment. Its proximity to areas of the medial prefrontal cortex and the basal nuclei, as well as studies of patients with damage to this area, suggest a close connection between the anterior cingulate gyrus and brain systems of emotion, attention, and working memory (Damasio, 1994; Saladin, 2008).

The prefrontal cortex (PFC), in which the medial prefrontal and orbitofrontal cortices are located, is a very important center of cognitive and emotional function. The PFC is involved in everything from the motor aspects of speech to controlling anger to foresight and cognitive functions (Saladin, 2008). The PFC is highly involved in the processing of emotion, with special emphasis in the right hemisphere (Damasio, 1994). This area of higher cognitive control is consistently linked to various features of affective processing, and damage to this region has long been associated with impaired control over the magnitude of emotional expression (Anderson, Bechara, H. Damasio, Tranel, & Damasio, 1999).

#### *The Interconnectivity of Brain Structures Controlling Attention, Emotion and Cognition*

In the field of psychotherapy, the current trend has begun to shift from models favoring top-down interventions to models that favor a more bottom-up approach, contending for the importance of affect in assessing and treating matters of health and well being. The findings of many leading psychologists as well as neurologists, is that the processes of the deep, subcortical structures of the brain are inseparable from the processes of the higher cortical structures. Subsequently, they conclude that rationality, as well as emotion regulation, occur only as a result of these systems working together (Damasio, 1994; Foshia et al., 2009).

Joseph (1996) explains that the brain stem, which is the lowest, most basic brain structure, supports important brain functions, both simple *and* complex. The brain stem supports the functions of breathing, heart rate, movement and auditory perception, as well as emotional arousal, and the mediation and control of attention. Posner, Rothbart, Sheese, and Kieras (2008) found that the processes of attention used by infants and children are related to the self-regulation of cognition and emotion. Considering that many subcortical structures, such as the cerebellum and the brain stem, as well as cortical structures, such as the PFC, are involved in the mediation and control of attention, this study also supports the growing consensus that the subcortical and cortical structures of the brain work together more closely and in more brain functions than was previously understood (Beer & Lombardo, 2007; Saladin, 2008). Additionally, the structures of the brain involved in the mediation and control of attention seem to be especially inter-related to the structures of the brain that process emotion and cognition.

Damasio highlights the importance of brain structures involved in attention when he explains a concept he refers to as “time-binding.” “Time-binding,” Damasio suggests, occurs when, in an attempt to make a decision, focused activity occurs in different brain regions at the same time, resulting in meaningful combinations that lead to a decision. This process requires the ability to sustain attention, and especially involves the PFC and some limbic structures, such as the anterior cingulate gyrus. Once again, these attention-moderating structures are also implicated in the generation of emotion (Damasio, 1994).

Kaiser (2003) explains another way of understanding brain activity when he describes networks of neurons in different parts of the brain communicating and consequently producing oscillatory activity. This activity can be measured in EEG and MEG potentials and fields. Oscillations in the 30-100 Hz range are designated as “gamma-band” oscillations. This level of

neuron activity has been related to perception as well as the cognitive functions of attention, learning and memory. But purely cognitive stimuli are not the only stimuli that can produce gamma-band oscillations.

Emotional experiences are commonly reported while listening to music, and many report this phenomenon as a primary motivation for listening to music (Juslin & Laukka, 2004; Juslin & Västfjäll, 2008). However, the effects of music extend beyond what we typically think of as the emotional circuitry of the brain. According to the studies of Kaiser (2003) and Trainor, Shahin, and Roberts (2009), music has the ability to increase gamma-band activation in the brain. As previously stated, this type of oscillatory activity has been related to cognitive functions such as attention, learning and memory. Therefore, music is a prime example of the interconnectivity of brain structures controlling attention, emotion and cognition. Now that the inseparability of these brain systems has been established, the word “emotion” and the concept of “emotion regulation” as it relates to music will now be used more broadly, in order to include some studies that address music’s effects on cognitive and attentional outcomes as well.

### Music and Emotion Regulation

#### *Implications of Current Neuroscience Research (Non-Clinical studies)*

The use of music to regulate emotions is a well-documented phenomenon. Emotion is strongly related to most people’s primary motives for listening to music (Juslin & Laukka, 2004). Numerous studies have confirmed music’s ability to change, release, induce, and match emotions (Dimaio, 2010; Juslin & Västfjäll, 2008; Kenealy, 1988; Panskepp & Bernatzky, 2002). Blood and Zatorre (2001) conducted a study that examined the regions of the brain where blood flow changes occurred in response to music-induced chills. They found blood flow changes in the following structures: the orbitofrontal cortex, which is involved in decision-making, planning

behavior, and emotion; the dorsal midbrain, which is the location of the PAG (which modulates awareness of pain) and structures concerned with vision and eye movement; the ventral striatum, which is the location of the nucleus accumbens, which is dominated by gratification centers; and the insula, which is thought to play a role in taste, hearing and visceral sensation (Saladin, 2008). These findings support the use of music to regulate emotions, as well as produce a number of other outcomes, such as improving executive function, and decreasing awareness of pain.

In their study on mood changes while listening to music, Panskepp and Bernatzky (2002) reported that mood changes induced by music outlast the music by about 10 minutes. They conclude that these short-lived mood changes are mediated by the attention-focusing arousal effects of music. This finding supports the ineffectiveness of simply playing a happy song in order to address an emotional goal in a music therapy setting, because the mood change that may occur as a result of this would likely not last longer than 10 minutes. The music therapist must tap into the sense of accomplishment, emotional expression, personal insight, and/or social connection that engaging in musical activities can bring, in order facilitate an experience that is truly therapeutic. This kind of an experience goes beyond the effects that music can have on an individual's superficial mood.

Also interesting to note are the findings of a study by LeDoux (2000) on the inhibitory affects of the nucleus accumbens on amygdala output. He found that the nucleus accumbens, which is dominated by gratification centers, could actually have an inhibitory effect on the output of the amygdala, which is dominated by aversion centers. When combined with the findings of the above-mentioned study by Blood and Zatorre (2001), it would seem that music has the ability to stimulate the nucleus accumbens, and thus, to inhibit negative emotional impulses of the amygdala.

The temporal lobe is another important brain structure to consider when examining the dynamics of music and emotion in the brain. The temporal lobe is involved in hearing, smell, learning, memory, and some aspects of vision and emotion (Saladin, 2008). Beer and Lombardo (2007) found that the frontal and medial temporal lobes play a significant role in the psychological processes by which individuals modify the magnitude of their emotional responses once emotion has been generated. Interestingly, Schneider, Scherg, Dosch, Specht, and Gutschalk (2002) found that part of the primary auditory cortex, which is located in the superior temporal gyrus, and is the first cortical structure to process incoming auditory information, is 100% larger in professional musicians. It seems clear that actively making music causes changes in certain structures of the brain, and that some of these structures are involved in the processing of emotion.

Many other studies have further authenticated the notion that music can cause changes in the structures of the brain. Pascual-Leone, Nguyet, Cohen, Brasil-Neto, Cammarota, and Hallett (1995) observed anatomical changes in the brains of their participants, whose ages ranged from 19 to 51, even after just two hours of musical practice. Svard (2010) affirmed that new connections could be established in adult brains in response to new experiences, such as exposure to music or musical training. Schlaug (2003) reported anatomical changes in the cerebellum and corpus callosum of musicians. This is especially interesting when considering that the corpus callosum connects the right and left hemispheres of the brain and facilitates communication between them.

Brain structures associated with music are very widespread in the brain, impacting a large number of brain structures, and the same is true of brain structures associated with emotion processing (Beer & Lombardo, 2007; Levitin, 2006; Trainor, Shahin, & Roberts, 2009).

Additionally, neurological studies have shown that musicians appear to recruit more neural tissue or to use it more efficiently than do non-musicians (Peretz & Zatorre, 2005). Foran (2009) reported that children with high levels of musical training have increased ability to manipulate information in working and long-term memory. She connects this to the fact that music activates the motor cortex, subcortical structures, and the cerebellum, along with other brain structures, such as the PFC.

The studies of Ivry and Keele (1989), and Peretz and Zatorre (2005) point toward the cerebellum as the brain structure most involved in the rhythmic aspect of music. Ivry and Keele report that individuals with cerebellar damage experienced impaired execution of musical rhythmic tasks, impaired motor abilities, and deficiencies in discrimination of auditory intervals. Peretz and Zatorre confirm this assertion, reporting that individuals with damage to the lateral cerebellar hemispheres show greater variability in rhythmic accuracy. The cerebellum is involved in mediating attention and it has been found that many children with Attention-Deficity Hyperactivity Disorder (ADHD) have abnormally small cerebellums (Saladin, 2008). When considering Schlaug's (2003) study that found anatomical changes in the cerebellum as a result of exposure to music, it would seem that the rhythmic aspect of music could be of special benefit to individuals with ADHD. According to the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (Public Law 106-402), an individual with ADHD is considered developmentally disabled when his/her ADHD causes substantial functional limitations in three or more areas of major life activity, such as self-care, receptive and expressive language, learning, and capacity for independent living (U.S. Department of Health and Human Services, 2010).

### *Implications of Current Neuroscience Research (Clinical Studies)*

A number of clinical studies have shown music to be an effective medium for inducing positive emotional changes. In one study, patients about to undergo a medical procedure associated with a high level of anxiety (gastrointestinal endoscopy) listened to music for 15 minutes before the procedure. When compared with a control group, the anxiety scores of those in the music group revealed a significant reduction in anxiety, which was maintained for all age groups. This finding led the researchers to conclude that music is a cheap, safe, non-invasive and effective non-pharmalogical, anxiolytic agent, capable of reducing sedation dosages (El-Hassan et al., 2009).

In their study on the effect of music on emotions, immune, and endocrine parameters during physiotherapy treatments of patients with infectious lung conditions, LeRoux, Bouic, and Bester (2007) found that Bach's Magnificat, which is written in a major key, communicated an emotion that activated the positive emotional center of the brain – the nucleus accumbens. They also found significant changes in several medically significant parameters in those who were exposed to Bach's Magnificat, such as cortisol to DHEA ratio, which is associated with the body's ability to handle stress and is connected to many positive health outcomes.

Dimaio (2010) conducted a case study in which music therapy protocols were used to alleviate pain in hospice clients. One of the key music therapy principles utilized in her research protocols was the iso-principle. The iso-principle states that after the therapist has matched music to the mood of a client, the client's mood can be altered by gradually changing the music (Dileo & Bradt, 1999). It is interesting to note that both mood and perception of pain were addressed simultaneously through individualized music therapy protocols.

Götell, Brown, and Ekman (2009) found that, in the care of persons with dementia, when compared with no music, the presence of background music and caregiver singing improved the mutuality of the communication between caregiver and patient, creating a joint sense of vitality. They found that, among those who received the music condition, positive emotions were enhanced, aggressiveness was diminished, and the individuals showed an improved ability to express positive emotions and experience arousal and vigilance. Furthermore, Sacks (2007) reported that individuals with amnesia, aphasia, stroke, depression, and other disorders have used music to improve their moods, recall lyrics and manage anxiety.

Despite the multiple and varied populations for which music has been therapeutically applied in order to address some form of maladaptive emotion regulation, there is a marked lack of any literature of this nature applied to adults with developmental disabilities. This deficit is apparent in the experimental literature of the music therapy journals (Hooper et al., 2008). This absence seems a great oversight, especially considering the high percentage of individuals with developmental disabilities that are currently taking medications in an attempt to alleviate emotional and behavioral problems (Antonacci & Attiah, 2008; Holden & Gitlesen, 2004). However, this oversight may largely be due to the old and prevalent misconceptions that are associated with the concept of emotion. These misconceptions are widespread and are certainly not limited to any particular discipline.

#### Music Therapy for Decreasing Maladaptive Emotionally Regulative Behaviors in Adults with Developmental Disabilities

As has previously been established, there is considerable overlap in brain structures controlling attention, emotion and cognition. Adding “development of emotion regulation skills” to the list of commonly addressed music therapy goals would not be out of line with goals



already in existence in the emotion domain, and doing so might broaden the scope of practice for music therapists. Additionally, music therapists might even come to be seen as providing an alternative to medication in some cases. If, while clients with developmental disabilities are experiencing some kind of maladaptive emotion regulation, music therapists were prepared to engage them musically in a manner that would help them work through the troubling emotions, this could help to decrease the duration of such instances of elevated levels of maladaptive emotionally regulative behaviors for these individuals. This alone would be beneficial, because decreasing negative affect has been linked with positive mental health outcomes (Fredrickson & Losada, 2005; Sroufe, 1996). In addition, over time this exposure to music could have the positive effect of decreasing the duration of these instances of maladaptive emotion regulation, even when the music therapist is not present. This is possible because repetitive exposure to music has been shown to have a positive impact on various brain structures, such as the cerebellum, that contribute to an individual's ability to process and regulate their own emotions. Repeated exposure to music has been shown to actually structurally change these parts of the brain, improving their ability to function (Ivry & Keele, 1989; Peretz & Zatorre, 2005; Saladin, 2008; Schmahmann, 2010; Strick, 2009).

The Nordoff-Robbins approach to music therapy, which relies heavily on improvisational techniques, has been reported as successfully addressing emotional goals in adults with developmental disabilities (Aigen, et al, 2004; Andsell, 1995; Clarkson, 1991; C. M. Robbins & Robbins, 1991). Hooper (2001) conducted a study that found music-based activities to be as effective as indoor ball games in increasing positive interaction and diffusing the stress often associated with interaction among four adults with developmental disabilities, supporting the use of non-verbal interventions for this population. In their review of the music and intellectual

disability literature, Hooper, Wigram, Carson, and Lindsay (2008) compiled a list of reported benefits of addressing emotional goals, despite the fact that only a small number of clinicians provided detailed accounts of the interventions they used to do so. The reported benefits listed were: expressing emotion, alleviating agitation, enhancing accomplishment, and improving self-esteem. This list could be seen as a starting point for a new list that current research suggests is now primed and ready for expansion.

In the current research climate, and in light of the common knowledge of music's impact on emotions, it is exciting to consider the possibilities for the field of music therapy. It has been stated that music exercises more parts of the brain than almost any other single activity, and that it is especially suited for individuals with learning problems because it appears to help them access parts of their brains that function poorly or not at all (Levitin, 2006). The research of modern psychologists and neuroscientists on the far-reaching impact of the brain structures involved in emotion processing, and current clinical research on the effectiveness of music for creating positive emotional outcomes, have brought increasing support to the field of music therapy and its use with adults with developmental disabilities who experience maladaptive emotion regulation.

#### Purpose of Study

The purpose of this study was to examine the effectiveness of individualized music therapy protocols in decreasing the duration of instances of maladaptive emotionally regulative behaviors in adults with developmental disabilities. According to the literature, no experimental research has been conducted on the use of individualized music therapy protocols to specifically address maladaptive emotion regulation in adults with developmental disabilities, though some studies have reported the emotional benefits of music therapy interventions for this population.

A limited amount of research has been done on this topic despite the prevalence of emotional challenges within this population, and current research that has brought emotions to the forefront of the scientific fields of psychology and neuroscience. The independent variable was the treatment that included two conditions: (1) interacting with participants after they began exhibiting maladaptive emotionally regulative behaviors, using non-music interventions recommended by staff, (2) interacting with participants after they began exhibiting maladaptive emotionally regulative behaviors, using individualized music protocols. The dependent variable was the time that elapsed from the onset to the conclusion of each instance of a heightened emotional state, as verified by staff members who reported the presence of maladaptive emotionally regulative behaviors.

This study was designed to answer the following research questions:

- 1. Can individualized music therapy protocols be used to decrease the duration of instances of elevated levels of maladaptive emotionally regulative behaviors in adults with developmental disabilities?*
- 2. Can such music therapy protocols decrease the duration of these instances of elevated levels of maladaptive emotionally regulative behaviors more effectively, resulting in shorter instances of elevated behavior levels, than the techniques normally used by staff members?*

## CHAPTER III

### METHOD

#### *Participants*

Four adults with developmental disabilities were recruited from a local not-for-profit organization that serves adults with developmental disabilities. The researcher asked for recommendations from the Work Enrichment Coordinator of possible participants for the study, based on the presence of severe and/or frequent instances of maladaptive emotionally regulative behaviors. All participants were above the age of 20, had significant limitations in intellectual functioning, communication and adaptive behavior, and were involved in the work service program. All of the participants lived either in group homes with 24 hour supervision or with family and were brought to the facility during the day. Three males, ages 29, 49 and 60, and one female, age 37, participated in the study.

#### *Design*

An ABAB reversal design was used to examine the effectiveness of the usual staff techniques (condition A) and the individualized music therapy protocols (condition B) in decreasing the duration of instances of maladaptive emotionally regulative behaviors. The researcher was present and available for data collection and intervention three times a week, for three hours, from the beginning of the study, until all data was collected. Two of the participants worked in the south room, and the other two worked in the north room. The researcher switched between the two rooms during each three-hour time period, depending on which participants seemed to be having more behaviors. The researcher only intervened with condition A or B one time per day for each participant, and only if one of the participants was identified as currently experiencing a heightened emotional state. A heightened emotional state was identified by the

presence of maladaptive emotionally regulative behaviors at or above a pre-determined rate per minute (calculated after four weeks of observing and tracking the behaviors of each participant while they were experiencing a heightened emotional state, as confirmed by staff members) for three consecutive minutes. On several occasions the researcher tracked behavior occurrences, but did not intervene due to the low level of behaviors. Also, on several occasions a participant experienced more than one heightened emotional state during the three-hour period. The researcher only intervened with condition A or B for the first instance of a heightened emotional state during each three-hour block. When the first instance of elevated emotion occurred, the researcher intervened using the usual staff techniques (condition A), such as responding to repetitive verbalizations with a reminder of when the desired activity would be taking place. These individualized techniques (Table 1) were learned through observation and interview of the staff members who worked most closely with each participant. The next time maladaptive emotion regulation was observed for that same individual during a subsequent observation (never on the same day), the researcher intervened using the individualized music therapy protocols listed in Table 2 (condition B). This process then repeated until all four subjects received both treatment conditions two times each (ABAB) over the course of at least four days (though none of them actually finished this soon due to low levels of behaviors on certain days), receiving only one instance of one condition per day. An instance of heightened emotion was regarded as having ended when maladaptive behavior levels had decreased to typical levels for three consecutive minutes.

Table 1

*Comprehensive List of Staff Techniques Used with Each Participant*

<b>Participant 1</b>	<b>Participant 2</b>	<b>Participant 3</b>	<b>Participant 4</b>
Redirect 1 to another part of the room, using minimal physical redirection	Verbally respond to 2 in a playful tone of voice, saying, counting to ten, or spelling his name	Respond to verbalizations with a reminder of when desired activity will be taking place	Give 4 a piece of paper or a paper towel to rip up
Remain in close proximity to 1	Redirect 2 to playing with his stuffed animals	Engage 3 in looking through a book, magazine or newspaper	Help 4 out of her wheelchair and onto the mat
Direct 1 to a table with magazines and a pen, using minimal physical redirection	Give 2 his space and make sure the room is quiet	Ignore repetitive verbalizations	Get 4's basket of toys and engage her in handling them
If 1 is having trouble communicating, tell him to use his words or signs	Ignore repetitive negative verbalizations and vocalizations	Help 3 to get from his wheelchair into his recliner	Engage 4 in a game of grabbing something off of the table or clearing the table
Engage 1 in dancing and clapping playfully			Take 4 to a quiet room

*Independent Variable*

The independent variable was the treatment, which included two conditions: (1) interacting with each participant while he or she is exhibiting the targeted maladaptive regulative behaviors at a rate per minute that exceeded the participant's usual rate per minute (determined during

Table 2

*Comprehensive List of Targeted Maladaptive Emotionally Regulative Behaviors for Each Participant*

<b>Participant 1</b>	<b>Participant 2</b>	<b>Participant 3</b>	<b>Participant 4</b>
Non-compliance with staff requests	Negative undistinguishable verbalizations	“No”	Screaming
Hitting others	Yelling	“Wanna eat”	Hand biting
Eloping to another room or leaving the building	Saying, “No” without an apparent reason	“Wanna go home”	Self-hitting
Taking objects that belong to others	Crying sounds	“Break”	Hitting the floor or other objects
Invading others clients’ personal space		Other negative verbalizations	
Choke-hold hugging or touching others’ hair		Undistinguishable negative vocalizations	
Trying to instigate behaviors in other clients			

observations), using non-music interventions recommended by staff, (2) interacting with each participant while he or she was exhibiting the targeted maladaptive regulative behaviors at a rate per minute that exceeded the participant’s usual rate per minute, using individualized music therapy protocols. Both staff techniques and music therapy protocols were implemented only after each client had been identified as currently experiencing a heightened emotional state. Staff techniques were used after the first and third instance of heightened emotion, and individualized music therapy protocols after the second and fourth instance.

Table 3

*Comprehensive List of Music Therapy Interventions Used with Each Participant*

<b>Participant 1</b>	<b>Participant 2</b>	<b>Participant 3</b>	<b>Participant 4</b>
Listening to and/or singing preferred songs with live guitar accompaniment	Listening to preferred songs played on the guitar and sung live	Listening to preferred songs played on the guitar and sung live	Listening to preferred songs played on the guitar and sung live
Listening to familiar melodies played live on the flute	Listening to live, improvised ambient flute or guitar music	Listening to live, improvised ambient flute music	Listening to familiar melodies played live on the flute
Listening to live, improvised ambient guitar or flute music	Improvised vocalizations with live, improvised flute music, in a back-and-forth manner	Listening to familiar melodies played live on the flute	Listening to familiar songs sung live while tapping on the drum with the researcher
Improvising on percussion instruments with musical support from the researcher	Listening to familiar melodies played live on the flute		Blowing bubbles with researcher to unaccompanied live singing of preferred songs

A participant was identified as currently experiencing a heightened emotional state using a behavior ratio developed with the staff during the observation period that was conducted prior to the study. For instance, if the researcher recorded Participant 4 as engaging in self-hitting, self-biting, and/or screaming at a rate at or above 1 per minute for three consecutive minutes, she was considered to be currently experiencing a heightened emotional state. At this point the researcher intervened with condition A or B. The researcher used a detailed minute-by-minute data chart to record behavior occurrences for each participant (Appendix A).



During the observations, the researcher observed the maladaptive emotionally regulative behaviors of the participants and asked the staff to state the point at which they would identify the participant as exhibiting a level of maladaptive behaviors that was unusually high for that participant. Once the staff member who worked most closely with the participant stated that the participant was currently exhibiting an unusually high level of the specified maladaptive behaviors, the researcher recorded the number of these behaviors that occurred in the next ten minutes. After four observations of unusually high levels of maladaptive emotionally regulative behaviors in each participant, the researcher averaged the number of behavior occurrences over the four ten minute intervals subsequent to a staff member positively identifying the participant as experiencing an unusually high level of the behaviors being tracked, and divided this number by ten to come up with a per minute behavior ratio that signaled an instance of heightened emotion for each participant. If this number was a decimal, the researcher rounded up to the nearest whole number.

The individualized music therapy protocols (Table 3) were designed by the researcher and were based on the researcher's clinical experience working with adults with developmental disabilities, the data gathered during the observations of each participant, and the thirty-minute music therapy assessment session conducted by the researcher with each participant. The music therapy interventions were used in the order listed in Table 3 each time the music therapy condition was implemented for each participant. The researcher moved to the next intervention if the participant's behavior occurrences did not decrease after several minutes, or when the intervention was sufficiently completed. Using music interventions to address the emotional needs of adults with developmental disabilities is supported by Bruscia (1998), Clarkson (1991), and Hooper et al. (2008). Didden et al. (1997) supports the effectiveness of response-contingent

interventions, in contrast to response noncontingent, antecedent control, or pharmacological treatment, in dealing with the problem behaviors of adults with developmental disabilities. Bruscia (1998), Wigram, Pedersen, and Bonde (2002), and C. M. Robbins and Robbins (1991) support the use of music improvisation interventions in addressing emotional needs. Clair (2000) supports the use of familiar songs in music therapy.

### *Dependent Variable*

The dependent variable was the time that elapsed from the onset to the conclusion of each instance of heightened emotion, as observed and recorded by the researcher and one pre-selected staff member for each participant. The researcher used a timer to measure the dependent variable for both treatment conditions. The researcher identified the onset of each instance of heightened emotion when a participant exhibited maladaptive emotionally regulative behaviors at or above the predetermined rate per minute for three consecutive minutes. The instance of heightened emotion was regarded as having ended when the pre-selected staff member who recorded behavior occurrences while the researcher conducted one of the treatment conditions observed and recorded a decrease in the behaviors associated with maladaptive emotion regulation to typical levels, sustained for three consecutive minutes, using the same minute-by-minute data chart the researcher had been using. At this point, the staff member recording the behavior occurrences informed the researcher of the decrease to normal levels.

### *Procedure*

Two fifteen minute individual music therapy assessment sessions were conducted for each of the four participants by the researcher in order to determine music style and instrument preferences, and to determine which materials and types of interventions each participant appeared most motivated to engage in. Music styles, instruments, materials and interventions

presented in the assessment were based on the researcher's clinical experience working with adults with developmental disabilities. The music styles included folk, country, rock, religious, ambient, and blues. All pre-composed songs were played on the guitar and sung or played on the flute, except the ambient music, which was played on the guitar or flute with no vocals.

After the assessment sessions were conducted, the researcher created individualized music therapy interventions that utilized the interventions each participant responded positively to during the assessment (Table 3). During the study, the researcher observed two participants in a given three-hour period, tracking occurrences of the targeted behaviors (Table 2). As soon as a heightened emotional state was positively identified in one of the participants by the researcher by tracking the number of behaviors per minute, the researcher handed the pre-selected staff member a detailed data collection sheet (Appendix A) and a pencil, re-started the timer, left the timer on a chair next to the staff member, approached the participant in the environment in which the maladaptive emotion regulation was taking place, and implemented condition A (staff techniques) the first and third time, and condition B (music therapy protocols) the second and fourth time that a heightened emotional state was identified. The music therapy protocol included music styles and songs preferred by the client (Clair, 2000) as well as instruments, materials and interventions identified in the assessment as most likely to engage the participant. Once the behaviors associated with a heightened emotional state decreased to normal levels for three consecutive minutes, as recorded by the staff member, the staff member informed the researcher of the decrease to normal levels.

Prior to beginning the study, the researcher made all staff members who would be in the room aware of the importance of the researcher, participant, and selected staff member not being disturbed while the researcher was implementing one of the treatment conditions. The other

clients in the room were doing whatever they would normally be doing and had the assistance of a number of other staff members. If other clients were interfering with the treatment in any way, the researcher signaled for the nearest staff member to assist in dealing with the distraction. However, this was not a significant problem due to the consistently positive responses of the other clients towards music in general, the spacious rooms in which the treatment conditions were implemented, and due to the high staff-client ratio.

### *Materials*

The instruments that were used included an ocean drum, egg shaker, hand drum, jingle bells, and a triangle. Materials included bubbles to be used while singing unaccompanied songs, blowing the bubbles between song phrases. The instruments and materials were carried in an enclosed case that was only opened to access one instrument or material at a time, in order to avoid excess distraction to the other clients in the room. Music therapy interventions (Table 3) included listening to familiar songs, singing familiar songs, listening to live, improvised ambient flute or guitar music, hand-over-hand instrument playing, instrumental improvisation with musical support from the researcher on flute or guitar, improvised vocalizations with live, improvised flute music in a back-and-forth manner, and blowing bubbles (between phrases) with the researcher to unaccompanied live singing of preferred songs. The instruments, materials and interventions chosen were identified as effective and preferred by the participants during their assessment sessions.

### *Data Collection*

The staff member who worked most closely with each participant assisted the researcher in the data collection process for that participant. Each pre-selected staff member participated in reliability training conducted by the researcher prior to the first day of data collection. Before

the researcher began observing a given participant in an attempt to be present at the onset of an instance of a heightened emotional state, the researcher reminded the staff member of the behaviors being tracked in order to positively identify a heightened emotional state, and reminded him/her of the protocols the researcher would be engaging the participant in and the role the staff member would play in the data collection process once a heightened emotional state was identified.

Once a heightened emotional state was positively identified, the researcher handed the staff member a pencil and a data collection sheet (Appendix A) that the researcher familiarized each staff member with prior to implementation (detailing all target behaviors being tracked with tally marks, minute by minute), started the timer, left the timer on a chair or table next to the staff member, and approached the participant in order to engage them in one of the treatment protocols. Once the staff member identified a decrease in the targeted behaviors to a rate per minute that was below the rate that signaled a heightened emotional state (for example, 2 behaviors per minute) for three consecutive minutes, he/she informed the researcher of the decrease to typical levels.

After each treatment condition was completed, the researcher was able to check that the staff members had stopped taking data after three consecutive minutes of behavior rates below the rate per minute associated with a heightened emotional state using the data collection sheets filled out by the staff members. If the staff member recorded data for longer than three minutes of typical behavior ratios, the researcher decreased the total time elapsed (dependent variable) to reflect only three minutes of typical behavior ratios.

### *Data Analysis*

After all data was collected, the researcher analyzed them. Graphic analyses were completed across both treatment conditions for each participant. The graphs show the duration of time that each participant experienced a heightened emotional state, as evidenced by maladaptive behavior rates per minute at or above the rate per minute associated with an unusually high level of maladaptive behaviors, while the researcher engaged them in two non-music conditions, and in two music therapy conditions (ABAB).

## CHAPTER IV

### CASE STUDY I

#### *Background*

Participant 1 is a 29-year old male diagnosed as having a severe intellectual disability and attention deficit hyperactivity disorder (ADHD). At the time of the study Participant 1 was taking the antipsychotic, Quetiapine (Seroquel), the anticonvulsant, Valporic Acid (Depakote), as well as several other medications to treat things such as high blood pressure. Participant 1 has been in the work enrichment program since 2001. In this program he engages in recreational and learning experiences throughout the community, as well as on-site, that support his personal and social skills. Participant 1 grew up with his birth family until the age of 8, at which time he moved into a foster home. He currently lives in a house next to his foster family's house where he receives 24-hour support from staff. Participant 1 went through the special education program at his local public school from kindergarten through high school.

Participant 1 demonstrates deficits in intellectual functioning, emotion regulation, communication, and social skills. Participant 1 demonstrates functionality in fine and gross motor coordination. Participant 1 has moderate receptive skills but limited verbal skills. Because his birth mother, who is deaf, raised him until the age of 8, he learned sign language before verbal speech and still uses this in conjunction with his verbal speech. He has no trouble making eye contact and enjoys interacting with the staff and his peers by giving hugs, signing, and saying words such as "mom." His attempts at social interaction are usually not socially adaptive. He sometimes invades others' personal space and also does not understand or practice proper boundaries with strangers. He is usually smiling and he laughs frequently.

It is difficult to predict when Participant 1 will enter an emotionally heightened state, as he has no consistent triggers. His moods seem to rise and fall in cycles that sometimes last only minutes, and sometimes for weeks. When Participant 1 is in an emotionally heightened state he sometimes does things to provoke others such as turning up the radio volume excessively loud, taking objects that belong to others, and invading others' personal space. He also sometimes cries, raises his voice and leaves the room without permission. When he leaves the room unexpectedly, his primary staff member has to follow him in order to bring him back to his room.

### *Assessment Findings*

The researcher conducted two fifteen-minute individual music therapy assessment sessions in order to strengthen interpersonal rapport and determine instrument and musical style preferences. Participant 1 was familiar with the researcher because she had been conducting group music therapy sessions once a week at this facility on a volunteer basis for several months before she began collecting research data. Participant 1 did not usually attend these sessions, but the researcher would often say hello to Participant 1 and interact with him for several minutes before leaving.

Participant 1 had trouble participating in the music therapy protocols during the first few minutes of his assessment sessions. He laughed and looked away frequently, and then wanted to give the researcher an extended hug, but began listening more attentively when he recognized the song she was singing. He made eye contact with the researcher and occasionally made vocalizations while she sang his preferred songs and accompanied them on the guitar. He also listened attentively and seemed to become more relaxed while listening to the researcher play familiar melodies on the flute. He laughed and participated somewhat in improvising on the



ocean drum and the hand drum while the researcher sang songs preferred by Participant 1. Participant 1 did not demonstrate the ability to maintain a steady beat for any length of time or to sustain his attention to any one activity for more than two or three minutes. Participant 1 demonstrated a preference for religious songs with which he was familiar, as well as folk and country songs.

### *Implementation Procedures*

Staff techniques (condition A) were carried out on the first and third day that Participant 1 exhibited an unusually high level of maladaptive behaviors while the researcher was present and available for data collection, and music therapy protocols (condition B) were carried out on the second and fourth days. Treatment A and B were implemented in the morning or early afternoon, depending on when Participant 1 exhibited an unusually high level of the targeted maladaptive behaviors. The researcher never implemented any treatment protocols unless Participant 1's behaviors reached the pre-determined level of one behavior per minute for three consecutive minutes, signaling an unusually heightened emotional state.

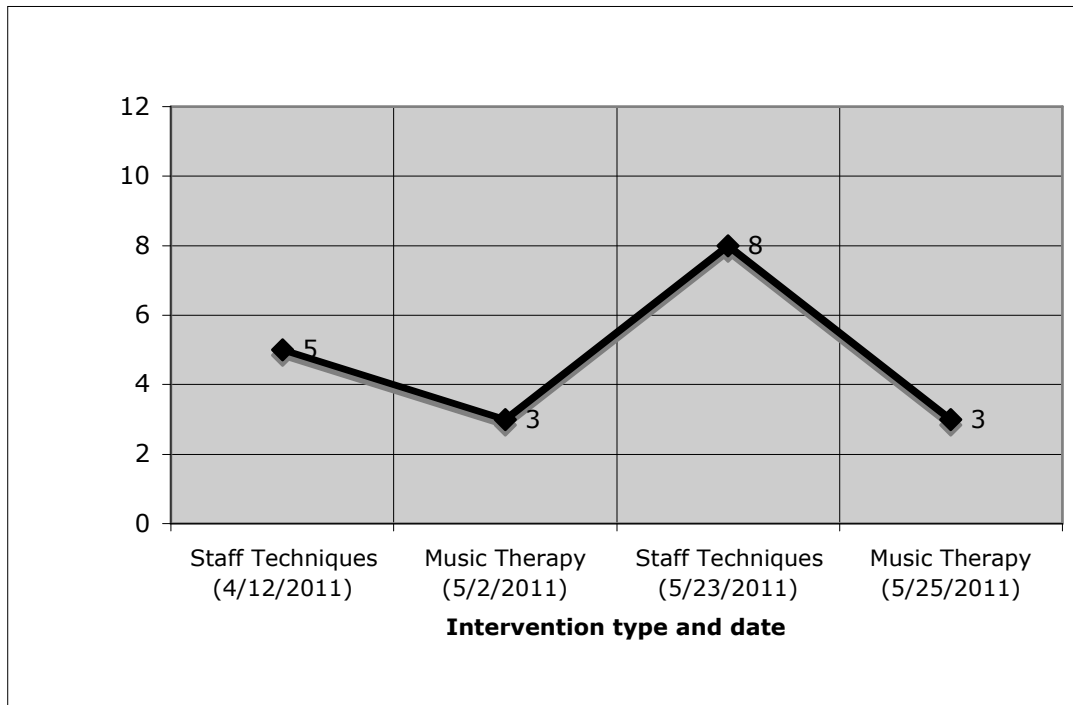
During condition A, the researcher implemented the usual staff techniques such as redirecting Participant 1 to another part of the room using minimal physical redirection. During condition B, the researcher carried out the individualized music therapy protocols identified as most effective during assessment, such as playing and singing familiar songs with Participant 1 with live guitar accompaniment.

### *Results*

While the researcher implemented conditions A and B, Participant 1's primary staff member recorded the occurrence of the targeted maladaptive behaviors. Duration recording was used by the primary staff members by making tally marks in a minute-by-minute behavior chart

(Appendix A) while the researcher was implementing condition A or B. After each condition was implemented, the researcher reviewed the behavior chart (Appendix A) as filled out by the primary staff member, to ensure that the timer had been stopped after three minutes of typical behavior levels. Each data point on the graph (Figure 1) represents the number of minutes Participant 1 maintained unusually high levels of the targeted behaviors during treatment A or B after the initial three minutes used to identify a heightened emotional state.

Visual analysis of the graphed data (Figure 1) shows that the data points for music therapy protocols (condition B) were lower than the data points for staff techniques (condition A). The first time staff techniques were implemented it took five minutes for Participant 1's behaviors to return to typical levels. The second time staff techniques were implemented it took eight minutes for Participant 1's behaviors to return to typical levels. In contrast, the first and second time music therapy protocols were implemented it only took three minutes for Participant 1's behaviors to return to typical levels.



*Figure 1.* Duration of the instances of heightened levels of maladaptive emotionally regulative behaviors of Participant 1 during staff techniques (condition A) and music therapy protocols (condition B) in minutes.

### *Observations*

When the researcher first began observing Participant 1 his general mood state seemed to be happy and some days very tired. His staff members confirmed this, stating that he was currently in a mood cycle where he was usually either happy or drowsy, though his maladaptive behaviors did show up sporadically during this generally happy cycle. It took nearly six weeks for the researcher to collect data for all four conditions. Participant 1's maladaptive behaviors began showing up more and more, especially during the last week of observation. His staff members verified that he was beginning to cycle into a more active and slightly manic mood state.

Prior to the first implementation of staff techniques, Participant 1's behaviors were higher than usual, though not considerably, with a total of five behaviors in the three minutes prior to

implementation. Participant 1 was leaving the room more frequently than usual and took an object belonging to another client. Once the researcher began redirecting him from leaving the room and remained in close proximity to him, his behaviors returned to more typical levels over the course of five minutes, exhibiting a total of five maladaptive behaviors, with four behaviors occurring in the first two minutes of implementation, and one occurring in the fifth minute.

Prior to the first implementation of music therapy protocols (treatment B), Participant 1's behaviors were slightly more elevated than they had been before the first implementation of staff techniques, with a total of six behaviors in three minutes. Participant 1 was leaving the room often as well as showing non-compliance toward staff requests, and had one instance of hitting another client. However, in response to the music therapy protocols, Participant 1's behaviors quickly returned to typical levels within three minutes, exhibiting only two maladaptive behaviors (leaving the room two times, and coming back in the room within 10 seconds each time with no prompting from researcher or staff) in the first three minutes of implementation.

Prior to the second implementation of staff techniques, Participant 1 exhibited four maladaptive behaviors over the course of three minutes. He was non-compliant with staff members two times, left the room once, and tried to instigate behaviors in another client by flapping his hands in his face once. When the researcher began implementing staff techniques, redirecting him and remaining in close proximity to him, his behaviors increased to four per minute in the first minute and three per minute in the second minute and then decreased to two or one per minute for the next four minutes. It took a total of eight minutes for Participant 1's behavior levels to return to normal. All of his behaviors were either non-compliance with researchers redirections or leaving the room, sometimes causing the researcher to chase after him if he did not return within 10 seconds.

In the three minutes prior to the second implementation of music therapy protocols, Participant 1 had exhibited eight maladaptive behaviors, which is quite high for him. Five of the behaviors were leaving the room and three were taking objects belonging to others. Despite this high level of behaviors, once the researcher began implementing the music therapy protocols, Participant 1's behaviors completely disappeared for three consecutive minutes, which signaled a return to typical behavior levels and completed the trial. He smiled, made vocalizations, clapped and made eye-contact with the researcher while she sang religious songs that were preferred by Participant 1 and accompanied them on the guitar.

Although it did not seem to significantly affect Participant 1's responses to treatment protocols, it is worth mentioning that another adult with DD who was in the same room as Participant 1 during all treatment conditions exhibited behaviors that interfered somewhat with the treatment protocols on two occasions. During the second implementation of staff techniques this client was singing loudly on the other side of the room intermittently. While the music therapy protocols were being carried out, this client sang along with the songs the researcher was singing.

Participant 1 showed a very positive response to music therapy protocols, even when he had previously been exhibiting a high level of maladaptive behaviors. This positive response may have been in part due to his previous positive associations with music. Participant 1's staff members communicated that he had attended church with his mother while growing up and that gospel music was often played in his home, explaining his strong positive response to songs such as "Amazing Grace." According to the results of this study, music therapy protocols helped to decrease Participant 1's maladaptive emotionally regulative behaviors in less time than staff techniques.

## CASE STUDY II

### *Background*

Participant 2 is a 49-year old male diagnosed as having a severe intellectual disability and Reye's syndrome. He was not taking any medication at the time of the study. Participant 2 has been in the work enrichment program since 1998. In this program he engages in recreational and learning experiences throughout the community, as well as on-site, that support his personal and social skills. Participant 2 grew up with his family until the time that he was diagnosed as having Reye's syndrome. After the onset of Reye's syndrome, he was admitted to an institution. When he came to the work enrichment program in 1998 he began living in the group home where he currently lives, with 5 other individuals, receiving 24-hour support from staff.

Participant 2 demonstrates deficits in intellectual functioning, fine and gross motor coordination, emotion regulation, communication, and social skills. He has limited receptive and verbal skills. He can say several words such as "no," but it is often difficult to tell what he wants or doesn't want. He usually seems to be in a negative mood, often frowning and yelling if approached. However, if one of his staff interacts with him in a playful manner, his affect can quickly change from frowning to smiling and laughing. He enjoys interacting with familiar people who approach him playfully, but his interactions sometimes involve hitting others playfully, and are not entirely socially adaptive. In addition to interacting with familiar people, Participant 2 also enjoys listening to country music and playing with his toys. Participant 2 has limited mobility and tunnel vision, which make him very dependent on help from others to make it through the day. He is often fearful of unfamiliar noises or people, partly because of his poor eyesight.

Participant 2 sometimes becomes upset if the noise level in the room gets too high, if he hears an unfamiliar noise, or if he is approached by an unfamiliar person. When Participant 2 is in an emotionally heightened state he usually makes negative undistinguishable verbalizations, says “no” repeatedly, and sometimes yells or makes crying sounds.

### *Assessment Findings*

The researcher conducted two fifteen-minute individual music therapy assessment sessions in order to strengthen interpersonal rapport and determine instrument and musical style preferences. Participant 2 was familiar with the researcher because she had been conducting group music therapy sessions once a week at this facility on a volunteer basis for several months before she began collecting research data. Participant 2 did not usually attend these sessions, but the researcher would sometimes interact with Participant 2 before leaving by standing near him, saying his name in a playful tone of voice, as previously modeled by staff members, and waiting for him to stand up and walk slowly over to her.

Participant 2 had trouble participating in the music therapy protocols during the first minute or two of each assessment, but this was most likely due to the researcher moving closer to him, causing him some anxiety. He said “no” and made negative verbalizations, but this soon stopped and he seemed to be listening to the music. He seemed to be calm and engaged for the rest of both of the assessments and even interacted with the researcher by making undistinguishable verbalizations while the researcher improvised on the flute, imitating and responding to his verbalizations.

### *Implementation Procedures*

Staff techniques (condition A) were carried out on the first and third day that Participant 2 exhibited an unusually high level of maladaptive behaviors while the researcher was present

and available for data collection, and music therapy protocols (condition B) were carried out on the second and fourth days. Treatment conditions A and B were implemented in the late morning or early afternoon, depending on when Participant 2 exhibited an unusually high level of the targeted maladaptive behaviors. The researcher never implemented any treatment protocols unless Participant 2's behaviors reached the pre-determined level of one behavior per minute for three consecutive minutes, signaling an unusually heightened emotional state.

During condition A, the researcher implemented the usual staff techniques such as verbally responding to Participant 2 in a playful tone of voice. During condition B, the researcher carried out the individualized music therapy protocols identified as most effective during the assessments, such as playing and singing familiar songs with guitar accompaniment while Participant 2 listened.

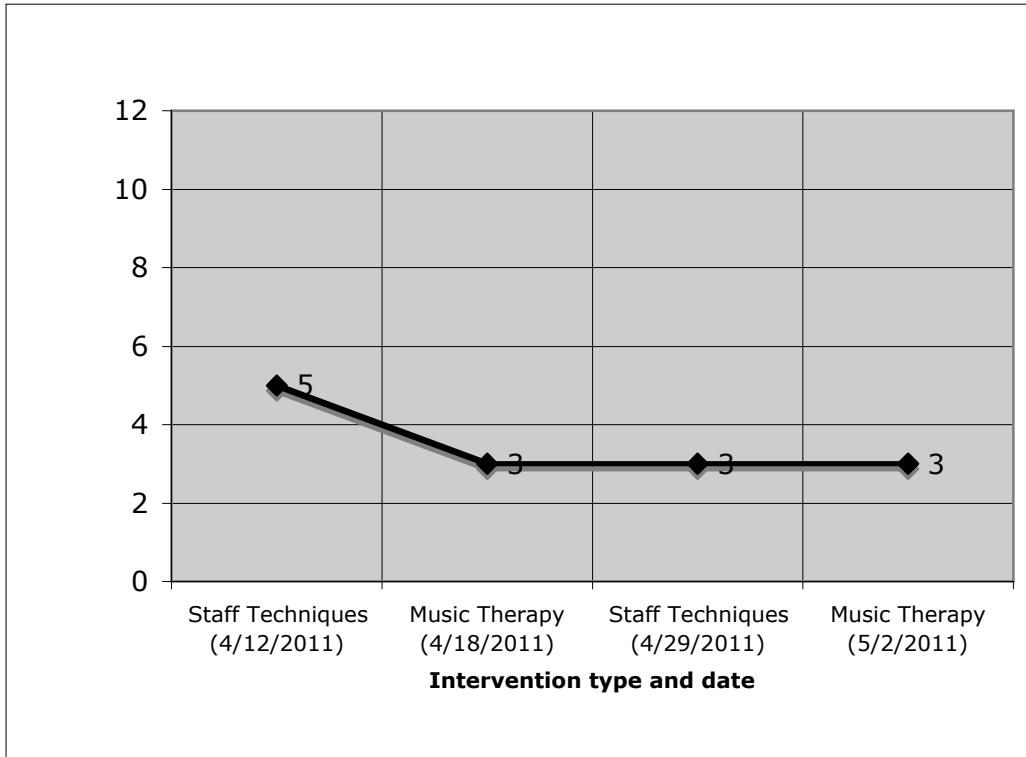
### *Results*

While the researcher implemented condition A and condition B, the occurrence of the targeted maladaptive behaviors was recorded by Participant 2's primary staff member. The primary staff members used duration recording by making tally marks in a minute-by-minute behavior chart (Appendix A) while the researcher was implementing condition A or B. After each treatment was implemented, the researcher reviewed the behavior chart (Appendix A) as filled out by the primary staff member, to ensure that the timer had been stopped after three minutes of typical behavior levels. If the timer was stopped after more than three minutes of typical behavior ratios, the researcher decreased the total duration (dependent variable) to reflect only three minutes of typical behavior ratios. Each data point on the graph (Figure 2) represents the number of minutes Participant 2 maintained unusually high levels of the targeted behaviors



during condition A or B after the initial three minutes used to identify a heightened emotional state.

Visual analysis of the graphed data (Figure 2) shows that the data points for music therapy protocols (condition B) were, on average, lower than the data points for staff techniques (condition A), though only slightly. The first time staff techniques were implemented it took five minutes for Participant 2's behaviors to return to typical levels. For all other trials of both staff techniques and music therapy protocols, it only took three minutes for Participant 2's behaviors to return to typical levels.



*Figure 2.* Duration of the instances of heightened levels of maladaptive emotionally regulative behaviors of Participant 2 during staff techniques (condition A) and music therapy protocols (condition B) in minutes.

### *Observations*

Participant 2 exhibited maladaptive emotionally regulative behaviors quite often, usually due to the noise level in the room getting too high, or because he wanted attention. Because Participant 2 was familiar with the researcher, he responded well to the interactions and seemed to appreciate the attention. When the researcher engaged in staff techniques for the first time, his behaviors increased slightly during the second minute of interaction, but then dropped off over the course of the next three minutes. He seemed to enjoy interacting with the researcher while she spoke to him playfully. Participant 2 responded even better to the researcher when she engaged in staff techniques the second time, exhibiting only one maladaptive behavior during the first minute of interaction.

During the first music therapy condition, Participant 2's maladaptive behaviors completely disappeared once the music started. Although he made no attempts at interacting with the researcher, he did stop his behaviors and seemed to be listening intently to the music. The music seemed to have a calming effect on Participant 2. He also had no adverse reaction to the researcher being about two feet away from him, though sometimes having someone in close proximity causes an increase in his behaviors. Participant 2 responded similarly during the second music therapy condition, exhibiting no maladaptive behaviors once the music started. The researcher continued engaging in the music therapy protocols for several minutes after the data was completed, and Participant 2 continued to listen intently to the music.

Participant 2 responded very positively to music therapy protocols. His staff members verified that Participant 2 especially enjoys music, and that when one of them is driving him somewhere and his maladaptive behaviors are increasing, he will usually calm down if they turn the radio on to a station that plays old country songs. Live music therapy, however, has the

advantage of an actual music therapist, who is able to respond and tailor interventions to the specific preferences and needs of each individual. According to the results of this study, music therapy protocols helped to decrease Participant 2's maladaptive emotionally regulative behaviors in less time than staff techniques.

## CASE STUDY III

### *Background*

Participant 3 is a 60-year old male diagnosed as having a severe intellectual disability, cerebral palsy, Tourette syndrome, tardive dyskinesia, dystonia, and intermittent explosive disorder. At the time of the study, Participant 3 was taking the antipsychotic drug, Aripiprazole (Abilify), the depressant, Ativan (Lorazepam), as well as several other medications to control things such as nausea. Participant 3 has been in the work enrichment program since 1992. In this program he engages in recreational and learning experiences throughout the community, as well as on-site, that support his personal and social skills. Participant 3 grew up with his family until age 15, when he was admitted to a large institution until age 28. At this point he was enrolled in the work enrichment program and began residing in group homes with three to five other people, receiving 24-hour support from staff. Participant 3 took part in a modified public school program until he was admitted to the institution where he received vocational and life skills training.

Participant 3 demonstrates deficits in intellectual functioning, fine and gross motor coordination, emotion regulation, communication, and social skills. Participant 3 also has mild hearing loss and his vision is impaired so that he can only see out of one eye at a time. He has moderate receptive skills and low to moderate verbal skills. He knows a lot of words but does not use complete sentences and usually sticks to the same few words and phrases. He is able to express what he wants, but due to his severe anxiety, he often repeats his requests over and over again, even after it is explained to him when his desired activity, such as eating lunch, will be taking place. He almost always has a negative or flat affect, and usually says “no” to any question. Participant 3 uses a wheelchair and requires assistance to complete most daily

activities. He responds well to looking through books, being read to, watching movies, and listening to the radio.

Participant 3's anxiety level seems to increase in response to things such as loud noises, being alone, being in the dark, not knowing what is happening, having strangers get too close to him, or having to do something he doesn't want to do. When Participant 3 is in an emotionally heightened state he usually repeats certain words or phrases over and over again, such as "no" and "wanna eat." He also sometimes makes other undistinguishable negative verbalizations.

### *Assessment Findings*

The researcher conducted two fifteen-minute individual music therapy assessment sessions in order to strengthen interpersonal rapport and determine instrument and musical style preferences. Participant 3 was familiar with the researcher because she had been conducting group music therapy sessions once a week at this facility on a volunteer basis for several months before she began collecting research data. Participant 3 began sitting in the circle while the sessions were taking place during the month prior to the study. The researcher took time to briefly talk with Participant 3 before and after most of the sessions and he would sometimes respond positively by saying "hello" or "thank you," usually with prompting from staff members.

Participant 3 had no unusual reactions during the first few minutes of his music therapy assessment, but continued to repeat the negative verbalizations he had previously been saying. However, after several minutes, his verbalizations began to decrease, he made fleeting eye contact with the researcher and he seemed to be listening to the music. He even interacted with the researcher for several minutes by blowing bubbles with her while she sang familiar songs.

### *Implementation Procedures*

Staff techniques (condition A) were carried out on the first and third day that Participant 3 exhibited an unusually high level of maladaptive behaviors while the researcher was present and available for data collection, and music therapy protocols (condition B) were carried out on the second and fourth days. Treatment conditions A and B were implemented in the morning or early afternoon, depending on when Participant 3 exhibited an unusually high level of the targeted maladaptive behaviors. The researcher never implemented any treatment protocols unless Participant 3's behaviors reached the pre-determined level of three behaviors per minute for three consecutive minutes, signaling an unusually heightened emotional state.

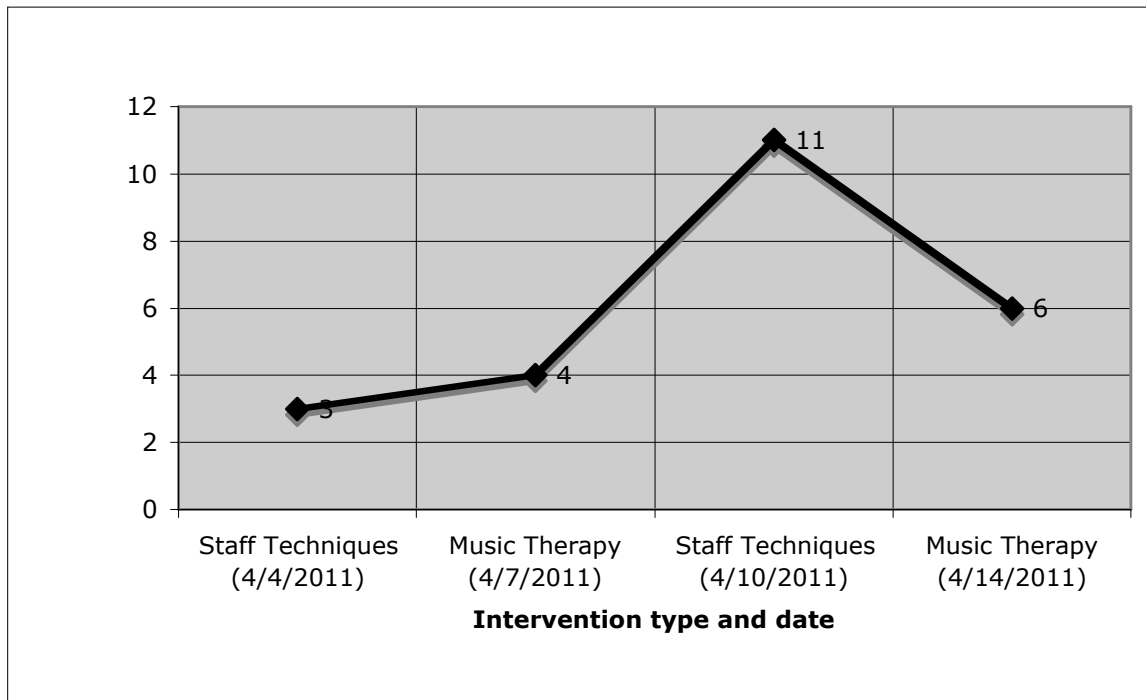
During condition A, the researcher implemented the usual staff techniques such as responding to repetitive negative verbalizations with a reminder of when the desired activity would be taking place. During condition B, the researcher carried out the individualized music therapy protocols identified as most effective during the assessments, such as playing and singing familiar songs with guitar accompaniment while Participant 3 listened.

### *Results*

While the researcher implemented conditions A and B, Participant 3's primary staff member recorded the occurrence of the targeted maladaptive behaviors. Duration recording was used by the primary staff members by making tally marks in a minute-by-minute behavior chart (Appendix A) while the researcher was implementing condition A or B. After each treatment condition was implemented, the researcher reviewed the behavior chart (Appendix A) as filled out by the primary staff member, to ensure that the timer had been stopped after three minutes of typical behavior levels. If the timer was stopped after more than three minutes of typical behavior ratios, the researcher decreased the total duration (dependent variable) to reflect only

three minutes of typical behavior levels. Each data point on the graph (Figure 3) represents the number of minutes Participant 3 maintained unusually high levels of the targeted behaviors during condition A or B after the initial three minutes used to identify a heightened emotional state.

Visual analysis of the graphed data (Figure 3) shows that the data points for music therapy protocols (condition B) were, on average, lower than the data points for staff techniques. The first time staff techniques were implemented it took three minutes for Participant 3's behaviors to return to typical levels. The first time music therapy protocols were implemented it took four minutes for Participant 3's behaviors to return to typical levels. The second time staff techniques were implemented it took 11 minutes for Participant 3's behaviors to finally return to typical levels. The second time music therapy protocols were implemented it took six minutes for Participant 3's behaviors to return to typical levels.



*Figure 3.* Duration of the instances of heightened levels of maladaptive emotionally regulative behaviors of Participant 3 during staff techniques (condition A) and music therapy protocols (condition B) in minutes.

*Observations*

Participant 3 exhibited maladaptive emotionally regulative behaviors somewhat sporadically. Some days he was very quiet and unresponsive, hardly saying one word for the entire three hours the researcher was present and available for data collection. Other days he was much more verbal, and this usually coincided with a higher occurrence of maladaptive behaviors. According to staff members, his bad days coincided with things such as less preferred staff members getting him ready that morning or unexpected changes in his daily routine.

Interestingly, Participant 3 responded, on average, more quickly to music therapy protocols despite the fact that prior to the first and second implementation of music therapy protocols, Participant 3's behaviors were occurring at a substantially higher frequency than prior to the first and second implementation of staff techniques. In the three minutes prior to the first



staff techniques condition, Participant 3 exhibited a total of 12 maladaptive behaviors, and a total of 13 maladaptive behaviors prior to the second staff techniques condition. In contrast, in the three minutes prior to the first music therapy condition, Participant 3 exhibited 21 maladaptive behaviors, and exhibited 20 maladaptive behaviors in the three minutes prior to the second music therapy condition. Participant 3 exhibited a total of 43 maladaptive behaviors during the two staff techniques conditions and a total of 34 behaviors during the two music therapy conditions.

Also interesting to note is that, on average, Participant 3 showed a slightly higher number of behaviors per minute during the music therapy conditions (34 behaviors divided by 10 minutes) than during the staff techniques conditions (43 behaviors divided by 14 minutes). This could be in part due to the higher levels of behaviors prior to implementation of music therapy protocols that did not immediately drop off, but did still decrease quickly enough to produce a faster return to typical levels than staff techniques.

Participant 3 responded very well to music therapy protocols, despite the high frequency of behaviors prior to both music therapy trials. He seemed to become increasingly calm while listening to the music, as evidenced by a more pleasant facial affect and the rapid decrease of his anxiety-induced verbalizations. His staff members verified his unusually positive response to music therapy protocols, despite his usual resistance to change and new experiences. According to the results of this study, music therapy protocols helped to decrease Participant 3's maladaptive emotionally regulative behaviors in less time than staff techniques.

## CASE STUDY IV

### *Background*

Participant 4 is a 37-year old female diagnosed as having a severe intellectual disability, Cystic fibrosis, cerebral palsy and seizure disorder. At the time of the study, Participant 4 was taking the selective serotonin reuptake inhibitor (SSRI), Fluoxetine (Prozac). Participant 4 has been in the work enrichment program since 1995. In this program she engages in recreational and learning experiences throughout the community, as well as on-site, that support her personal and social skills. Participant 4 grew up in a foster home and lives with this family currently. Participant 4 went through the special education program at her local public school from kindergarten through high school.

Participant 4 demonstrates deficits in intellectual functioning, fine and gross motor coordination, emotion regulation, communication, and social skills. Though her verbal skills are extremely limited, she does seem to understand some of what her staff members say to her. She communicates her wants through non-verbal behaviors such as screaming, hitting herself, or stomping. She is able to make eye contact. Sometimes she seems very alert and makes eye contact easily, and other times she has difficulty looking up or even staying awake. She usually has a flat affect but will express her mood by frowning, and very rarely, by smiling. Participant 4 uses a wheelchair and requires assistance to complete daily activities. She responds well to handling toys, handling and ripping up paper, being helped to walk around the room, and playing a game of grabbing objects off of the table.

Participant 4's anxiety level seems to increase in response to things such as loud noises, not knowing what is happening, being approached by unfamiliar people, having anyone get too close to her, boredom, or having to do something she doesn't want to do. When Participant 4 is

in an emotionally heightened state she usually screams, bites her hand, hits herself and stomps her foot repeatedly.

### *Assessment Findings*

The researcher conducted two fifteen-minute individual music therapy assessment sessions in order to strengthen interpersonal rapport and determine instrument and musical style preferences. Participant 4 was familiar with the researcher because she had been conducting group music therapy sessions once a week at this facility on a volunteer basis for several months before she began collecting research data. Participant 4 usually sat in the circle and participated as much as she was able during the music therapy sessions. The researcher took time to briefly talk with Participant 4 before and after most of the sessions and she would sometimes respond positively by making eye contact and smiling at the researcher.

Participant 4 had a negative reaction to the music during the first few minutes of her first assessment, most likely because the researcher moved closer to her and this, combined with not knowing what was going to happen next, caused her some anxiety. She screamed and bit her hand, but calmed down after about five minutes of music. She responded positively to songs that were upbeat and in major tonalities by quieting down and smiling. She also responded positively to listening to familiar melodies played on the flute, and to tapping a drum with the researcher while the researcher sang songs preferred by Participant 4.

### *Implementation Procedures*

Staff techniques (condition A) were carried out on the first and third day that Participant 4 exhibited an unusually high level of maladaptive behaviors while the researcher was present and available for data collection, and music therapy protocols (condition B) were carried out on the second and fourth days. Condition A and B were implemented in the morning or early

afternoon, depending on when Participant 4 exhibited an unusually high level of the targeted maladaptive behaviors. The researcher never implemented any treatment protocols unless Participant 4's behaviors reached the pre-determined level of 1 behavior per minute for three consecutive minutes, signaling an unusually heightened emotional state.

During condition A, the researcher implemented the usual staff techniques such as giving her a piece of paper or a paper towel to rip up, and engaging her in handling her toys. During condition B, the researcher carried out the individualized music therapy protocols identified as most effective during the assessments, such as listening to the researcher sing and play preferred songs on the guitar, and tapping the drum with her while singing preferred songs.

### *Results*

While the researcher implemented condition A and B, the occurrence of the targeted maladaptive behaviors was recorded by Participant 4's primary staff member. Duration recording was used by the primary staff members by making tally marks in a minute-by-minute behavior chart (Appendix A) while the researcher was implementing treatment condition A or B. After each condition was implemented, the researcher reviewed the behavior chart (Appendix A) as filled out by the primary staff member, to ensure that the timer had been stopped after three minutes of typical behavior levels. If the timer was stopped after more than three minutes of typical behavior ratios, the researcher decreased the total duration (dependent variable) to reflect only three minutes of typical behavior ratios. Each data point on the graph (Figure 3) represents the number of minutes Participant 4 maintained unusually high levels of the targeted behaviors during condition A or B after the initial three minutes used to identify a heightened emotional state.

Visual analysis of the graphed data (Figure 4) shows that the data points for music therapy protocols (condition A) were exactly the same as the data points for staff techniques. The first time staff techniques (condition B) were implemented it only took three minutes for Participant 4's behaviors to return to typical levels. It also only took three minutes for her behaviors to return to typical levels the first time music therapy protocols were implemented. The second time both staff techniques and music therapy protocols were implemented, it took six minutes for Participant 4's behaviors to return to typical levels.

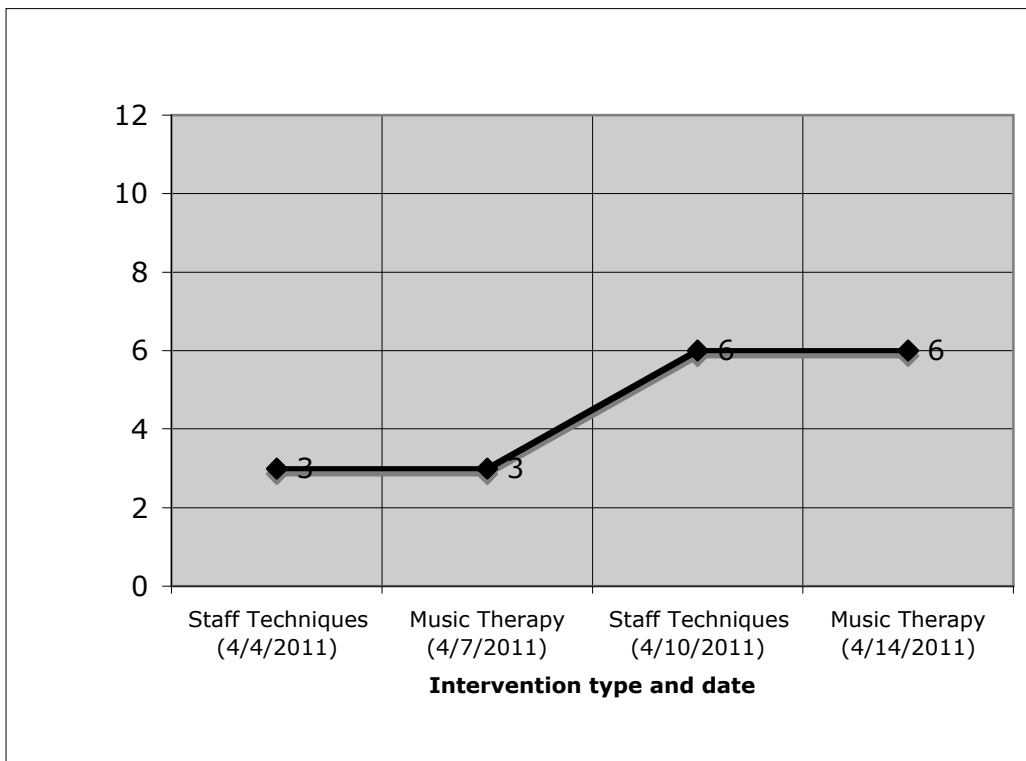


Figure 4. Duration of the instances of heightened levels of maladaptive emotionally regulative behaviors of Participant 4 during staff techniques (condition A) and music therapy protocols (condition B) in minutes.

## *Observations*

Participant 4 exhibited maladaptive emotionally regulative behaviors quite often. However, because she was non-verbal, it was often difficult to know the cause of the increases in her maladaptive behaviors. The researcher never intervened with condition A or B when the staff members suspected that needing to go to the bathroom or hunger was the source of Participant 4's behaviors, since this was not a primarily emotional issue.

When the researcher engaged in staff techniques for the first time, Participant 4's maladaptive behaviors immediately stopped, despite being at an average of 14 behaviors per minute during the three minutes prior to engaging in staff techniques. This dramatic decrease in response to staff techniques suggests that Participant 4 was mainly wanting attention. The same response occurred in response to music therapy protocols the first time they were used, though the decrease was not as dramatic, with an average of three behaviors per minute during the three minutes prior to music therapy protocols being implemented. Just as in the first trial of staff techniques, Participant 4's behaviors immediately stopped once the music therapy protocols were implemented.

During the second trial of staff techniques, Participant 4's behaviors increased during the first two minutes of implementation, but then quickly decreased. During the second trial of music therapy protocols, Participant 4's maladaptive behaviors increased during the first minute of implementation, dramatically decreased during the second minute, went back up slightly during the third minute, and then dropped off, with only one more behavior in the fourth minute. The total number of minutes it took for Participant 4's behaviors to return to typical levels was exactly the same for both trials of staff techniques and music therapy protocols. The total number of maladaptive behaviors recorded during the staff technique and music therapy

conditions were also very similar, with a total of 24 behaviors recorded during staff technique conditions and 27 behaviors recorded during music therapy conditions.

It was difficult for the researcher, as well as Participant 4's staff members, to identify the reason behind her behavior increases. It seemed to the researcher that Participant 4 experienced a lot of frustration at not being able to communicate her wants and needs and that many times her behaviors were primarily caused by a frustrated desire to communicate something or frustration over not being physically able to do something for herself. Although Participant 4 was severely limited by her multiple disabilities, she was very aware of her surroundings and had distinct opinions that she expressed through her behaviors.

It seemed to the researcher that Participant 4 was not especially helped by music therapy protocols during instances of heightened emotions because many of her behaviors seemed to be motivated by a strong desire to communicate, and the music therapy protocols were not yet helping her to do that. The music therapy protocols did not seem to be harmful in any way as Participant 4 responded equally well to the music therapy protocols as to the usual staff techniques, but it may be more beneficial for Participant 4 to receive music therapy during moments when she is more calm. If Participant 4 receives music therapy at moments when her maladaptive behaviors are at more typical levels, indicating a more calm emotional state, she might be able to have positive, communicative experiences during the music interventions that could later translate into moments of emotional distress due to not being able to communicate.

## CHAPTER V

### DISCUSSION

The purpose of this study was to examine the effectiveness of individualized music therapy protocols in decreasing the duration of instances of maladaptive emotionally regulative behaviors in adults with developmental disabilities. In order to compare the effectiveness of individualized music therapy protocols and the usual staff techniques, the participants were presented with two different conditions. The researcher intervened with the usual staff techniques when a participant was in an emotionally heightened state during condition A and intervened with individualized music therapy protocols during condition B.

Findings in this study suggest that music therapy protocols can be used to decrease the duration of instances of elevated levels of maladaptive emotionally regulative behaviors in adults with developmental disabilities. Additionally, findings suggest that music therapy protocols can decrease these behaviors more quickly than the usual staff techniques in most cases. Three out of four participants responded better to music therapy protocols than the usual staff techniques, as evidenced by a shorter average duration of instances of elevated levels of maladaptive emotionally regulative behaviors during music therapy conditions. The one participant for whom this was not true responded to music therapy protocols and staff techniques exactly the same in terms of average duration of instances of elevated levels of maladaptive emotionally regulative behaviors.



Table 4

*Response Times of Participants in Minutes with the Required First Three Minutes Subtracted Out in Order to Show When the Behavioral Change Occurred*

	Staff Techniques	Music Therapy Protocols	Staff Techniques	Music Therapy Protocols
Participant 1	2	0	5	0
Participant 2	2	0	0	0
Participant 3	0	1	8	3
Participant 4	0	0	3	3

Another finding of this study is that music therapy protocols might be effective for individuals with a wide variety of developmental disabilities. Participants in this study were diagnosed as having ADHD, Reye’s syndrome, cerebral palsy, Tourette syndrome, Cystic fibrosis and seizure disorder.

In addition, this study found that music therapy tended to be effective in decreasing the duration of instances of elevated levels of maladaptive behaviors in adults with DD more quickly than staff techniques, even when an individual is exhibiting more extreme levels of maladaptive behaviors, as in the cases of Participants 1 and 3. Another finding is that music therapy seems to regulate many different types of emotions, from overly elevated, manic emotions, as in the case of Participant 1, to anger and anxiety, as in the cases of Participants 2, 3, and 4.

The last finding of this study is that music therapy is not always the best option for helping to decrease the duration of instances of elevated levels of maladaptive behaviors, as in the case of Participant 4, whose behaviors seemed to be caused by a frustrated desire to

communicate her wants and needs. It may be more helpful for individuals such as Participant 4 to be exposed to music therapy protocols during moments of emotional calm. If the music therapist can help these individuals to learn to use music protocols in a way that addresses the source of their frustration, such as communicating wants and needs through a song in which the individual is given the chance to point to a picture of what it is they want, it may then be possible to use music therapy protocols to decrease the duration of instances of heightened levels of maladaptive emotionally regulative behaviors in less time than the usual staff techniques.

The results of this study support the findings of Didden, Duker and Korzilius (1997) concerning the effectiveness of response-contingent interventions in dealing with the problem behaviors of adults with DD. Music therapy protocols allow the therapist to respond to the individual experiencing the heightened emotional state, providing the type and style of music that elicits the most positive response and/or matches the individual's current mood, and adjusting the volume and tone quality of the singing voice according to the response of the individual. The results of this study also support the findings of Dimaio (2010) concerning the effectiveness of the Iso-principle in music therapy. The Iso-principle states that after the therapist has matched music to the mood of a client, the client's mood can be altered by progressively changing the music (Dileo & Bradt, 1999). For example, in the current study, when Participant 1 was in an elevated, manic mood that caused him to leave the room many times without permission and to try to instigate behaviors in other clients, the researcher was able to match his manic mood through up-tempo songs and gradually slow the tempo of the songs in order to bring him to a more calm emotional state

Clair's (2000) finding concerning the effectiveness of familiar songs was supported by the results of this study. Familiar songs seemed to elicit more positive responses than did songs

with which the participants were not as familiar. Hooper, Wigram, Carson and Lindsay's (2008) findings in their review of the literature on music and intellectual disability concerning the reported effectiveness of music therapy interventions in reducing stress and in improving the emotions of adults with DD was also supported by the results of this study, as evidenced by a shorter average duration of instances of elevated emotions and improved affect in response to music therapy protocols.

In addition, the results of this study support the findings of El-Hassan, McKeown and Muller (2009) who found music to be a cheap, safe, noninvasive, and flexible treatment medium for reducing anxiety, as evidenced in this study by a decrease in maladaptive behaviors and improved affect. The responses of Participant 1, 2 and 3 to music supported Panskepp's (2009) assertion that playfulness is an effective means of rerouting adults who have long been in maladaptive emotional patterns onto positive affective tracks. Lastly, as evidenced by a decrease in maladaptive behaviors and improved affect, this study supports the findings of Juslin and Vastfjäll (2008) concerning music's ability to change, induce, release, and match emotions.

The first limitation of this study was the small sample size. It is difficult to predict if these findings would be representative of the general population of adults with DD because of the small number of participants. The second limitation of this study was the use of staff members to collect data. The staff members who were tracking the behavior occurrences sometimes seemed distracted by the behaviors of other clients in the room, even though other staff members were available to attend to these clients. It might have been better to have another person who was not in any way responsible for other clients available to record the data while the researcher conducted conditions A and B. However, it would need to be someone who the participants were familiar with and someone who was familiar with the behaviors being tracked.

Additionally, one way to improve this study would be to have a quiet room nearby where participants could be taken in order to carry out staff techniques and music therapy protocols in a more controlled environment. It was not usually a problem to carry out the treatment conditions in the room with other clients and staff members because of the high staff to client ratio. However, the behaviors of one particular client may have had an impact on Participant 1 during several of the treatment protocols, and having a quiet room to go to may have improved the study data by eliminating this variable.

Further research is warranted to provide greater support of the effectiveness of music therapy protocols in reducing the maladaptive emotionally regulative behaviors of adults with DD. Studies with larger sample sizes and more rigorous experimental and statistical models would be the most useful, although this would be quite time consuming given the lengthy observation requirements of the study. It also may be difficult to gain access to a large number of adults with DD in one region who exhibit maladaptive emotionally regulative behaviors at a high frequency. Perhaps a number of researchers could collaborate to compile a more scientifically impacting number of participants.

Despite the small sample size of this study, useful information was gained that has the potential to further the field of music therapy, providing a basis for offering music therapy services to adults with DD in order to address problems associated with maladaptive emotionally regulative behaviors. If, as this study has found, music therapy protocols can help to reduce the maladaptive emotionally regulative behaviors of adults with DD in less time than the usual staff techniques, music therapists should come to be recognized as able to provide safe and effective protocols for improving the mental and emotional well being of individuals with DD experiencing maladaptive behaviors. Also, music therapists should come to be seen as able to

reduce the number of behaviors, not only in the clients who receive the music therapy, but also in other clients in the vicinity of this client, because client behaviors are often contagious. This decrease in client behaviors could also cause a reduction in staff turnover. Therefore, music therapists should also come to be recognized as providers of a service that saves facilities time and money, thus improving the efficiency of facilities serving adults with DD. Although more research on this topic is needed, this study may also provide a foundation for future studies on the use of music therapy in conjunction with, or as a potential alternative to pharmacological treatment in some cases.

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APPENDIX A  
DATA CHARTS



## Participant 1's Data Chart

1 behavior/minute or higher for 3 consecutive minutes = maladaptive emotion regulation

Behaviors being tracked:

	1 <sup>st</sup> minute	2 <sup>nd</sup> minute	3 <sup>rd</sup> minute	4 <sup>th</sup> minute	5 <sup>th</sup> minute
Non-compliance with staff requests					
Hitting others					
Eloping to another room or leaving the building					
Taking objects that belong to others					
Invading other clients' personal space					
Choke-hold hugging or touching others' hair					
Trying to instigate behaviors in another client					

## Participant 2's Data Chart

1 behavior/minute or higher for 3 consecutive minutes = maladaptive emotion regulation

Behaviors being tracked:

	1st minute	2 <sup>nd</sup> minute	3 <sup>rd</sup> minute	4th minute	5 <sup>th</sup> minute
Negative undistinguishable verbalizations					
Yelling					
Saying "no" without an apparent reason					
Crying sounds					

	6 <sup>th</sup> minute	7 <sup>th</sup> minute	8 <sup>th</sup> minute	9 <sup>th</sup> minute	10 <sup>th</sup> minute
Negative undistinguishable verbalizations					
Yelling					
Saying "no" without an apparent reason					
Crying sounds					

## Participant 3's Data Chart

3 behaviors/minute or higher for 3 consecutive minutes = maladaptive emotion regulation

Behavior being tracked:

	1 <sup>st</sup> minute	2 <sup>nd</sup> minute	3 <sup>rd</sup> minute	4 <sup>th</sup> minute	5 <sup>th</sup> minute
“No”					
“Wanna eat”					
“Wanna go home”					
“Break”					
Other negative verbalizations					
Undistinguishable negative vocalizations					

	6 <sup>th</sup> minute	7 <sup>th</sup> minute	8 <sup>th</sup> minute	9 <sup>th</sup> minute	10 <sup>th</sup> minute
“No”					
“Wanna eat”					
“Wanna go home”					
“Break”					
Other negative verbalizations					
Undistinguishable negative vocalizations					

## Participant 4's Data Chart

1 behavior/minute or higher for 3 consecutive minutes = maladaptive emotion regulation

Behaviors being tracked:

	1st minute	2 <sup>nd</sup> minute	3 <sup>rd</sup> minute	4 <sup>th</sup> minute	5 <sup>th</sup> minute
Screaming					
Hand biting					
Self-hitting					
Hitting the floor or other objects					

	6 <sup>th</sup> minute	7 <sup>th</sup> minute	8 <sup>th</sup> minute	9 <sup>th</sup> minute	10 <sup>th</sup> minute
Screaming					
Hand biting					
Self-hitting					
Hitting the floor or other objects					

APPENDIX B  
CONSENT FORM

## PARENT/GUARDIAN CONSENT FORM

### THE EFFECT OF MUSIC THERAPY ON THE MALADAPTIVE EMOTIONALLY REGULATIVE BEHAVIORS OF ADULTS WITH DEVELOPMENTAL DISABILITIES

#### INTRODUCTION

The Department of Music Education and Music Therapy at the University of Kansas supports the practice of protection for human subjects participating in research. The following information is provided for you to decide whether you wish your dependent to participate in the present study. You may refuse to sign this form and not allow your dependent to participate in this study. You should be aware that even if you agree to allow your dependent to participate, you are free to withdraw at any time. If you do withdraw your dependent from this study, it will not affect your relationship with Cottonwood, Inc., the services provided by Cottonwood, Inc., or the University of Kansas.

#### PURPOSE OF THE STUDY

The purpose of this study will be to examine the effectiveness of music therapy activities on decreasing the length of instances of elevated levels of maladaptive emotionally regulative behaviors in adults with developmental disabilities. Maladaptive emotionally regulative behaviors can be defined as emotional reactions of individual participants to their own internal or external stressors that are not socially adaptive.

#### PROCEDURES

Once proper consent procedures have been completed, the researcher will gather background data on each of the four participants recruited from Cottonwoods, Incorporated as part of their assessment. This information will include diagnosis, behavior history and what medications the participants are currently taking. The researcher needs this information in order to be informed about the participants and able to more fully discuss the outcomes of the study in the final chapters of her thesis. This information will be kept confidential by assigning a number to each participant and using this instead of a name, and storing the information on the researcher's password protected computer. The researcher will then conduct individual thirty-minute music therapy assessment sessions, playing different styles of music and implementing various music activities such as listening to improvised flute music or singing familiar songs, and observing participant reactions to the music, in order to identify musical preferences and music activities preferred by each participant.

The researcher will examine the effectiveness of the usual staff techniques (condition A) and the music therapy activities (condition B) in decreasing the length of instances of elevated levels of maladaptive emotionally regulative behaviors. The staff techniques will be learned through observation and questioning of staff members. The researcher will be present and available for data collection at Cottonwood, Incorporated, three times a week, for three hours, from the beginning of the study, until all data have been collected. The total length of the study will not

exceed six weeks. The researcher will observe two participants per day and will only intervene with condition A or B one time per day for each participant, and only after a participant is identified as currently experiencing a heightened emotional state.

A heightened emotional state will be identified by the presence of maladaptive emotionally regulative behaviors at or above a pre-determined rate per minute (determined with the help of primary staff members during observations) for five consecutive minutes. Once a participant has been identified as experiencing a heightened emotional state, the researcher will confirm it with the participant's primary staff member, start the timer, leave the timer and a detailed behavior chart with the staff member, and will intervene with A or B while the staff member tracks behavior occurrences per minute on the chart.

During condition A, the researcher will interact with the participant using the same order and types of protocols that the staff members usually use when trying to decrease occurrences of maladaptive behaviors. Such protocols include verbally responding to a participant with a reminder of when a desired activity will be taking place, or engaging a participant in an activity such as looking through a book. During condition B, the researcher will intervene with the music therapy activities identified during assessment as most likely to positively engage each participant. If music activities (condition B) cause an increase in the frequency of maladaptive behaviors, standard Cottonwood protocol will be implemented. Once the primary staff member has recorded a decrease in behavior levels to normal for three consecutive minutes while the researcher is implementing condition A or B, the staff member will stop the timer and inform the researcher. All data collected will be stored on the researcher's password protected computer. No names will be used as identifiers.

## RISKS

No risks, burdens, or inconveniences are associated or anticipated with this study.

## BENEFITS

Participants may benefit from participating in this study. The potential benefits of participation include decreased duration of instances of elevated levels of maladaptive emotionally regulative behaviors while the music protocol of the study is being carried out, and possible improved emotion self-regulation if the skills learned during the implementation of the music protocol transfer into other instances of heightened emotions beyond the study.

## PAYMENT TO PARTICIPANTS

Participants will not be paid for participating in this study.

## INFORMATION TO BE COLLECTED

To conduct this study, the researcher will collect information about your dependent. This information will be obtained from Cottonwood, Inc. health care files. Also, information will be collected during the study, as listed the Procedures section of this consent form. Your

dependent's name will not be associated in any way with the information collected or with the research findings from this study. The researcher will use a number instead of your dependent's name. The information collected will be used by the researcher, Lisa Bender, and by Dr. Cynthia Colwell, the researcher's faculty supervisor.

The researcher will not share information about your dependent with anyone not specified above unless required by law or unless you give written permission. Permission granted on this date to use and disclose your information remains in effect indefinitely. By signing this form you give permission for the use and disclosure of your dependent's information for purposes of this study at any time in the future. Again, your or your dependent's name will not be associated in any way with the information disclosed.

#### REFUSAL TO SIGN CONSENT AND AUTHORIZATION

You are not required to sign this Consent and Authorization form and you may refuse to do so without affecting your right to any services you are receiving or may receive from the University of Kansas or to participate in any programs or events of the University of Kansas. However, if you refuse to sign, your dependent cannot participate in this study.

#### CANCELLING THIS CONSENT AND AUTHORIZATION

You may withdraw your consent to allow participation of your dependent in this study at any time. You also have the right to cancel your permission to use and disclose further information collected about your dependent, in writing, at any time, by sending your written request to: Lisa Bender 13352 W 88<sup>th</sup> Circle Apt J Lenexa, KS 66215

If you cancel permission to use your dependent's information, the researcher will stop collecting additional information about your dependent. However, the researcher may use and disclose information that was gathered before receiving your cancellation, as described above.

#### QUESTIONS ABOUT PARTICIPATION

Questions about procedures should be directed to the principal investigator, Lisa Bender, using the contact information listed at the end of this consent form.

#### PARTICIPANT CERTIFICATION:

I have read this Consent and Authorization form. I have had the opportunity to ask, and I have received answers to, any questions I had regarding the study. I understand that if I have any additional questions about my dependent's rights as a research participant, I may call (785) 864-7429, write to the Human Subjects Committee Lawrence Campus (HSCL), University of Kansas, 2385 Irving Hill Road, Lawrence, Kansas 66045-7568, or email mdenning@ku.edu.

I agree to allow my dependent to take part in this study as a research participant. By my signature I affirm that I have received a copy of this Consent and Authorization form. Also, by my signature I affirm that I am 18 years or older.



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Print Participant's Name

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Date

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Parent/Guardian Name (Please print)

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Parent/Guardian Signature

Researcher Contact Information

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