MUSIC THERAPY IN THE BEREAVEMENT OF ADULTS WITH INTELLECTUAL DISABILITIES: A FEASIBILITY STUDY

A Thesis by JESSICA NEWSOME HOYLE

Submitted to the Graduate School Appalachian State University in partial fulfillment of the requirements for the degree of MASTER OF MUSIC THERAPY

> August 2010 Hayes School of Music

MUSIC THERAPY IN THE BEREAVEMENT OF ADULTS WITH INTELLECTUAL DISABILITIES: A FEASIBILITY STUDY

A Thesis by JESSICA NEWSOME HOYLE August 2010

APPROVED BY:

Cathy H. McKinney Chairperson, Thesis Committee

Sharon Richter Member, Thesis Committee

Liz Rose Member, Thesis Committee

William L. Pelto Dean, Hayes School of Music

Edelma D. Huntley Dean, Research and Graduate Studies Copyright by Jessica Newsome Hoyle 2010 All Rights Reserved

ABSTRACT

MUSIC THERAPY IN THE BEREAVEMENT OF ADULTS WITH INTELLECTUAL DISABILITIES: A FEASIBILITY STUDY (August 2010)

Jessica Newsome Hoyle, B.M., M.M.T., Appalachian State University Chairperson: Cathy McKinney

This study explored the effect of music therapy on the issues associated with the bereavement in 3 adults with intellectual disability (ID). Adapted from the work of Hilliard (2007), it employed a 9-week group music therapy protocol designed to educate individuals about death and how to deal with feelings that arise when a loved one dies. The Brief Psychiatric Rating Scale for Developmental Disabilities (BPRS-DD; Bodfish, 1995) was administered at weeks 1, 9, and 13 to assess any behavioral changes as observed by staff psychologists. Following the series of music therapy sessions, 1 of the 3 individuals exhibited a reduced level of negative behaviors, as measured by the BPRS-DD, which was maintained through the follow-up measure. The other 2 participants' BPRS-DD scores remained static. Of the 3 participants, 2 demonstrated improved social skills in the group music therapy.

TABLE OF CONTENTS

Abstract	iv
Chapter 1: Introduction	1
Chapter 2: Grief, Loss, and Adults with Intellectual Disabilities	4
Chapter 3: Method	14
Chapter 4: Case Studies	17
Chapter 5: Discussion	
References	
Table 1	
Appendix A	
Appendix B	41
Appendix C	
Biographical Sketch	68

Chapter 1

Introduction

According to the American Association on Intellectual and Developmental Disabilities, intellectual disability (ID) is defined as "a disability characterized by significant limitations both in intellectual functioning (reasoning, learning, problem solving) and in adaptive behavior, which covers a range of everyday social and practical skills. This disability originates before the age of 18" (American Association on Intellectual and Development Disabilities, 2010).

American society has changed drastically within the last 40-70 years, most notably within the fields of healthcare and technology. Due to these changes, life expectancy has increased for almost all people. This includes persons with intellectual disabilities. Deinstitutionalization and the civil rights movement of the 1960s and 1970s led to better treatment of persons with ID; less restrictive environments and inclusion in school, work, and living arrangements; and protection from harm that often occurred in large institutions. The improvements in health care throughout the latter part of the 20th century also contributed to the increased life expectancy for persons with ID (Doka & Lavin, 2003; World Health Organization, 2000).

Due to the advancement of technology and treatment for persons with ID and their related needs, persons with ID are living longer than ever before. The expected age of persons with ID has increased by over 350% since 1930 (McCallion & Nickle, 2008). In 1930, the life expectancy of persons with ID was 18.5 years. This figure is quickly

approaching the expected age of persons without ID (International Association for the Scientific Study of Intellectual Disabilities, 2002). The projected number of individuals with ID over 60 years old is 1.5 million by 2030 (Heller, 2004).

In the last century, the persons with ID have experienced a radical change in all aspects of life: healthcare, employment, education, recreation, and living situation (World Health Organization, 2000). Because of increased life expectancy and opportunities to function successfully in the community, individuals with ID now often outlive their parents, which rarely happened when life expectancy was much lower. The move from primarily institutional life to living with family members and in smaller community settings has magnified issues once unacknowledged in this population, including the grief and bereavement felt when one faces the death or loss of a significant person in one's life (Doka, n.d.).

People with ID experience loss, as do typically developing individuals. However, special considerations must be made for this population due to communication and cognitive needs (Kauffman, 1994; LoConto & Jones-Pruett, 2008). People with ID are at greater risk for experiencing traumatic grief symptoms due to secondary loss, communication barriers, and difficulty or inability to find meaning in the loss (Brickell & Munir, 2008).

Problem Statement and Definition of Key Terms

The need for acknowledgement and treatment of the grief of individuals with ID is growing, and will continue to grow as the life expectancy of persons with ID inches closer to that of the general population. The longer people live, the more opportunities they have to form meaningful relationships and, in turn, experience significant losses. Music therapy can provide an environment in which persons with ID, who often experience communication impairments, can express themselves nonverbally and work through the issues associated with bereavement. It is the purpose of this study to examine the effects of music therapy on the mood of persons with ID who have experienced a significant loss. It is hypothesized that following music therapy treatment, participants will exhibit improved mood and decreased negative behaviors as measured by the Brief Psychiatric Rating Scale (Developmental Disabilities version; Bodfish, 1995) and supported by observational data.

Key terms.

Bereavement: period of grief and mourning after a death (NIH, 2010).

Intellectual disability: "a disability characterized by significant limitations both in intellectual functioning (reasoning, learning, problem solving) and in adaptive behavior, which covers a range of everyday social and practical skills. This disability originates before the age of 18" (American Association on Intellectual and Development Disabilities, 2010).

Music therapist: a nationally-board certified professional who has completed an American Music Therapy Association approved training program and internship.

Music therapy: "the clinical and evidence-based use of music interventions to accomplish individualized goals within a therapeutic relationship by a credentialed professional who has completed an approved music therapy program" (American Music Therapy Association, 2010).

Significant loss: the death or removal of a person who is of great importance in one's life (e.g., a mother, father, sister, brother, primary caregiver, best friend, etc.).

Chapter 2

Grief, Loss, and Adults with Intellectual Disabilities

The experience of loss is often associated with, but not limited to, the death of a loved one. Other significant losses may occur with the retirement or relocation of a caregiver, when a friend moves to a different residential placement, and so on. The literature regarding bereavement of individuals with ID focuses on bereavement due to death of a loved one. Treatment of individuals with ID experiencing bereavement may include counseling, changes in environment, and social work techniques (Dowling, Hubert, White, & Hollins 2006; LoConto & Jones-Pruett, 2008; Stoddart, Burke, & Temple 2002; Summers & Witts, 2003). Music therapy also may be a treatment for individuals with ID who are experiencing loss.

Effects of grief and loss on adults with intellectual disabilities

Changes in healthcare status and cognitive ability combine with sociological issues to create a unique challenge for adults with ID. Doka and Lavin (2003) described aging with an intellectual or developmental disability as a "paradoxical problem" (p. 136) due to a decline in internal and external supports when the person with ID needs an increase in those supports. Adults with ID often live with aging parents and, unlike earlier in the 20th century, adults with ID now often outlive their parents. Those who live with aging parents may have few or no transition plans for if and when the parent is unable to care for them. Adults with ID also tend to have small social circles on which to rely in times of need (LoConto & Jones-Pruett, 2008).

For nearly all people, the experience of a significant loss creates feelings of sadness, grief, and guilt and may seem devastating and unbearable. However, most adults have the ability to cope with the secondary losses that often accompany the death of a loved one (e.g., financial support, companionship, etc.). For example, a person may be able to adjust his or her budget to meet financial needs or find companionship in a neighbor following the death of a significant other. In persons with ID, the ability to cope with secondary losses may not be present. If one lives with his parent (and primary caregiver), and the parent dies, the person with ID may have to move to a new living situation or rely on another family member to take care of him. This may lead to feelings of fear that they will not be cared for, or that they will become a burden to those who are now responsible for their wellbeing (Brickell & Munir, 2008).

Case examples suggest that although persons with ID experience grief, they may grieve in atypical ways and have difficulty expressing their feelings due to communication impairments. Persons with ID are often well aware of the loss and can experience grief to the same extent as someone without ID, but may not be able to communicate that experience in the same way as the typically developed adult (Kauffman, 1994).

LoConto and Jones-Pruett (2008) described bereavement of individuals with ID from a Social Interactionism framework. Within this framework, "self" is seen as an object that is changed through interaction with others. The death of a loved one results in the loss of self or identity for the survivor. Persons with ID have limited close relationships and thus fewer identities on which to rely when one of those relationships is ended.

When a person with ID experiences a significant loss, s/he may often be unable to communicate his/her feelings in socially acceptable ways (LoConto & Jones-Pruett, 2008).

This difficulty in communication may contribute to negative behaviors and subsequent frustration for, or misdiagnosis by, caregivers and therapists (Clements, Focht-New, & Faulkner, 2004; MacHale & Carey, 2002).

In the event of a death, the person with ID may be given incorrect information and/or may not be involved in the funeral process. The explanations for why people leave are often minimized or misrepresented to the person with ID for fear the person with ID would not understand the situation (Clements, et al., 2004) or because people are often hesitant to give people with ID information that "might upset them" (Brickell & Munir, 2008; p. 6). This may lead to ineffective or delayed grieving (Clements, et al., 2004). Clements, et al. suggested that persons with ID may benefit from straightforward explanations when experiencing loss.

Persons with ID are sometimes excluded from bereavement rituals due to concerns that they will behave inappropriately, display too much emotion, or interfere with the rituals. A study of funeral directors revealed a lack of knowledge and experience of inclusion of persons with ID in funeral rituals (Raji, et al., 2003).

Dodd, et al. (2008) administered the Complicated Grief Questionnaire for People with Intellectual Disabilities (CGQ-ID), an adapted Bereavement History Questionnaire, and the Index of Social Competence (McConkey & Walsh, 1982) to the caregivers of 76 individuals with ID. Of the total sample, 38 individuals had experienced a parental bereavement within the previous 2 years and the other 38 had not. The CGQ-ID was developed to assess complicated grief symptoms in individuals with ID who had experienced bereavement. The bereaved group scored higher than the non-bereaved comparison group on all three assessment tools used. The results indicated that those who were most involved in bereavement rituals scored higher on overall complicated grief and "separation distress." The authors noted that, although there was a positive correlation between involvement in bereavement rituals and complicated grief, the extent to which one participates should be based on an individual's needs and prior experience with death and bereavement rituals.

Treatment of Bereaved Individuals with Intellectual Disabilities

Researchers and clinicians have just recently begun to explore and understand the implications of grief and bereavement on individuals with ID. Research in the treatment of bereavement in individuals with ID, however, remains in infancy with few studies published in this area.

In a theoretical article, LoConto and Jones-Pruett (2008) provided implications for caregivers and service providers. The authors suggested provision of an atmosphere in which people can overcome their grief. The approach used by the service provider should be with the goal of creating a new self to minimize the self strongly associated with the deceased. Techniques and approaches suggested by the authors include creation of a family tree, artwork, life story work, drama, and poetry.

Summers and Witts (2003) presented a case study of a woman with moderate to severe ID who had begun exhibiting negative behaviors and somatic symptoms following the death of her father. The woman had been in intermittent residential placement since age 8 and was admitted to an institution at age 17. There were suggestions that she had been physically neglected and physically and sexually abused as a child. After her father's death, she began to make odd and ambivalent statements regarding her father, which prompted a referral to a psychology service with professionals who specialized in intellectual disabilities. She worked individually with a therapist who helped her to better understand the meaning of death by using verbal interventions and a book designed for individuals with intellectual disabilities. The therapist encouraged the client to express herself verbally and through drawing. Following psycho-educational and psychodynamic therapies, the client exhibited an improved mood with decreased negative behaviors and somatic symptoms.

Dowling, et al. (2006) compared the effectiveness of bereavement counseling provided by volunteers who were trained to adapt strategies to fit the needs of adults with ID (particularly in the area of communication) and an "integrated intervention" that offered support specific to be eavement needs which was provided by people who knew the participant. The staff and family caregivers who participated also received training on bereavement issues and expected therapeutic intervention. Two people were identified for each participant, one to support the individual at home and another to provide support at the individual's day placement. Of the 56 participants who originally consented, data were analyzed for 11 who received treatment through the integrated intervention and 20 who received the counseling intervention. The researchers found adapted bereavement counseling to have a positive impact on adults with ID who had encountered the death of a parent or sibling. Pre- and post-test change in scores on the Aberrant Behavior Checklist - Community (ABC-C) and the Health of the Nation Outcome Scales for People with Learning Disabilities (HoNOS-LD) indicated positive mental and behavioral outcomes for adults receiving bereavement counseling, regardless of when the loss was experienced. The integrated approach was not as effective due to caregivers being unable or unwilling to implement the approach due to time constraints or feelings of inadequacy in dealing with the topic of death.

In a study of 21 people with borderline to severe intellectual disability, Stoddart, et al. (2002) examined the effect of bereavement groups for the participants. Each of the participants had experienced the death of a parent, roommate, or sibling within the previous

10 years. The therapists involved in the study provided eight 1.5 hour sessions in which the goals were (a) allow for the sharing of experience and emotions related to the loss, (b) educate participants about grief and the process of mourning, (c) increase awareness that such a loss is not unique, (d) help participants progress toward life without the deceased, and (e) assist with the process of mourning so that potential for unresolved grief is reduced. Following the group therapy, participants exhibited significantly lower scores for depression as measured by the Children's Depression Inventory – Short Form (CDI-SF). Changes in scores for anxiety and knowledge of death and bereavement issues were not significant.

Tools for Caregivers

There are some tools commercially available for professionals who serve adults with ID. The Books Beyond Words series (available from the Royal College of Psychiatrists, London) addresses several serious topics faced by adults with ID. These books consist of pictures with a suggested storyline and are age appropriate for adults. Two of the books, *Going Into Hospital* (Hollins, Avis, & Cheverton, 1998) and *When Somebody Dies* (Hollins, Dowling, & Blackman, 2003) can be valuable tools when addressing the topics of going to the hospital and death of a loved one, respectively. In addition to providing age appropriate subjects and pictures, these books also contain tips for professionals not accustomed to serving people with ID.

People Planning Ahead (Kingsbury, 2009), published by the American Association on Intellectual and Developmental Disabilities, is a helpful resource to assist persons with ID in preparing for their own deaths. It utilizes the person-centered planning approach to discuss the topic of end-of-life wishes with people who have ID. This can be a positive experience to help one prepare for his/her own death and to help persons with ID cope with the death of a loved one.

Music Therapy and Intellectual Disabilities

Music therapists have served people with ID since the earliest years of the profession (Gaston, 1968). Published music therapy literature specific to adults with intellectual disabilities addresses a wide range of needs and target behaviors including self injurious behaviors, positive social interaction, use of technology to participate in music creation, community involvement, behavior and musical skills, and range of motion (Boso, Emanuele, Minazzi, Abbamonte, & Politi, 2007; Curtis & Mercado, 2004; Farnan, 2007; Ford, 1999; Hooper, 2001; Ingber, 2003; Wigram, 1996). Types of music therapy interventions found to be effective when providing music therapy for individuals with ID include music listening and keyboard playing (Ford, 1999), active music therapy (Boso, et al., 2007; Hooper, 2001), use of MIDI technology (Ingber, 2003), inclusive community performance groups (Curtis & Mercado, 2004), vibroacoustic therapy (Hooper & Lindsay, 1997; Persoons & De Backer 1997; Wigram, 1996; Wigram, McNaught, Cain, & Weekes, 1997).

Music Therapy and Bereavement

Music therapy literature concerning bereavement is sparse, with a few studies related to adults and children who have experienced loss. There is no published research related to the use of music therapy with adults with ID who have experienced loss.

Smeijsters and van Den Hurk (1999) described the use of music therapy with a woman who had experienced the death of her husband 3 years prior to receiving music therapy treatment. She was referred for music therapy after progressing little in 21 sessions of verbal psychotherapy. The music therapists used instrumental and vocal improvisation and verbal processing to address the client's issues of lost identity, low self-esteem, difficulty expressing emotion, and difficulty forming new relationships. Through music therapy, the client found her own melody, her "self." The client's self-report indicated an improvement in mood and a motivation to continue to change and grow.

Music therapy also has been used with children and adolescents experiencing loss. Dalton and Krout (2006) described the use of a song-writing based music therapy protocol with bereaved adolescents. The protocol was based on the thematic analysis of 123 songs written by bereaved adolescents. After the themes of the music were analyzed, the researchers identified five grief process areas ("understanding, feeling, remembering, integrating, and growing" [p. 95]), upon which a protocol was developed. During this protocol, adolescents created original songs focused on the identified grief process areas. The researchers reported that, following a 7-week protocol, participants exhibited increased rapport and trust with peers and creativity in expressing their feelings related to the five grief process areas.

In a pilot study of 18 school-aged children, Hilliard (2001) used "singing, songwriting, rap-writing, rhythmic improvisation, structured drumming, lyric analysis and music listening" (p. 296) in an eight-session series to explore topics related to death. The 18 children were split into a music therapy treatment (n = 9) and control group (n = 9). These topics included development of group rapport and trust, death education, normalization of death, causes of sorrow and ways to cope, causes of anger and ways to cope, remembering the deceased, reinforcement of previous objectives, and promotion of continued use of coping skills and supports. Results showed significant (p < .05) reduction in grief symptoms and in-home behavioral problems in the music therapy group. Based on reports of school

personnel, children participating in the music therapy condition were motivated to attend the groups and often expressed enjoyment in participating in music therapy.

Hilliard (2007) compared Orff-based music therapy and social work groups designed to follow an 8-week grief curriculum for children in a study of 26 children who had experienced death of loved one in the previous 2 years. The researcher administered pre- and post-tests using two measures: Bereavement Group Questionnaire for Parents/Guardians and the Behavior Rating Index for Children. The Orff-based music therapy group utilized precomposed and improvised music and songwriting. The social work group used play therapy, sand trays, counseling, discussion, drama, and art making.

The curriculum used for the treatment groups focused on different themes each week and were similar to the topics used in the pilot study performed by Hilliard (2001):

Session 1 – Establishment of therapeutic and group rapport

Session 2 – Basic education regarding death

Session 3 – Education of death as a normal change

Session 4 - Recognition of sorrow and identification of coping skills

Session 5 - Recognition of anger and learning safe ways to express anger

Session 6 – Identification of memories of the lost loved one

Session 7 – Reinforcement of what was learned previously and how to progress

Session 8 - Encouragement of continued use of supports and positive coping skills (Hilliard, 2007).

Hilliard (2007) found significant (p < .05) improvement in grief symptoms and behavioral problems for the participants in both music therapy and social work groups when compared to the control group. There were no significant differences between the music therapy and social work groups. This study provides support for use of music therapy and social work in treatment of childhood bereavement.

Although there is no music therapy literature related to the bereavement of adults with ID, concepts from the existing literature may be applied to adults with ID. Musical improvisation can provide a way for a person to express emotions and ideas when one's disability prevents extensive verbal processing. Precomposed music may provide a familiar structure in which to explore thoughts and feelings related to the bereavement of a person with ID. Songwriting, singing, lyric analysis, improvisation, and structured music playing may offer ways for individuals to explore and work through bereavement and the associated feelings (Dalton & Krout, 2006; Hilliard, 2001; Hilliard, 2007; Smeijsters & van Den Hurk, 1999).

The purpose of this study was to examine the effect of music therapy on the bereavement process of adults with ID. It was a feasibility study to explore the effect of the 9-week music therapy protocol adapted from the work of Hilliard (2007) for adults with ID who had experienced the loss of a significant person.

Chapter 3

Method

Participants

Participants were recruited from a state residential facility for persons with moderate to profound intellectual disabilities. Informed consent forms were sent by facility social workers to 11 residents and were returned for 7. Of those, 5 assented to participate in the study. Of the 5 who assented to participate, 2 attended either one or two sessions before refusing to continue for unknown reasons and were not included in the report of results below. The number of participants who completed the study was 3. Case managers, psychologists, and social workers served as sources of referral for participants to the program. The social workers contacted guardians to secure informed consent prior to referral to the researcher.

Eligible participants were those who had expressive and receptive language sufficient for basic communication and had experienced a significant loss within the past 4 years. Individuals were also eligible if the treatment team determined that unresolved issues related to bereavement were present if the loss was greater than 4 years prior to the study.

Individuals who were unable to communicate verbally were not included in this study. Individuals were also excluded at the suggestion of the treatment team due to unstable mental status and recent changes in medication.

Measures

The Brief Psychiatric Rating Scale, Developmental Disabilities version (BPRS-DD; Bodfish, 1995; see Appendix A) was used to assess the participants' frequency of negative behaviors. The BPRS-DD is comprised of 14 Likert scale items completed by a caregiver to reflect behaviors and symptoms exhibited by the client during the week prior to the assessment. Staff psychologists completed the BPRS-DD. In addition to the quantitative data, the music therapist kept narratives of each session, and communicated regularly with caregivers to assess any additional changes in behavior.

Procedure

During an initial meeting with each referred individual, the researcher discussed the study in plain language and secured assent for participation. Due to the low number of participants, there was only one group. The group met twice weekly for 5 weeks, with the exception of one week in which there was only one meeting. This protocol featured different themes each week as adapted from the work of Hilliard (2007). The session themes were as follows:

Session 1 – Establishment of therapeutic and group rapport

Session 2 – Basic education regarding death

- Session 3 Education of death as a normal change
- Session 4 Recognition of sorrow/sadness and identification of coping skills
- Session 5 Continued identification of coping skills
- Session 6 Recognition of anger and learning safe ways to express anger
- Session 7 Continued identification of safe ways to express anger and coping skills
- Session 8 Identification of memories of the lost loved one

Session 9 – Reinforcement of what was learned previously and how to progress Music therapy sessions used musical improvisation, songwriting, and pre-composed music to introduce and reinforce the themes. (See Appendix C for a description of the music therapy experiences used in each session.)

Data Collection Techniques

Each participant's psychologist completed the BPRS-DD and brief questionnaire before music therapy began, after the ninth session, and 4 weeks following the end of music therapy sessions. The music therapist also kept narrative accounts of each session, which were used to describe the cases outlined below.

Data Analysis

Data were analyzed as multiple case studies. BPRS-DD scores at the three time points were examined for each participant to observe for changes across time. The responses to the brief questionnaire included with the BPRS-DD informed the researcher of any significant losses or significant changes experienced by the participants during the study. The therapist's narratives were used to assess behavioral changes throughout the course of the music therapy sessions and to provide additional information about the process experienced by the participants.

Chapter 4

Case Studies

Mary

Mary was a 33-year-old female with moderate mental retardation whose mother and father died within a month of each other 5 years prior to the study. Her treatment team referred her to the study because of concerns that she had not had an opportunity to process the deaths of her parents. Mary's spiritual background was Protestant; her guardian (her mother's sister) was Catholic. She had lived at the facility for 6.5 years at the time of the study. She was also involved with the facility resident choir, which was directed by the researcher. Mary was present for eight of nine treatment sessions.

Session 1: Establishment of therapeutic and group rapport. When the study began, Mary participated in all of the experiences, but refused to sing during the goodbye song. During the first session, she seemed to have some difficulty separating the bereavement group from her involvement in the resident choir. She asked several times, "What songs are we going to learn?" This behavior was not observed after the second session.

At the beginning of the first session, Mary told the other participants that the group was for people who had "lost their families." She began to cry when talking about this. The music therapist (MT) helped her identify living people to whom she was close and who loved her. This helped her recognize positive relationships in her life and redirect her to what the group was doing in the moment. Session 2: Basic education regarding death and loss. The MT used an adult picture book (Hollins, et al., 2003) in Session 2 to illustrate what happens when someone dies from the perspective of a bereaved individual with an intellectual disability. The MT led the group in a discussion about the main character and her feelings. Mary contributed several ideas while looking at the book and accurately described scenes in the book. After discussing the book, Mary chose and played emotions using the drum. Mary congruently played "sad," "stressed," and "angry." She sang "Turn! Turn! Turn!" (Seeger, 1959) with the group, and requested to sing the verse again ("A time to live, a time to die") because she said, "That part means a lot to me."

After the second session, Mary's home coordinator reported that she had exhibited atypical negative behaviors including, "anger, regression, overeating, increased anxiety, refusing to work, and obsessing about negative past events." It was later discovered that the beginning of the bereavement group coincided with the start of swim season, which previously had been observed to increase Mary's stress level.

Session 3: Education of death as a normal change. Mary exhibited flat affect for the majority of the third session. She sang with the group and contributed to group discussion. She needed prompts to take turns with peers, as she often spoke when others were trying to speak. She did not mention her parents' deaths on this day.

Session 4: Recognition of sorrow and identification of coping skills. During Session 4, Mary spoke about her mother's and father's deaths as if they happened at the same time, rather than a month apart. She described how it felt when parents died by saying it "hurt" and "ached." She said she was "stressed," and that she had "cried." She played the drum to reflect sadness by hitting the drum and letting her hand fall off. She chose to play "sad" while the group played "support." After playing, she said that playing sadness "hurt." Her affect during this session was mostly flat, but changed when talking about and playing "sad," when her affect reflected the feeling.

Session 5: Recognition of sorrow and identification of coping skills (continued). When asked in Session 5 to describe the previous session, Mary gave an accurate account of the session. She said, "We talked about how it feels when somebody dies. We played 'sad' on the drum and talked about what it's like to feel sad." She again discussed her mother's and father's deaths, and this time described them as separate events. She said that she had come to live at the present facility because her aunt (current guardian) and her mother wanted her to be somewhere "safe." When asked if she felt "safe" at the facility, she said, "Yes" and began to talk about the positive things she is involved in at the facility (swimming, work, etc.). During this session, the MT used icons (see Session Plan 7 in Appendix C) to aid in songwriting about sadness and coping with the feeling of sadness. The use of icons helped Mary remain focused and provided concrete ideas for the songwriting. Mary talked about not wanting to eat after her parents died because she felt "sad, and I wanted to go to heaven to be with them." When transitioning to the goodbye song, Mary said she was not ready to go. After the MT reviewed the coping strategies with her, she said she was ready to leave. She helped write a verse for the goodbye song and read the verse during the song. This was the most participation she had demonstrated in the goodbye song to date.

Session 6: Recognition of anger and learning safe ways to express anger. Session 6 addressed how to recognize anger and how to deal with anger in ways that do not hurt one's self, others, or property. When Mary was prompted to play "angry" using the drum, she

hit the drum with her fist, slapped the drum, and made the statement, "That's like how I used to hit and slap myself when I was angry, but I don't do that anymore." She suggested positive ways to deal with anger, including "going to my room" and "talking to somebody." At times, it was difficult to redirect Mary from focusing on perceived anger from others toward her. For example, Mary perseverated on the idea that a staff member would be angry with her for forgetting to get a walking pass to come to the session that day.

Session 7: Reinforcing safe ways to express anger. Mary was not present for Session 7. She told a staff member that she "had too much to do." She was preparing for a swim meet out of town the following weekend.

Session 8: Using music to memorialize loved ones. When asked to identify positive memories of her mother and father in Session 8, Mary spoke only of her mother. She said "My mama took care of me." She shared memories about going shopping and going on out of state trips. Mary shared memories of her mother taking her to see family members. When she began to talk about negative events, Mary began to rock in her chair and the volume of her voice increased. She was redirected easily. She chose several songs for the group CD, including "Turn! Turn! Turn!," "Jesus Loves Me," "Standing on the Promises," and "The Old Rugged Cross."

Session 9: Reinforcement of what was learned previously and how to progress. The final session included reinforcement of previous learning with a focus on moving forward. During this session, Mary drew a church and a graveyard on her CD cover, and named her CD "The Church of God." She had difficulty focusing in this session, perhaps due to an upcoming trip the following weekend and a trip out that night. She helped write the goodbye song and identified experiences from past sessions when given repeated prompts. **BPRS-DD results**. On the short questionnaire administered concurrently with the BPRS-DD, there were no significant losses or changes noted for Mary during the course of this study. As shown in Table 1, Mary scored 23 on the BPRS-DD administered one week prior to the beginning of the study. Her psychologist completed all three of her evaluations. She scored at least a 2 or 3, indicating "mild" to "moderate" presence of the following behaviors: anxiety/tension, social withdrawal, depressed mood, blunted affect, excitement, irritability, mood changes quickly, compulsive/ritualistic/perseverative, and noncompliant/uncooperative. Following completion of the study protocol, Mary scored 2 on the BPRS-DD, with the behaviors blunted affect and excitement rated 1, or "very mild." On the final administration of the BPRS-DD, 4 weeks following the end of the study protocol, Mary scored 6, with "very mild" to "mild" scores on the following behaviors: anxiety/tension, depressed mood, blunted affect, excitement, and mood changes quickly.

Summary. Over the course of the study, Mary exhibited improvements in group social skills and decreased frequency of negative behaviors. During the first half of the sessions, Mary needed repeated reminders to allow other participants to contribute to group discussion. By the end of the study, however, Mary had improved in taking turns with others without repeated prompts. Mary was very open in discussing the deaths of her parents with the group throughout the study. The changes in Mary's BPRS-DD scores indicated a drastic decrease in negative behaviors from the initial assessment to the last two assessments.

James

James was a 60-year-old male with moderate mental retardation whose sister and former guardian died 3.5 years prior to this study. His mother and brother-in-law also died within the previous decade. According to his treatment team, James talked about his sister's death only with his guardian and special friend. With others he did not discuss specific people but did talk about going to heaven. Both James and his family had Protestant backgrounds. He had lived at the facility for 44 years prior to the study. James was present for all treatment sessions.

Session 1: Establishment of therapeutic and group rapport. James participated in all experiences when given prompts. During the discussion about preferences, James talked about money he had saved in a popcorn box. He perseverated on that topic for most of the session. He appeared tense as evidenced by tight shoulders and nervous movements.

Session 2: Basic education regarding death and loss. James was quiet unless asked a direct question. His body was more relaxed than in the previous session. He talked about his popcorn box of money some, until the group looked at and talked about the adult picture book that illustrates what happens when someone dies (Hollins, et al., 2003). After looking at the book, he said, "I'm going to be buried next to my sister." He played "angry" using the drum. At first, he hit the drum lightly, and then hit the drum harder after encouragement from a peer. When the music therapist told the group they were going to sing "Turn, Turn, Turn," James first began to sing alone and then sang the song with the group.

Session 3: Education of death as a normal change. James's contributions to group discussion were relevant when given specific, direct questions. He remained quiet except when directly addressed. James exhibited flat affect for the majority of the session. He exhibited nervous behaviors (i.e., tense shoulders, blinking) when directly addressed.

Session 4: Recognition of sorrow and identification of coping skills. At the beginning of the session, James was quiet. He talked some about money and his popcorn box and was easily redirected. He played "sad" on a drum with slow, steady beats when given the

opportunity to play by himself. He did not play with the group despite prompts. When asked about his experience with death, James said, "My sister's in heaven." He sang "Stand by Me" with the group, and added "played the drum" to the goodbye song.

Session 5: Recognition of sorrow and identification of coping skills (continued). When asked how he was feeling at the beginning of the session (and given icon choices: happy, sad, angry, or sick), James said he was "not feeling too good... I've got post nasal drip." When asked if there was anything he wanted to share about his sister's death or funeral, he said, "I saw her in the casket" and "She was a good sister." He said, "Yes" when asked if he had felt sad. During the songwriting experience, James chose icons to fill in the blanks. For a coping skill, he repeatedly chose and identified "hug." He sang all songs with the group when given verbal prompts.

Session 6: Recognition of anger and learning safe ways to express anger. When asked how he felt at the beginning of the sixth session, James said he "had the crud." For the majority of the session, he was preoccupied with something that had happened in his home. He said that he felt a staff member was angry with him. The music therapist was unable to redirect him to a different subject even when asking direct questions and offering to discuss the situation after the session. When a peer tried to interrupt him, James put his hand up to tell her not to talk.

Session 7: Reinforcing safe ways to express anger. When asked how he was feeling, James said, "Not too good," and said he had not eaten breakfast that day because he did not like oatmeal. James was much more focused on this date than during the previous week's session. He talked some at the beginning of the session about his sandbox and the cost of sand, but he was easily redirected. He participated in the group songwriting and identified coping skills using icons as clues. When asked to choose behaviors that were "not good choices," given the option between negative and positive, he was unable to identify negatives using only icons. However, he was able to identify negative behaviors when told what the icons represented. He sang with the group with few prompts.

Session 8: Using music to memorialize loved ones. When asked to share memories about his sister, James said, "She was good to me," "She'd take me to the fish camp," "She was a good sister," and "I miss her." He was very calm when talking about his sister. When asked for a song suggestion for the group CD (in memory of their loved ones), James suggested "Rocka My Soul."

Session 9: Reinforcement of what was learned previously and how to progress. During the final session, James was quiet unless directly addressed. He was preoccupied with a trip he was going on that evening. He said he had a "men's night out" planned. He sang with the group when prompted. When talking about coping skills, James identified the "hug" card correctly. He decorated his CD cover by writing his name 3 times with a dark green marker. When asked to describe it to the group, he shrugged his shoulders and said nothing.

BPRS-DD results. On the short questionnaire administered concurrently with the BPRS-DD, there were no significant losses or changes noted for James during the course of this study. James's psychologist completed all three of his evaluations using the BPRS-DD. James scored a 14 one week prior to the beginning of the study. He scored at least a 3 on blunted affect, indicating "moderate" presence of that behavior. For the behavior "unusual verbalizations or actions," James received a score of 4, indicating "moderately severe" presence of that behavior. Following completion of the study protocol, James scored 14 on the BPRS-DD, with identical scores for all behaviors as on the first test. On the final

administration of the BPRS-DD, 4 weeks following the end of the study protocol, James scored 13, with excitement decreasing from a 1 ("very mild") to a 0 ("not present").

Summary. When the study first began, James was very quiet unless directly addressed and was easily distracted by other group members. Over the course of the study, James began to be more assertive when contributing to the group (e.g., in Session 6, James held up his hand to quiet a peer when she tried to interrupt his sharing something important to him). James's responses also became more relevant. This could be due to the fact that the researcher began to ask James more direct questions and offer icon cards when needed once it was observed that James required that level of support to be successful in group experiences. Almost no change was seen in the BPRS-DDs completed by the home psychologist.

Nancy

Nancy was a 51-year-old female with moderate mental retardation whose mother died 3.5 years prior to the study. According to her treatment team, she spoke about her mother occasionally. She had lived at the facility for 45 years at the time of the study. According to her chart, Nancy was originally admitted to the center at the age of 6 for hyperactivity and aggression, which was stated to have contributed to an increased level of stress for her family. Over the years, she visited her family at home regularly, and her mother reportedly became "more warm" toward her. When her mother died of cancer, Nancy was able to say good-bye to her and attended a family ceremony. At the time of the study, Nancy was involved with the facility resident choir. She was present for seven of nine treatment sessions.

Session 1: Establishment of therapeutic and group rapport. Nancy participated in all experiences during the first session. She exhibited bright affect during the greeting song and while playing the drum. She shared with the group some things she liked doing and interacted with staff and peers. When asked at the end of the session if anyone had any questions, Nancy said, "My sister coming?" According to her social worker, Nancy had a close relationship with her sister, and the sister visited often.

Session 2: Basic education regarding death and loss. Nancy again participated in all group experiences in the second session. The group looked at and collectively narrated an adult picture book called "When Someone Dies" (Hollins, et al., 2003). While the group narrated and discussed the scenes in the book, Nancy repeatedly asked, "Why?" After the book, she said several times, "My mama died" with flat affect. During the discussion of and instrumental representation of feelings, Nancy chose to play the emotion "happy" using the drum. She played a moderate steady tempo with her hand bouncing off of the drum.

Session 3: Education of death as a normal change. In the third session, Nancy sang all songs with the group. She contributed to group discussion when directly addressed and took turns with peers. During a discussion and songwriting about seasons, Nancy accurately identified events and characteristics of different seasons.

Session 4: Recognition of sorrow and identification of coping skills. Nancy was not feeling well during the fourth session. When asked about her experience with death, she said, "My mama died." When asked how she felt when her mother died, Nancy chose "hurt" from options given by a peer (sad, hurt, mad, upset). When interrupted by a peer, she seemed to forget the question. She responded appropriately when reminded and given time to answer. She hit the drum loudly and slowly when playing "sad." She played "support" with the group, and contributed a steady beat. Nancy sang all songs with the group and exhibited mostly flat affect.

Session 5: Recognition of sorrow and identification of coping skills (continued). Nancy was not present for Session 5. She was preparing to go on an outing and was unable to attend the session.

Session 6: Recognition of anger and learning safe ways to express anger. Nancy was not present for Session 6. On this date she was visiting her sister.

Session 7: Reinforcing safe ways to express anger. Nancy said she was "happy" about going out the night of the seventh session. She identified positive coping skills and negative behaviors both with and without icons. She contributed to songwriting and sang with the group. She was able to distinguish between positive and negative ways to express anger independently.

Session 8: Using music to memorialize loved ones. Nancy seemed to have difficulty identifying specific memories of mother. When asked about her mother, Nancy said, "Love her." "I love my mama." She began to cry when talking about her mother and cried for 1-2 minutes. A peer encouraged her to keep crying, which may have caused her to become more upset than she was when initially talking about her mother. When prompted to choose a song for the group CD, she chose "The B-I-B-L-E."

Session 9: Reinforcement of what was learned previously and how to progress. Nancy said she was "happy" about going out in the evening after the final session and then focused on the session. She drew oblong circles in purple and brown on her CD cover, and told the group "It's a house." Nancy chose the title, "Songs that Make Me Feel Good" for her CD. **BPRS-DD results.** On the short questionnaire administered concurrently with the BPRS-DD, there were no significant losses or changes noted for Nancy during the course of this study. Nancy scored a 2 on all BPRS-DDs administered during this study: one week prior to the beginning of the study, the week after the completion of the study protocol, and 4 weeks following the end of the study protocol. Her psychologist completed all three of her evaluations. The only behavior present was blunted affect, for which Nancy scored a 2 ("mild").

Summary. Throughout the study, Nancy talked very little about her mother and, instead, focused on the present (i.e., "My sister coming?"). On only one occasion when talking about her mother did Nancy exhibit any affect (see Session 8). The relationship Nancy had with her mother is uncertain; however, she had lived at the facility for 45 years since the age of 6. Therefore, it is likely that she did not have the type of relationship one might have when living with a parent for a longer period of time.

There was no change in the BPRS-DD scores for Nancy. Her initial score was very low and her scores remained low for the duration of the study.

Chapter 5

Discussion

Following the series of music therapy sessions, 1 of the 3 participants exhibited a decrease in the frequency of negative behaviors. Two participants demonstrated improved group social skills during the course of music therapy sessions. All participants expressed negative behaviors associated with feelings of anger and sadness and identified positive ways to cope with these feelings and behaviors.

Of the 3 participants, 2 had resided in the state facility for 44 and 45 years, respectively. The third participant had only lived at the facility for 6.5 years. Of the three participants, the one who had lived with her parents the longest had the highest initial BPRS-DD score and exhibited the most change in behavior as measured by the BPRS-DD. It is speculated that, because she lived at home longer, she may have formed a stronger relationship with her parents than did the participants who had lived away from their families since childhood. When working with adults who grew to adulthood in the family home, there may be a stronger identification with the relationships within the home. These adults may experience a stronger grief reaction when the family member dies. This grief reaction also may apply when the adult is initially placed in a residential facility away from aging parents.

Death is often referred to in symbolic terms (e.g., passed away, lost, etc.). People with ID are unable to think abstractly in the same way as typically developed adults. Therefore, discussion of death with adults with ID must be straightforward and may sometimes be uncomfortable for clinicians who find comfort in the symbolic. This was evidenced in Session 3: Death as a Normal Change. The researcher used the symbol of changing seasons to illustrate the circle of life. Although the participants were aware of the meaning of weather seasons, they were unable to draw the similarities between the changing of seasons and death. Based on the response of the participants in this study, this researcher recommends that death be discussed in literal, rather figurative, terms.

Some of the themes used in the original protocol were not relevant to the participants in this study. For example, in Session 3: Education of Death as a Normal Change, all of the adults in the group were familiar enough with death that they knew it happened to everyone, and that those who die do not come back. When implementing this protocol it would be important for the clinician to be aware of the extent to which participants understand and know about death. This information could be assessed individually prior to initiating the group or in Session 2: Basic Education Regarding Death and Loss.

As described by Kauffman (1994) and LoConto and Jones-Pruett (2008), persons with ID often have difficulty expressing feelings of grief in effective and socially appropriate ways. The experiences in this study related to anger and sadness provided participants with an outlet to express feelings verbally and musically in the form of group discussion and improvisation. The songwriting experiences ("Stand By Me" and "When I Get Angry") exposed participants to appropriate vocabulary and strategies for coping with sadness and anger.

Limitations of the Study

The group was small (3 participants) due to availability of participants who met the criteria, whose guardians were willing to provide consent, and who were willing to assent to participation. The study was limited to residents in a state facility for individuals with ID and

therefore may not generalize to those who are living in other settings. One guardian refused to provide consent due to reluctance to raise the subject of death to her brother, whom she said "was happy" and did not need to be disturbed in that way. This is consistent with research that has found that caregivers are sometimes unwilling to discuss death with people with ID because of fears of "upsetting" the person with ID (Brickell, & Munir, 2008; Clements, et al., 2004).

The results of this study are also limited by the amount of time between the loss and the implementation of the intervention. Grief groups for typically developed adults typically occur within the first months after the death of the loved ones. In the present study, participants' family members had died 3.5-5 years prior to the initiation of the bereavement group. The process and results of bereavement groups for individuals with ID who have experienced more recent loss may vary from the present results. Nevertheless, as demonstrated by one participant, behavioral effects of grief may persist for years beyond the loss and may be mitigated by music therapy bereavement treatment in some individuals.

Recommendations for Clinicians

The clinician must be sensitive to the individual needs of group members. Persons with ID are unique, even if they carry the same label. Some of the members of the group in this study had the ability to read. Others needed assistance with communication by asking direct, simple questions and using icons or other visual aids. It is recommended that the clinician make every effort to get to know the participants as well as possible when beginning this type of session series. The assessment should include the participant's knowledge of and experience with death, preference of and experience with music, communication needs, and familiarity with structured group activities.

The themes of the sessions are recommended as useful for this population; however, the specific details of the sessions should reflect individual needs of the clients involved. For example, the style of music used may be changed to meet the preferences of the individuals in the group. The duration of the session also may change depending on the attention spans of the persons involved. With this group of participants, a 45-minute session was most effective in giving time to explore the issues presented without exhausting the attention spans of those involved.

In the sessions on sadness and anger, the group needed additional time to deal with the issues presented. Therefore, the researcher extended those themes over the course of two sessions. This allowed participants additional time to explore the feelings discussed and focus on the coping strategies presented.

The session plans outlined in this paper reflect the unique needs and responses of the people in the study group. Nevertheless, the themes and strategies included in the session plans may be used with other groups of adults with ID who are experiencing bereavement. However, the individualized nature of music therapy will lend variability to further applications of the protocol.

This protocol could be modified for individual sessions. In smaller living communities, there may not be three or more individuals who experience bereavement during the same period. Also, there may be an individual who would benefit more from individual sessions than group sessions due to a lack of group interaction skills or nature of the loss. When implementing this protocol in an individual session, the element of peer support will be lost. However, the sessions may be more individualized in nature and the clinician will have more flexibility in allowing the person to progress at his/her own pace without having to factor in the personal processes of other group members.

Implications for Future Research

As this study was limited in sample size, further research is needed to examine the effects of music therapy on the bereavement process of adults with intellectual disabilities. A larger sample size with a control group is needed to determine any possible significant differences. Future studies need to examine the effects of such intervention for individuals who have experienced more recent loss. Additional measures may also be used to assess the effectiveness of treatment as the BPRS-DD used in this study assessed only the presence of negative behaviors.

Conclusion

The purpose of this study was to explore the use of music therapy in the bereavement of adults with intellectual disabilities. Through songwriting, improvisation, and singing, participants were given the opportunity to express and explore feelings associated with bereavement. As persons with ID continue to age and have the opportunity to form more meaningful relationships, it is important that clinicians be prepared to meet the challenges faced by adults with ID when those relationships change due to death or other loss. Further research is needed to determine best practice for the use of music therapy in this area. Nevertheless, the results of this study indicate that music therapy may be a useful intervention for helping bereaved persons with ID express and explore feelings related to significant loss and for teaching effective coping skills that may result in decreased negative behaviors associated with the loss of a significant person in one's life.

References

American Association on Intellectual and Developmental Disabilities. (2010). FAQ on intellectual disability. Retrieved June 6, 2010, from http://aamr.org/content 100.cfm?navID=21

- American Music Therapy Association (1998-2010). What is the profession of music therapy? Retrieved June 6, 2010, from http://www.musictherapy.org
- Bodfish, J. W. (1995). Brief psychiatric rating scale for developmental disabilities (BPRS-DD). Morganton, NC: Western Carolina Center Research Report.
- Boso, M., Emanuele, E., Minazzi, V., Abbamonte, M., & Politi, P. (2007). Effect of longterm interactive music therapy on behavior profile and musical skills in young adults with severe autism. *The Journal of Alternative and Complementary Medicine*, 13, 709-712.
- Brickell, C., & Munir, K. (2008). Grief and its complications in individuals with intellectual disability. *Harvard Review of Psychiatry*, 16, 1-12.
- Clements, P. T., Focht-New, G., & Faulkner, M. J. (2004). Grief in the shadows: Exploring loss and bereavement in people with developmental disabilities. *Issues in Mental Health Nursing*, 25, 799-808.
- Curtis, S. L., & Mercado, C. S. (2004). "Community music therapy for citizens with developmental disabilities." *Voices: A World Forum for Music Therapy*. Retrieved October 30, 2008, from http://www.voices.no/mainissues/mi40004000162.html

- Dalton, T. A., & Krout, R. E. (2006). The grief song-writing process with bereaved adolescents: An integrated grief model and music therapy protocol. *Music Therapy Perspectives*, 24, 94-107.
- Dodd, P., Guerin, S., McEvoy, J., Buckley, S., Tyrrell, J., & Hillery, J. (2008). A study of complicated grief symptoms in people with intellectual disabilities. *Journal of Intellectual Disability Research*, 52, 415-425.
- Doka, K. J. (n.d.). Individuals with intellectual disabilities: Struggling with loss and grief. Retrieved June 3, 2010, from http://www.ddhospicepalliativecare.org/ forum/ciwid.pdf
- Doka, K. J., & Lavin, C. (2003). The paradox of ageing with developmental disabilities: Increasing needs, declining resources. *Ageing International, 28,* 135-154.
- Dowling, S., Hubert, J., White, S., & Hollins, S. (2006). Bereaved adults with intellectual disabilities: A combined randomized controlled trial and qualitative study of two community-based interventions. *Journal of Intellectual Disabilities, 50,* 277-287.
- Farnan, L. (2007). Music therapy and developmental disabilities: A glance back and a look forward. *Music Therapy Perspectives*, 25, 80-85.
- Ford, S. (1999). The effect of music on the self-injurious behavior of an adult female with severe developmental disabilities. *Journal of Music Therapy*, *36*, 293-313.

Gaston, E. T. (Ed.). (1968). Music in therapy. NY: Macmillan.

Heller, T. (2004). Aging with developmental disabilities. In B. Kemp & L. Mosqueda (Eds.).*Aging with a Disability* (pp. 213-233). Baltimore, MD: The Johns Hopkins University Press.

- Hilliard, R. E. (2001). The effects of music therapy-based bereavement groups on mood and behavior of grieving children: A pilot study. *Journal of Music Therapy*, 38, 291-306.
- Hilliard, R. E. (2007). The effects of Orff-based music therapy and social work groups on childhood grief symptoms and behaviors. *Journal of Music Therapy, 44,* 123-138.
- Hollins, S., Avis, A., & Cheverton, S. (1998). *Going Into Hospital*. London, England: Gaskell.
- Hollins, S., Dowling, S., & Blackman, N. (2003). *When somebody dies*. London, England: Gaskell.
- Hooper, J. (2001). Overcoming the problems of deinstitutionalization: Using music activities to encourage interaction between four adults with a developmental disability. *Music Therapy Perspectives*, 19, 121-127.
- Hooper, J., & Lindsay, B. (1997). The use of the Somatron on the treatment of anxiety problems with clients who have learning disabilities. In T. Wigram, & C. Dileo (Eds.), *Music Vibration and Health* (pp.169-175). Cherry Hill, NJ: Jeffrey Books.
- Ingber, J. (2003). Using MIDI with adults who have developmental disabilities. *Music Therapy Perspectives*, *21*, 46-50.
- International Association for the Scientific Study of Intellectual Disabilities. (2002). Aging and intellectual disabilities fact sheet. Retrieved June 3, 2010, from www.ddas.vermont.gov/ddas.../fs-aging-intellectual-disabilities

Kauffman, J. (1994). Mourning and mental retardation. Death Studies, 18, 257-271.

Kingsbury, L. A. C. (2009). *People planning ahead: A guide to community healthcare and end of life wishes*. Washington, DC: AAIDD.

- LoConto, D. G., & Jones-Pruett, D. L. (2008). Utilizing symbolic interactionism to assist people with mental retardation during the grieving process. *Crisis & Loss, 16,* 21-35.
- MacHale, R., & Carey, S. (2002). An investigation of the effects of bereavement on mental health and challenging behaviour in adults with learning disability. *British Journal of Learning Disabilities*, 30, 113-117.
- McCallion, P., & Nickle, T. (2008). Individuals with developmental disabilities and their caregivers. *Journal of Gerontological Social Work*, 50 (Supplement 1), 245-266.
- McConkey, R., & Walsh, J. (1982). And index of social competence for use in determining the service needs of mentally handicapped adults. *Journal of Mental Deficiency Research*, 26, 47-61.
- NIH: National Institutes of Health. (2010). Bereavement. Retrieved June 6, 2010, from http://www.nlm.nih.gov/medlineplus/bereavement.html
- Persoons, J, & De Backer, J. (1997). Vibroacoustic therapy with handicapped and autistic adolescents. In T. Wigram, & C. Dileo (Eds.), *Music Vibration and Health* (pp. 143-148). Cherry Hill, NJ: Jeffrey Books.
- Raji, O., Hollins, S., & Drennan, A. (2003). How far are people with learning disabilities involved in funeral rites? *British Journal of Learning Disabilities*, 31, 42-45.
- Seeger, P. (1959). Turn! Turn! Turn! (to everything there is a season). On *The bitter and the sweet*. NY: Columbia Records. (1962).
- Smeijsters, H., & van Den Hurk, J. (1999). Music therapy helping to work through grief and finding a personal identity. *Journal of Music Therapy*, 36, 222-252.

- Stoddart, K. P., Burke, L., & Temple, V. (2002). Outcome evaluation of bereavement groups for adults with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 15, 28-35.
- Summers, S. J., & Witts, P. (2003). Psychological intervention for people with learning disabilities who have experienced bereavement: A case study illustration. *British Journal of Learning Disabilities*, 31, 37-41.
- Wigram, T. (1996). The effects of vibroacoustic therapy on clinical and non-clinical populations. Unpublished doctoral dissertation, St. George's Medical School, London University, United Kingdom.
- Wigram, T., McNaught, J., Cain, J., & Weekes, L. (1997) Vibroacoustic therapy with adult patients with profound learning disabilities. In T. Wigram, & C. Dileo (Eds.), *Music Vibration and Health* (pp. 157-167). Cherry Hill, NJ: Jeffrey Books.
- World Health Organization. (2000). Ageing and Intellectual Disabilities: Improving Longevity and Promoting Healthy Ageing: Summative Report. Geneva, Switzerland: World Health Organization.

Table 1. BPRS-DD Scores

Name	Pre-Test	Post-Test	Follow-Up
Mary	23	2	6
James	14	14	13
Nancy	2	2	2

Appendix A: Brief Psychiatric Rating Scale – Developmental Disabilities Version

BRIEF PSYCHIATRIC RATING SCALE (BPRS-DD) Short Form (Developmental Disabilities Version)

Name:	Date:	Rated By:	
choose the rating that you t week. Use this rating scale symptom is for this client c	hink best describes how below to choose your r compared to his/her peer	v severe that particular sympt ating for each item. When juc	the client over the past week. For each item, om has been for the client over the past dging severity, consider how severe the
Ratings:			
		B = moderate	
0 = not present		4 = moderately severe 5 = severe	
1 = very mild 2 = mild	6 = extrem	nely severe	
1. Anxiety/Tension			
anxious, worried, fearful, o			
appears uneasy; appears te	ense/nervous		
			()
does not relate to others; w		tuations; diminished or	
no response to social intera			()
appears sad, unhappy; crie			()
4. Unusual verbalizations	or Actions		()
unusual, odd, strange, biza	arre verbalizations or ac	tions, unusual mannerisms	
or postures			
			()
apparent lack of normal fe			
reduced emotional tone; la		of emotion	()
increased reactivity, heigh			()
boisterous: excessive talki	ng or smiling: appears r	pressured	
7. Disorientation		pressured	()
confusion: lack of proper a	association for person/p	lace/time	
8. Overactivity			
excessively active; on the	move		
9. Irritability			()
irritable mood; excessive,	easily provoked anger;	appears annoyed;	
impatient	lv		()
11. Compulsive / Ritualis	tic / Perseverative		()
apparently intentional, rep			
preoccupations (e.g. touch	ing, tapping, arranging,	hoarding), need for samenes	s
12. Hostility / Aggression	/ Destructive		()
acts aggressively towards	others; hostile; belligere	ent; destroys property	
13. Noncompliant / Unco	operative		()
resists daily living task der			
lack of readiness to cooper	ate with others		()
attempts to harm or injure			\mathbf{O}

TOTAL BPRS-DD SCORE-----()

Appendix B: Questionnaire

Please check "yes" or "no" for the following statements in reference to the client reviewed on the previous page. Please answer in reference to the period since the last assessment:

1. Has experienced a significant loss.	Yes	No
2. Has experienced a significant change (work, moved, etc.) If yes, please specify	Yes	No

Appendix C: Session Plans

ID & Bereavement Session 1 – Establishment of Therapeutic and Group Rapport

Experience 1 – Greeting Song

- 1. MT will sing to each participant and encourage the group to sing to each other and interact with peers.
- 2. Participants will be encouraged to share how they are feeling when it is their turn. Blues Hello (in E) Hello, [Name], it's so good to see you Hello, [Name], it's so good to see you Tell us... how are you?

Experience 2 – Getting to Know Each Other by Playing Together

Improvisation

- 1. MT will give participants choice of instrument (drums, shakers, tambourine, etc.).
- 2. Each person will have a turn to play their instrument for the group.
- The MT will facilitate a group improvisation over a steady beat (provided by the MT) and encourage everyone to play.

Experience 3 – What I Like

Discussion & Songwriting

- 1. The MT will lead a discussion about things that people enjoy (food, activities, etc.).
- 2. Answers will be used in the song below.
- 3. Participants will be encouraged to sing the chorus.
- To the tune of "Don't Worry, Be Happy" (in G)

Chorus:

Everyone has things they like,

From going to work to taking a hike,

How 'bout you...

What do you like?

Ooohh...

Verse
[Name] likes _____ and _____ and _____
[Name] likes _____ and _____ and _____
These are the things they like

Experience 4 – What to Expect Next Time

1. MT will give a brief description of the topic for the next session and ask if participants have any questions.

Experience 5 – Good-bye

1. MT will lead the group in singing the good-bye song. The verse will change each week to reflect what was done in that session.

"Music is Over" (Chorus to the tune of "We're Not Gonna Take It) (In B)

Chorus

Music is over

We'll see you next time

Music is over....

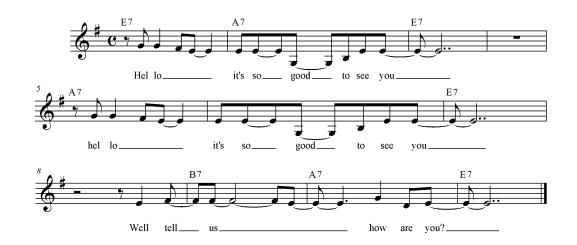
For today

We've shared some stories We've talked about what we like We've played together And now we're done...

Music is over We'll see you next time Music is over.... For today

Blues Hello

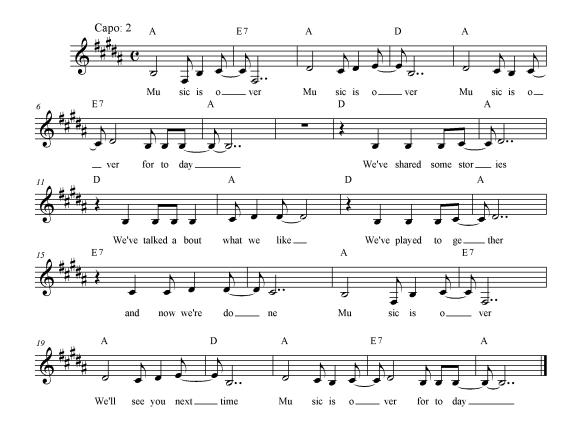
Jessica Hoyle



©2010

Music Is Over

Jessica Hoyle



©2010

ID & Bereavement Session 2 – Basic Education Regarding Death & Loss

Experience 1 – Greeting Song Same as Session 1

Experience 2 – When People We Love are No Longer with Us Book – *When Somebody Dies* (Hollins, et al., 2003) Discussion & improvisation

- 1. MT will lead the group in creating a story to match the pictures in the book, identifying the feelings felt by the main characters.
- 2. MT will lead discussion about how it felt for the characters to have someone they loved die.
- 3. The MT will model how to play a feeling using the drum.
- 4. Each person will be encouraged to choose a feeling and play that feeling on the drum.

Experience 3 – Turn, Turn, Turn

- 1. MT will pass out song sheets.
- 2. MT will talk about how there is a time for different events in life.
- 3. MT will lead the group in singing the song.
- 4. MT will encourage participants to talk about the song, and if there are any important parts of the song.

Experience 4 – What to Expect Next Time

1. MT will give a brief description of the topic for the next session and ask if participants have any questions.

Experience 5 – Good-bye Same as Session 1

ID & Bereavement Session 3 – Education of Death as a Normal Change

Experience 1 – Greeting Song Same as Session 1

Experience 2 – Turn, Turn, Turn

- 1. MT will ask participants what they remember from the last session, and will recap the session as needed.
- 2. MT will pass out words to "Turn, Turn, Turn."
- 3. MT will lead the group in singing "Turn, Turn, Turn."
- 4. After singing the song, MT will lead the group in discussion about the song.

Experience 3 – Changing Seasons

- 1. MT will lead discussion about what happens in different seasons.
- 2. MT will assist participants in using discussion to write song about changes that happen during the seasons, and how life continues after the winter (death).
- 3. Participant responses will be put into song to 12 bar blues pattern.

Experience 4 – What to Expect Next Time

1. MT will give a brief description of the topic for the next session and ask if participants have any questions.

Experience 5 – Good-bye

Same as Session 1

ID & Bereavement Session 4 – Recognition of Sorrow & Identification of Coping Skills

Experience 1 – Greeting Song Same as Session 1

Experience 2 – What Does it Mean to Miss Someone? (It's OK to cry)

- MT will ask participants how they express their sadness and if they felt sadness when their loved one died. "How do people know when you are sad?" (crying, not talking, not eating, easily angered, etc.) "Did you feel this way when your loved one died?"
- 2. MT will invite participants to play those feelings using the drum.
- 3. MT will invite participants to discuss other ways of expressing sadness. "What's another way people might know you are sad?" (i.e., tell a staff member).
- 4. MT will ask participants what kind of things helped them when they were feeling sad.
- 5. MT will talk to participants about what it means to have support.
- 6. MT will lead participants in a group improvisation reflecting sadness and support by inviting one person to play sadness and the rest of the group to provide support.

Experience 3 – Stand by Me (In G)

- 1. MT will ask a participant to pass out song sheets.
- 2. MT will lead the group in singing the original version of "Stand By Me" and will explain that we will sing the song again in the next session.

Stand by Me

When the night has come And the land is dark And the moon is the only light we'll see No I won't be afraid, no I won't be afraid Just as long as you stand, stand by me

So darling, darling, stand by me Oh, stand by me Oh, oh, stand, oh stand Stand by me

If the sky we look upon Should tumble and fall And the mountains should crumble to the sea I won't cry, I won't cry, no I won't shed a tear Just as long as you stand, stand by me

So darling, darling, stand by me Oh, stand by me Oh, oh, stand, oh stand Stand by me

Experience 4 – What to Expect Next Time

1. MT will give a brief description of the topic for the next session and ask if participants have any questions.

Experience 5 – Good-bye

Same as Session 1

ID & Bereavement Session 5 – Recognition of Sorrow & Identification of Coping Skills (continued)

Experience 1 – Greeting Song

Same as Session 1

Experience 2 – Discussion of Previous Session

1. MT will ask participants to share what they remember from the last session.

Experience 3 – Discussion of Memories

- 1. MT will give participants an opportunity to share any memories about their loved one's death.
- 2. MT will ask participants to identify feelings associated with the memories.

Experience 4 – Stand by Me (In G)

- 1. MT will ask a participant to pass out song sheets.
- 2. MT will lead the group in singing the original version of "Stand By Me."
- 3. MT will continue previous discussion of supports and ask who can be a support when participants are feeling sad.
- 4. MT will lead participants in a fill-in-the-blank rewrite of the song, "Stand By Me" using icons as needed.

Stand by Me

When the night has come And the land is dark And the moon is the only light we'll see No I won't be afraid, no I won't be afraid Just as long as you stand, stand by me

So darling, darling, stand by me Oh, stand by me Oh, oh, stand, oh stand Stand by me

If the sky we look upon Should tumble and fall And the mountains should crumble to the sea I won't cry, I won't cry, no I won't shed a tear Just as long as you stand, stand by me

So darling, darling, stand by me Oh, stand by me Oh, oh, stand, oh stand Stand by me Stand by Me Rewrite

When I'm feeling _____

And I _____

And I _____

I just might need _____

Oh I just might need _____

So won't you please, stand, stand by me

So darling, darling, stand by me

Oh, stand by me

Oh, oh, stand, oh stand

Stand by me

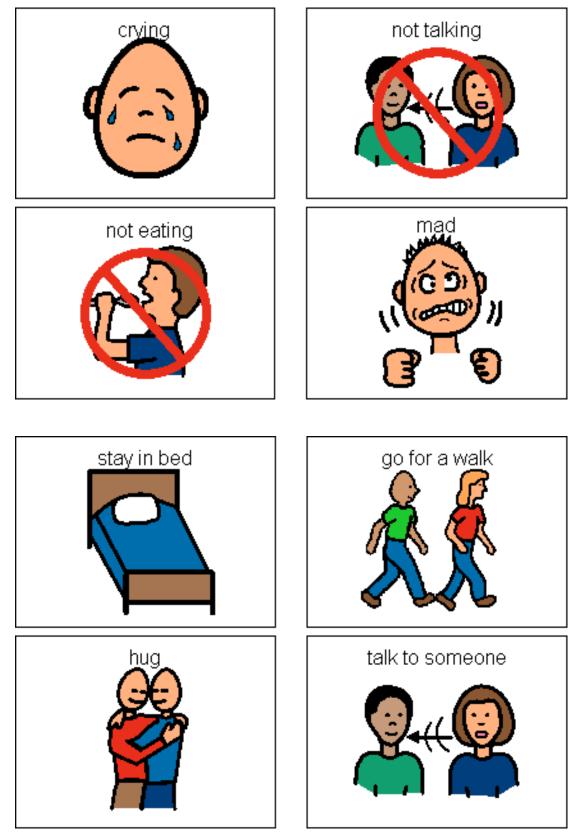
If you see me _____

And I'm

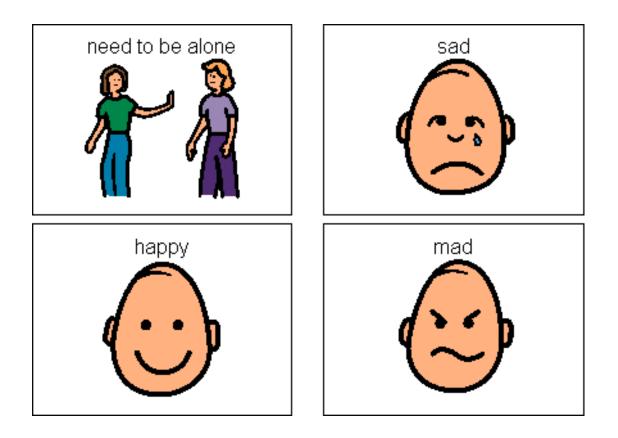
Then I need _____

I might cry, I might cry, yes I might shed a tear So won't you please, stand, stand by me

So darling, darling, stand by me Oh, stand by me Oh, oh, stand, oh stand Stand by me



Icons for "Stand by Me" Songwriting



Experience 4 – What to Expect Next Time

1. MT will give a brief description of the topic for the next session and ask if participants have any questions.

Experience 5 – Good-bye Same as Session 1

ID & Bereavement Session 6 – Recognition of Anger & Learning Safe Ways to Express Anger

Experience 1 – Greeting Song

Same as Session 1

Experience 2 – When I Get Mad... (Improvisation)

- 1. MT will ask participants to describe what they may do when they get angry.
- 2. MT will ask each participant to play "angry" using the drum.
- 3. After each participant has a turn, the group will play "angry" together.
- MT will ask participants for responses after playing (i.e., "How did that sound?" "How did you feel while playing?").

Experience 3 – What to Do When I'm Angry (Discussion)

- 1. MT will ask participants to share positive things they can do when they get angry.
- 2. These suggestions will be used in the next session for a songwriting experience.
- 3. Possibilities if participants need prompts:
 - a. talk to a friend you can trust
 - b. count to 10
 - c. get or give a hug
 - d. do jumping jacks or another exercise
 - e. draw a picture of your anger
 - f. sing along with the stereo
 - g. pull weeds in the garden
 - h. do something active

Experience 4 – What to Expect Next Time

1. MT will give a brief description of the topic for the next session and ask if participants have any questions.

Experience 5 – Good-bye Same as Session 1

ID & Bereavement Session 7 – Reinforcing Safe Ways to Express Anger

Experience 1 – Greeting Song Same as Session 1

Experience 2 – When I Get Angry (Songwriting)

- 1. MT will review coping skills shared in the last session.
- 2. MT will present icon cards representing destructive behaviors and coping skills.
- 3. MT will lead the participants in writing the song, "When I Get Angry," using the icons and original answers.
- 4. MT will lead the group in singing the song, and will repeat the song if needed.
- 5. MT will review coping skills after the song.

When I Get Angry (Em/D)

Em Am

There are times, when I get _____

B7 Em

And I just want to _____

Em Am B7 Em

But I know, that it won't help if I hurt myself or someone else

B7 Em

And so I might do these things instead:

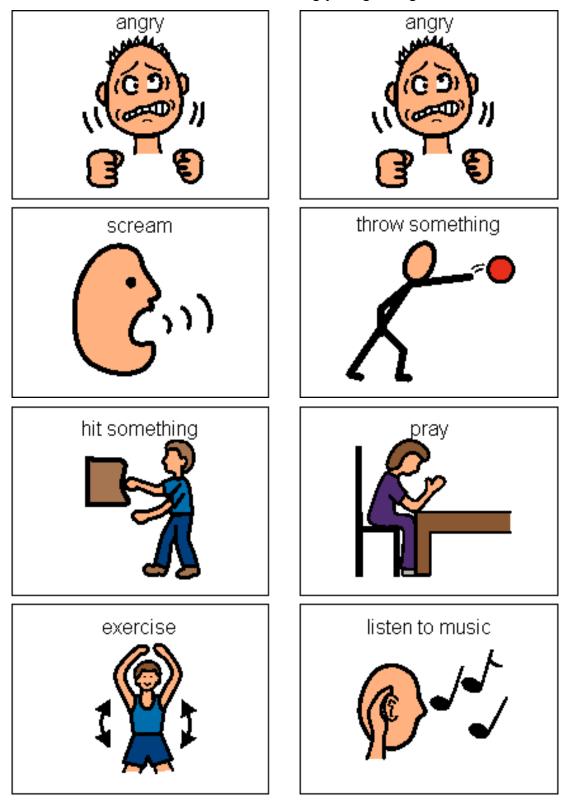
D	G			
I might		, or I could _		
D		G		
I could		, or		
D	G	A7	D	
I could		, I could even	1	
E	А			
Yes, there ar	e times, when I get _			
B7 E				

And now I know what I can do

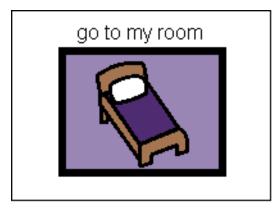
When I Get Angry

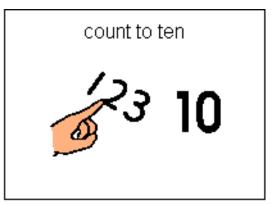


©2010



Icons for "When I Get Angry Songwriting"





Experience 4 – What to Expect Next Time

- 1. MT will give a brief description of the topic for the next session and ask if participants have any questions.
- 2. MT will remind participants that there are only 2 sessions left.

Experience 5 – Good-bye

Same as Session 1

ID & Bereavement Session 8 – Using Music to Memorialize Loved Ones

Experience 1 – Greeting Song Same as Session 1

Experience 2 – Remembering our Loved Ones (Discussion/Songwriting)

- 1. MT will ask participants to choose their favorite memory(ies) of their loved one(s) and share those with the group.
- 2. MTs will assist group members in writing individual verses for the song.
- 3. Group will sing the song and give each member an opportunity to share individual verses.

Experience 3 – Memorial CD (discussion/singing):

- 1. MT will ask participants to identify songs that remind them of their loved ones/give them comfort to be included on a CD.
- 2. If time, will sing some of the songs with the group.

Experience 4 – What to Expect Next Time

- 1. MT will give a brief description of the topic for the next session and ask if participants have any questions.
- 2. MT will remind group members that there is only 1 session left.

Experience 5 – Good-bye

Same as Session 1

ID & Bereavement Session 9 – Reinforcement of What Was Learned Previously and How to Progress

Experience 1 – Greeting Song

Same as Session 1

Experience 2 – CD Cover Decoration

- 1. MT will provide materials for participants to decorate cover of CDs as discussed in session 8.
- 2. MT will direct participants to decorate the covers in memory of their loved ones.

Experience 3 – Where Do We Go from Here? Discussion of Past Sessions/Identification of Positive Coping Skills

- 1. MT will lead participants in a brief discussion of past sessions (themes, etc.).
- 2. MT will lead participants in singing songs written/sung in past sessions.
 - a. Turn, Turn, Turn
 - b. Stand By Me
 - c. When I Feel Angry

Experience 5 – Good-bye

1. MT will lead the group in singing the good-bye song. The chorus is changed to reflect the end of the session series.

"Music Is Over" (Chorus to the tune of "We're Not Gonna Take It)

Chorus

Music is over

Music is over

Music is over....

Thank you for coming

 We've

 And

 And

_____....

Music is over

Music is over

Music is over....

Thank you for coming

Biographical Sketch

Jessica Newsome Hoyle was born in Goldsboro, NC on February 22, 1984. She graduated from Charles B. Aycock High School in Pikeville, NC in 2002. The following autumn, she entered Appalachian State University to study music therapy, and in August 2006, she was awarded the Bachelor of Music degree, *magna cum laude*, following completion of a 6-month internship at Broughton Hospital in Morganton, NC. She served as music therapist and activities director at Valley Nursing Home in Taylorsville, North Carolina from August 2006 to November 2007, when she accepted a position as Creative/Expressive Arts Therapist (Music Therapist) at J. Iverson Riddle Developmental Center in Morganton, NC. In August 2008, she began study toward a Master of Music Therapy degree, which she completed in August 2010 while continuing full time employment at J. Iverson Riddle Developmental Center.

Mrs. Hoyle is a member of the Cratis D. Williams Society, Alpha Epsilon Lambda, Alpha Chi, and Pi Kappa Lambda. Her professional memberships include the American Music Therapy Association, the Southeastern Region of the American Music Therapy Association, and Music Therapy Association of North Carolina, of which she is presidentelect. Her home address is 1309 Murray Place, Lenoir, NC. She is married to Mr. Jason C. Hoyle. Her parents are Mr. and Mrs. Mark Newsome of Goldsboro, NC.