# Potential for Music Therapy Intervention with Family Caregivers of Adults with an Intellectual Disability: A Survey Study

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## ABSTRACT

**Potential for Music Therapy Intervention with Family Caregivers of Adults with an Intellectual Disability: A Survey Study**

Karli Purscell

The purpose of this survey was to investigate the extent to which professional music therapists in North America are working with family caregivers of adults with an intellectual disability (ID), the nature of the work they are doing, and their perspectives on the types of music therapy services that would best serve this population. The survey was sent to 6083 Canadian and American music therapists. A total of 309 music therapists who fit the criteria for inclusion responded. Eighty-three percent of respondents had some kind of contact with family caregivers. More specifically, 190 respondents reported family caregivers were present during sessions but not as clients, 40 indicated that they provided services where family members and adults with an ID were in sessions together as clients, and 19 indicated that they provided services that focused solely on the needs of these family caregivers. Behavioral music therapy was the approach being used most often in most contexts. However, when providing direct services for family caregivers, the music therapy approaches being used and recommended music experiences often fell outside of a behavioral model. Participants' written comments and quantitative responses indicate that there is potential and desire to provide more formalized music therapy services and supports to family caregivers. Limitations of the study as well as implications for music therapy research and practice are presented.

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# Chapter 1. Introduction

Over the last five decades, deinstitutionalization initiatives in the United States and Canada have shifted the responsibility of care for adults with an intellectual disability (ID) from residential institutions to families and communities (Cushing & Lewis, 2002; Farnan, 2007; Lord & Hearn, 1987; Ontario Ministry of Community and Social Services, 2012; Perkins, 2009). Although many aspects of deinstitutionalization have been positive for persons with an ID (e.g., increased personal autonomy, improved quality of life, better integration into communities), this shift in responsibility and subsequent decentralization of services has placed additional strain on families, as there are many challenges associated with providing lifelong care for these individuals (Morgan, 2010; Taylor & Hodapp, 2012). In addition to having to cope with complex behaviors and changing needs of their family member over time, family caregivers of an adult with an ID may struggle with increased stress, decreased leisure time, and limited financial resources (Cramm & Nieboer, 2011; Hastings & Lloyd, 2007; Paster, Brandwein, & Walsh, 2009). As a child with an ID transitions into adolescence and adulthood, roles and role expectations change for both the family caregivers and the person with an ID (Hill-Weld, 2011; Minnes, Woodford, & Passey, 2007; Papay, 2011). This can escalate stress, which in turn may result in dysfunctional family patterns (Hill-Weld, 2011). Furthermore, as the person with an ID and the family caregiver age, physical care challenges may also increase (Cramm & Nieboer, 2011; Hill-Weld, 2011; Minnes et al., 2007). Finally, family caregivers may need to assume complex advocacy roles as they interact with a wide variety of professionals and policymakers who have the power to make decisions that may profoundly impact their lives and the lives of their loved ones (Fidell, 2000; Morgan, 2010).

I first developed a heightened awareness of the needs of caregivers when working as a music therapist at several community organizations as well as at a state institution for adults who had an ID. In those places, I had the opportunity to interact with both family and professional caregivers. Family caregivers sometimes attended their loved ones' music therapy sessions. During these sessions, I noticed how the act of making music together seemed to provide a forum where both parties could engage and interact in new and constructive ways. Although these sessions were focused on meeting the needs of the adults with an ID, I also noticed that the family caregivers also seemed to benefit. For example, they often appeared to relax during the sessions, interacted in more meaningful ways with their family members (e.g., shared stories,

made music together), and spoke to me about the joys and challenges of caregiving. Given the limits of my role (i.e., I was hired only to provide services to persons with an ID), I was unable to further explore or directly address the needs of these family caregivers. However, I began to wonder how music therapy interventions might be used more directly and specifically to support these individuals.

A review of the literature indicated that various types of support services have been developed for family caregivers at large. These include telephone help lines, in-home nursing consultations, and respite care services (Reinhard, Given, Petlick, & Bemis, 2008). Specialized support services have also been developed for families of persons with an ID. These include financial supports, household management services (e.g., house cleaning, caregiving skills development), behavioral consultation and supports, environmental adaptations, and mental health services (Rizzolo, Hemp, Braddock, & Schindler, 2009). However, the literature also indicated that the services being provided to these family caregivers are not as comprehensive as they should be in order to adequately address their complex and multifaceted needs (Cramm & Nieboer, 2011; Hooyman & Gonyea, 1995; Morgan, 2010; Rizzolo et al., 2009). Furthermore, there is very little research to support the effectiveness of specific caregiver support models including psychological interventions and caregiver skills training (Families Special Interest Research Group of IASSIDD, 2014; Marshall & Ferris, 2012). Therefore, it appears that more research is needed to better understand the types of support services that would most effectively address the unique needs of family caregivers who care for adults with an ID.

The literature review also revealed that music therapy intervention has been used with a variety of family caregiver populations. These include caregivers of: (a) persons with dementia (Baker, Grocke, & Pachana, 2012; Hammar, Emami, Engström, & Götell, 2011; Hanser, Butterfield-Whitcomb, Kawata, & Collins, 2011; Klein & Silverman, 2012; Narme et al., 2014); (b) persons receiving end of life care (Choi, 2010; Magill, 2009; O'Callaghan, Hudson, McDermott, & Zalcberg, 2011; Stewart et al., 2005); (c) persons with cancer (Dvorak, 2012); (d) young children at risk (i.e., early intervention programs; Edwards, 2011; Pasiali, 2010); and (e) children with an ID (Bull, 2008; Gilboa & Roginsky, 2010; Loth, 2008). Overarching goals of music therapy interventions for these family caregivers included: (a) reducing stress and burden related to caregiving (Choi, 2010; Dvorak, 2012; Hammar et al., 2011; Magill, 2009; Narme et

al., 2014); (b) addressing social stigma (Bull, 2008; Magill, 2009); (c) developing parenting skills (Pasiali, 2010; Thompson, 2012); (d) improving communication between caregivers and their loved ones (Decuir, 1991; Hammar, et al., 2011); (e) enhancing quality of life (Choi, 2010; Dvorak, 2012); and (f) facilitating healthy attachment between the care recipient and the caregiver (Archer, 2004; Bull, 2008; Loth, 2008; Oldfield, 2011; Pasiali, 2010; Thompson, 2012). However, no literature was found indicating that music therapy interventions were being used with family caregivers of adults with an ID.

Given that music therapy appears to be perceived positively as a mode of intervention for family caregivers at large and that it has potential to address identified needs of family caregivers of adults with an ID, it seems that music therapy programs should be developed for this population. However, the current author also suspected that music therapists may in fact be offering programs for family caregivers of adults with an ID and were simply not publishing this information. Finally, music therapists who work with adults with an ID and interact with family caregivers may have informed perspectives on what kinds of music therapy services or interventions might be most beneficial for these caregivers. Therefore, the purpose of this survey study was to investigate the extent to which professional music therapists in North America are working with these family caregivers, the nature of the work that they are doing, and their perspectives on the types of music therapy services that they feel would best serve this population.

**Research Questions**

The primary research question for this study was: How can music therapy be used with family caregivers of adults with an intellectual disability (ID)? Subsidiary research questions were: (a) To what extent is music therapy being used with family caregivers of adults with an ID?; (b) What specific music therapy programs or interventions are being used with family caregivers of adults with an ID?; and (c) In addition to services being offered, what other kinds of music therapy programs or interventions could potentially be of benefit to family caregivers of adults with an ID?

**Operational Definitions**

Within the context of this study, an ID was defined as "a disorder with onset during the developmental period that includes both intellectual and adaptive functioning deficits in

conceptual, social, and practical domains" (American Psychiatric Association, 2013, para. 10). An adult with an ID was defined as a person of 21 years of age or older who meets the diagnostic criteria for an ID as described above. A primary family caregiver was defined as any family member who provides a significant amount of the care and support (i.e., participates in or supervises activities of daily living several times per week) to an adult relative with an ID within a home or in an institutional environment. A family member may include, but is not limited to a parent, grandparent, or sibling.

**Overview of Chapters**

Following the Introduction, which outlines the significance and need for the current research, Chapter Two will review relevant literature in order to provide a detailed account of what is known about the general and specific topics related to the study. Chapter Three will describe the participants, as well as the data collection and data analysis procedures. Chapter Four will present the results of the survey. Finally, Chapter Five will present interpretations of the findings and limitations of the study as well as potential implications for clinical practice and research.

## Chapter 2. Literature Review

As discussed in Chapter One, music therapy appears to be perceived positively as an intervention for family caregivers at large but no publications were found on the use of music therapy interventions for family caregivers of adults with an ID. The literature does indicate, however, that other types of support services are being provided for these individuals. The purpose of the present chapter is to examine current literature and summarize information related to the topic of the present study. Information categories include: the needs and challenges of adults with an ID, the needs and challenges of family caregivers of adults with an ID, music therapy interventions that address the needs of family caregivers at large, and interventions for families that include an adult with an ID.

### Needs and Challenges of Adults with an Intellectual Disability

**The transition into adulthood.** As previously noted, adults with an ID have unique needs as compared to children with an ID. Life transitions, especially the transition from adolescence to young adulthood, are associated with many complicated challenges including role changes, physical changes, and increased family stress. These challenges can eventually lead to dysfunctional family patterns where the person with an ID may have increased anxiety and begin to develop behavioral and emotional disturbances (Hill-Weld, 2011; Larkin, Jahoda, MacMahon, & Pert, 2012; Minnes et al., 2007; Papay, 2011; Steinhausen, Eiholzer, Hauffa, & Malin, 2004). Research has also suggested that older adolescents with an ID transitioning from school into a different way of life may be in a sensitive developmental period, as there is a higher incidence of mental health issues in this population of adolescents compared to the general population (Hepper & Garralda, 2001; Masi, 1998). In the United States, transition planning services are legally required as part of the special education programs for students with an ID when they reach the age of sixteen (Papay, 2011). A supportive home environment and quality transition planning may serve to prevent mental health issues as persons with an ID transition out of school (Hepper & Garralda, 2001). However, it is important to note that once a person with an ID reaches 21 years of age, he or she is typically no longer eligible for any special education services.

**Support services.** Some services such as daytime activities, future planning services, vocational training, residential services, and financial services may be available to adults with an

ID, but they may not address complex issues such as behavioral concerns, major physical or mental health needs, and challenges with adaptive functioning (Lunsky, Tint, Robinson, Gordeyko, & Ouellette-Kuntz, 2014; Taylor & Hodapp, 2012). Furthermore, support services are often poorly funded and inconsistently administered (Haveman, Van Berkum, Reijnders, & Heller, 1997; Hooyman & Gonyea, 1995; Morgan, 2010). This leaves those who are not eligible for services increasingly dependent on family members for support (Haveman et al., 1997; Hepper & Garralda, 2001; Morgan, 2010).

**Impact of stigma on service delivery.** Adults with an ID may experience stigmatization from the community at large. They may be seen by members of society as being less worthy than others as they are often unable to follow life changes and experiences in the same way as typically-developed adults or achieve the expected societal standards of success (Cushing & Lewis, 2002; Snow, Snow, & D'Amico, 2008). Research has suggested that a large percentage of the population in the United States holds negative implicit attitudes toward people with an ID, which may influence the quality of care and impede service delivery (Wilson & Scior, 2014). Implicit discrimination on the part of local government and community agencies can result in bureaucratic decisions being made without consideration of the full range of impacts on persons with an ID (Morgan, 2010). Professionals may unnecessarily limit these individuals' life options in transitional service planning because of these attitudes (Papay, 2011; Wilson & Scior, 2014). For persons with an ID, this experience of stigma may cause increased aggression and mental health issues, which in turn may impact family caregivers (Larkin et al., 2012).

**Needs and Challenges of Family Caregivers of Adults with an Intellectual Disability**

The needs and challenges of family caregivers of persons with an ID are intertwined with those of their loved ones. These include challenges related to caregiving, societal stigma, and the cyclical nature of distress.

**Challenges of caregiving.** Providing care for an adult with an ID is often accompanied by numerous challenges as care-recipients may have complex care needs and exhibit challenging behaviors (Taylor & Hodapp, 2012). These family caregivers must also manage multiple stressors such as scheduling therapy and treatment for their loved one, adjusting to physical demands related to care, and processing complex emotions that arise knowing that their family member's life will not follow a *normal* trajectory (Fidell, 2000; Haveman et al., 1997; Paster et

al., 2009). Caregivers providing lifelong care to a person with an ID may also struggle economically due to the costs of treatment and care (Cramm & Nieboer, 2011; Families Special Interest Research Group of IASSIDD, 2014).

Some parental family caregivers may be at risk of failing to develop a strong attachment with their child as the nature of the child's disability may affect social interactions, which could potentially develop into negative outcomes (e.g., depression, early out-of-home placement) for both the caregiver and their family member with an ID (Haveman et al., 1997; Janssen, Schuengel, & Stolk, 2002). The concept of attachment could be applied to most primary caregivers as secure or insecure attachment relationships may have an impact on caregivers and persons with an ID (Watson, 2014). Although little research has been completed about attachment between caregivers of adults with an ID and care-recipients, Watson (2014) briefly described attachments fostered in music therapy between a young woman with an ID and her professional caregivers. Through improvisational experiences, the young woman was able to improve communication skills while strengthening her relationships with her caregivers.

Because of these challenges associated with caregiving, family caregivers have specific needs which may include: (a) financial assistance to provide the necessary care for their loved one, (b) opportunities to help them adapt to their role as a caregiver such as emotional support or caregiver education, (c) opportunities for self-care which may include a variety of therapeutic or leisure activities, and (d) more preventative type services rather than crisis-related services (Families Special Interest Research Group of IASSIDD, 2014; Haveman et al., 1997; Lunsky et al., 2014).

**Societal Stigma.** Just as adults with an ID may face marginalization and discrimination due to their disability, family caregivers may also find themselves being stigmatized. Furthermore, the experience of stigma toward persons with an ID can cause strain for these family caregivers as they must constantly advocate for high quality, safe, and appropriate services (Morgan, 2010). Government and organizational policies tend to favor organized community services over individualized support as these services are perceived as being more cost effective and efficient. A lack of individualized services can prevent individual caregivers from accessing needed respite and support that could mitigate or prevent financial, physical, and mental health issues (Hooyman & Gonyea, 1995; Morgan, 2010). Also, due to gender roles and

societal expectations, the majority of primary familial caregivers are women and research indicates that society frequently undervalues the care that is provided by women (Cushing & Lewis, 2002; Morgan, 2010; Talley & Montgomery, 2013). As a result of internalized stigmatization, female caregivers may ignore their personal needs and be less likely to access formal services such as mental health programs or respite care to address issues related to caregiver burden (Hooyman & Gonyea, 1999; Talley & Montgomery, 2013).

**The cyclical nature of distress.** While caregiver burdens impact the health and well-being of the caregivers, they also impact the behavior of the care-recipients with an ID (Abosh & Collins, 1996; Archer, 2004; Cramm & Neiboer, 2011; Hastings & Lloyd, 2007). Archer (2004) posited that, "The stressed relationship is also cyclical: high parent stress contributes to a worsening in child behavior problems, and extreme child behavior problems contribute to a worsening in parent stress" (p. 38).

The cyclical nature of distress that occurs between the family caregiver and the care-recipient with an ID indicates a need for supportive measures that teach caregivers (and adults with an ID) constructive coping skills. According to Paster, Brandwein, and Walsh (2009), coping is "what people do to manage stressful events or situations in their lives" (p. 1338). Coping strategies can involve problem-solving, learning to manage stress, reinterpreting stressful experiences, and developing a strong functioning family system (Gavidia-Payne & Stoneman, 1997; Minnes et al., 2007). This last point is especially important in that strong, supportive family connections have been found to be useful in mitigating the effects of depression on caregivers, decrease their reliance on services, and decrease their perceived caregiver burden (Losada et al., 2010; Morgan, 2010).

Although opportunities for informal social supports and interactions are crucial in decreasing distress and preventing mental health issues in family caregivers (Cramm & Nieboer, 2011; Dempsey, Keen, Pennell, O'Reilly, &Neilands, 2009; Perkins, 2009), more formalized support initiatives are needed to address the complex needs that may arise as part of providing lifelong care (Haveman et al., 1997; Talley & Montgomery, 2013) because long-term caregiving may break down some caregivers' social networks and support systems (Hooyman & Gonyea, 1999). Furthermore, more research on the effectiveness of these formalized support initiatives is

needed in order to provide the most effective support services possible (Families Special Interest Research Group of IASSIDD, 2014; Lunsky et al., 2014).

## Music Therapy Interventions for Family Caregivers

As noted in Chapter One, although the literature does not contain specific information on music therapy interventions for caregivers of adults with an ID, a variety of music therapy interventions have been developed for family caregivers of other populations. Music therapy interventions for caregivers whose needs seem most similar to the current study's population will be reviewed in this section as they may have relevance for the current study.

**Early childhood intervention.** Early childhood intervention is defined as "the provision or mobilization of supports and resources to families of young children from informal and formal social network members that either directly or indirectly influence and improve parent, family, and child behavior and functioning" (Dunst & Trivette, 2009, pp. 126-127). Five key elements are involved in family-based early childhood interventions which include: (a) a perspective that views the family within a social system, (b) an emphasis on empowerment, (c) strengths-based services, (d) social support, and (e) an emphasis on professionals providing help rather than being in an expert position (Dunst & Trivette, 2009).

Since early childhood intervention is multidisciplinary and the importance of music is widely recognized in child development, music therapy has often been used as a part of early childhood intervention. An example of this is *Sing and Grow*, a program developed in Australia in 2001, which addresses developmental, behavioral, social, and communication needs of young children (Nicholson, Berthelsen, Abad, & Williams, 2008). While it has successfully been used to target the needs of children, it has also been used as a parenting intervention to address parenting skills such as self-confidence in parenting, bonding with their child, and emotional responsiveness (Nicholson et al., 2008; Williams, Berthelsen, Nicholson, Walker, & Abad, 2012). Other music therapy programs have emphasized the parent-child relationship within sessions as the parent's participation can model positive interactions and parenting skills, motivate children to participate, reduce anxiety for both parties, and improve parents' self-esteem (Archer, 2004; Thompson, 2012). The family caregiver needs addressed within early intervention music therapy treatment contexts are similar to some of the needs of family

caregivers of adults with an ID thus indicating potential for music therapy intervention with this study's targeted population.

**Children's mental health.** Based loosely on Alvin's model of *Free Improvisation Therapy* (Bruscia, 1987), Oldfield (2006) has developed a model entitled *Interactive Music Therapy,* where children who have psychiatric issues and their parents improvise music together. Here, the non-verbal musical exchanges form the basis of the therapy, which Oldfield (2006) refers to as a positive approach "because I am focusing mostly on the enjoyable, playful and motivating force of music making" (p. 18). Improvisational conversations are encouraged between the parent and child, and the music therapist serves to adjust and support these developing relationships. This model of music therapy illustrates that music can be a motivating force that encourages positive interactions between children with psychiatric issues and their family caregivers. It seems feasible that a similar model could be developed to encourage positive (yet age appropriate) interactions between adults with an ID and their family caregivers.

**Chronic care.** Similar to family caregivers of persons with an ID, family caregivers of persons with chronic diseases such as dementia and cancer may end up providing care for long stretches of time. Developing coping skills is crucial in preventing mental health issues for many caregiver populations in general, but this is especially true in long-term caregiving situations. Music therapy techniques in chronic care have been created to facilitate these coping skills. For example, songwriting interventions may be an effective way of allowing caregivers of persons with dementia to develop insight and understanding of their self-care needs and how they might address those issues (Klein & Silverman, 2012). Some caregivers of cancer patients have reported using music as a strategy in their lives to serve specific purposes such as dealing with emotions, releasing stress, and dealing with the demands that come with the care-giving role (O'Callaghan et al., 2011). It has also been suggested that music-based strategies could be developed for use in the home environment for direct care tasks, such as dressing or bathing, to help improve communication and cooperation (Engström, Hammar, Williams, & Götell, 2011; Hanser et al., 2011; O'Callaghan et al., 2011). Music may be particularly beneficial for developing coping skills as it can bring out responses that might otherwise be hidden especially where the societal expectation is often for a caregiver to hide challenges (Bright, 2006).

**End-of-life care.** End-of-life care is unique in that the goals often target both the person receiving services and the family members who are impacted by the impending death of their relative. In keeping with this philosophy, music therapy interventions have been developed to specifically address the needs of family caregivers of persons receiving end-of-life care. These may include sharing songs, family group activities, and creating compositions, song diaries, legacy works, or music recordings (Magill, 2009; Tung, 2014). Interventions may be tailored to empower caregivers, increase resiliency, address trauma, decrease stress, address feelings of grief, improve quality of life, reduce fatigue, and mitigate distress (Choi, 2010; Magill, 2009; Stewart et al., 2005; Tung, 2014). Again, the areas of need targeted by these interventions are similar to those of family caregivers of adults with an ID.

**Interventions for Families that Include an Adult with an Intellectual Disability**

The literature indicates that the field of family therapy is providing some support services for this population. An understanding of these services may help to indicate how music therapy may address current gaps in services or enhance services that are being provided specifically to families at large that may include family caregivers.

**Family therapy.** A few articles have discussed the use and benefits of family therapy for families that include persons with an ID (Fidell, 2000; Hill-Weld, 2011). However, stigmatization of persons with an ID has resulted in limited formal supports for adults with an ID and their families; in other words, they have been largely ignored by the psychotherapeutic community (Fidell, 2000; Hill-Weld, 2011). Nonetheless, other writings indicate the potential application of family therapy models for families caring for an adult with an ID. Fidell (2000) indicated that family therapy would be helpful for this population as it could address issues related to loss, life transitions, issues with professional systems, and over- or under-protection of the person with an ID. Fidell (2000) further explained adaptations can be made to family therapy models to better incorporate adults with an ID into the sessions. These adaptations could include using materials that take into account both mental age and chronological age of the person with an ID, slowing the pace of therapy, using non-verbal activities such as art making, using pictures to facilitate conversations, and collaborating more actively with caregivers (Baum, 2007; Fidell, 2000).

One goal often addressed in family therapy is communication as challenges with communication can develop into dysfunctional family patterns (Banmen & Maki-Banmen, 2014; Rasheed, Rasheed, & Marley, 2011). Music therapy might work well to help address this issue within family therapy as music making inherently requires both verbal and non-verbal communication skills (Rasar, 2010).

**Systemic family therapy.** One perspective within family therapy that may be especially useful with this population is *Systemic Family Therapy* (Winek, 2010). Persons with an ID often end up living with their family or in group settings for much of their lives (Hill-Weld, 2011). As a result, these individuals often rely on and interact with many different people including family members, housemates, staff, professionals, and case workers (Hill-Weld, 2011). A systemic approach emphasizes discovering and thinking about the systems that affect the person and working within those systems to address the issue. Since caregivers often become experts of their own system, they could be empowered to become the problem-solvers in this type of therapy setting (Baum, 2007). Also, because of the cyclical nature of caregiver distress and care recipient behavior (as described above), involving the whole family could interrupt the process and allow the entire family to develop skills that would help them to better problem-solve and cope with issues that arise (Dempsey & Keen, 2008; Hill-Weld, 2011). Because *Systemic Family Therapy* emphasizes that the therapy session is a neutral medium through which family patterns are changed without judgment (Goldenberg & Goldenberg, 2008), music making may be helpful in creating this type of environment as it involves primarily nonverbal communication, group collaboration, and listening (Rasar, 2010).

## Summary

In summary, adults with an ID have a wide range of needs and challenges that include complicated life transitions, limited access to quality support services, and the experience of stigma in their daily lives. As a result of addressing the complex needs of their loved ones as well as facing associated challenges (e.g., financial, physical and emotional stressors), family caregivers of persons with an ID also need specially tailored support services. The literature contains examples of support initiatives that have been implemented with family caregivers of adults with an ID. However, the efficacy of many of these initiatives has not been investigated fully and areas of need are not always addressed in a comprehensive manner. Although music

therapy appears to have been used successfully with other caregiver populations, the researcher found no publications on the use of music therapy intervention with the targeted population. The current research set out to discover if music therapists are in fact working directly or indirectly with family caregivers of adults with an ID, and if so, what kinds of work they are doing. Music therapists' perspectives on the kinds of programs or interventions that they thought would be most beneficial for this population was also explored.

## Chapter 3. Methodology

### Participants

The *Invitation to Participate in a Music Therapy Survey* (see Appendix A) was sent via e-mail to 5,633 Board Certified Music Therapists (MT-BCs) using a list of e-mail addresses provided by the Certification Board of Music Therapists (CBMT; based out of the United States). The Canadian Association for Music Therapy (CAMT) distributed the same invitation via e-mail on behalf of the researcher to 449 Accredited Music Therapists (MTAs). There were two criteria for inclusion: (a) participants had to be a certified music therapist (MTA or MT-BC) in good standing, and (b) they had to have worked as a music therapist within the last 10 years with adults who had an ID. Participants were not required to have had direct experience working with family caregivers of adults with an ID.

### Materials

A descriptive survey method was employed, as it can be an effective way to gather facts, track behavior, and determine the opinions of a population (Gillham, 2008). The researcher developed a survey to gather information on how music therapy is being used and potentially can be used with family caregivers of adults with an ID (see Appendix B). Drafts of the survey were reviewed by the research advisor and by a Creative Arts Therapist who had expertise in survey development. The survey was revised according to their feedback.

The final version of the survey consisted of 28 questions. The first 11 questions gathered relevant demographic data. Questions 12 to 21 gathered categorical and free response data pertaining to music therapy approaches, clinical goals, and music experiences that respondents had used with family caregivers of adults with an ID in three different music therapy treatment contexts: (a) sessions where family caregivers were present but not considered to be clients, (b) sessions where family caregivers and the adults with an ID were present and both were considered to be clients, and (c) music therapy sessions where family caregivers were the primary clients and their loved ones with an ID were not present. Finally, questions 22 to 28 gathered categorical and free response data where respondents provided their perspectives on the types of music therapy approaches, experiences, and interventions that they felt would best serve the targetted population in the three contexts outlined above. Respondents could skip any question (other than two questions pertaining to criteria for inclusion). Missing data were taken

into account during the data analysis (i.e., when applicable, frequencies rather than percentages were cited as the total number of respondents for each question varied).

**Procedures**

Ethics approval for this study was obtained from Concordia University's Human Research Ethics Committee (UHREC) prior to any data collection or recruitment procedures. The survey was posted via the website host SurveyMonkey for the data collection process. An e-mail message was sent out to the certified members of the CBMT and the CAMT that included a detailed explanation of the study's intent and criteria for participation, along with an invitation and instructions on how to access the consent form and web-based survey. Once potential participants clicked on the link contained in the invitation, they were immediately directed to a consent form, which preceded the survey. Participants were asked to mark that they had read, understood, and consented to participate in the study (see Appendix C). Accessing and completing the survey further confirmed each individual's informed consent to participate. If a participant did not submit the survey, the researcher did not have access to this data. No personal identifying information was stored with the survey responses. Survey respondents were asked to withhold any identifying information in the open-ended questions and no identifying information was included in the analysis or final report.

**Data Analysis**

The survey was kept open for two weeks, and then closed by the researcher. The responses were saved via SurveyMonkey in a secure, password protected location. The researcher downloaded and saved the responses in Excel files onto two external hard drives that were stored in a locked box. The Excel file was then uploaded into an SPSS program file for statistical analysis. This file was saved on the two external hard drives stored in the locked box. All printed materials were kept in a locked filing cabinet. Only the researcher, thesis supervisor, and statistical consultants had access to the anonymous survey data.

A preliminary review of the raw data revealed some discrepancies. Based on responses to demographic questions it appeared that five respondents did not fit the criteria for inclusion as they indicated that they had not worked with adults with an ID. Their responses were subsequently removed from the data set. One data point pertaining to the total number of clients served by the respondent within the last ten years was identified as an outlier given how much

larger the number was compared to the sample mean (i.e., serving 2240 clients with an ID in the last ten years as compared to the sample mean of 60.9 clients) As this outlier did not seem like a feasible response, it was removed from the data set. Finally, Question 8 on the survey asked respondents to give their best estimate of how many years, out of the last 10 years, they had been working professionally with adults with an ID. Eight respondents gave an answer that exceeded 10 years. These responses were changed to 10 so that they could be included in the analysis. Following these adjustments, descriptive statistics of the revised data set were obtained.

Qualitative free response data were also reviewed and organized according to each corresponding survey question to assist in the interpretation of the quantitative results.

## Chapter 4. Results

The survey was sent via e-mail to a total of 6083 music therapists that included 5633 MT-BCs and 449 MTAs. A total of 381 music therapists initially responded to the survey, however only 309 met the criteria for inclusion resulting in a response rate of 5.08%. Respondents were given the opportunity to skip any question and the missing data were taken into account in the data analyses (i.e., when applicable, frequencies rather than percentages were cited as the total number of respondents for each question varied).

### Demographic Characteristics

The average age of respondents was 37 years ($SD$ = 12.4, $n$ = 297). Twelve respondents did not indicate their age. The respondents had an average of 10.7 ($SD$ = 10.6, $n$ = 299) years of professional experience with a range of 0.2 to 53 years of experience. Ten respondents did not indicate their years of professional experience. Table 1 contains frequencies and percentages pertaining to other demographic characteristics.

**Table 1**

*Demographic Characteristics of Survey Respondents*

| Variable | *n* | *f* | % |
|---|---|---|---|
| Professional Credentials | 309 | | |
| MT-BC | | 283 | (91.6) |
| MTA | | 24 | (7.8) |
| Both MT-BC and MTA | | 2 | (0.6) |
| Gender | 305 | | |
| Male | | 28 | (9.2) |
| Female | | 273 | (88.5) |
| Other | | 1 | (0.3) |
| Prefer not to say | | 3 | (1.0) |
| Level of Music Therapy Education | 303 | | |
| Bachelor of Music Therapy | | 166 | (54.8) |
| Equivalency Diploma | | 26 | (8.6) |
| Master's degree | | 103 | (34.0) |
| Doctorate/PhD | | 8 | (2.6) |
| Region | 302 | | |
| Great Lakes | | 66 | (21.9) |
| Mid-Atlantic | | 57 | (8.9) |
| Midwestern | | 29 | (9.6) |
| New England | | 10 | (3.3) |
| Southeastern | | 36 | (11.9) |
| Southwestern | | 30 | (9.9) |
| Western | | 40 | (13.2) |
| Atlantic Provinces | | 2 | (0.7) |
| Ontario | | 8 | (2.6) |
| Quebec | | 2 | (0.7) |
| Prairie Provinces | | 9 | (3.0) |
| British Columbia | | 5 | (1.7) |
| Canadian Territories | | 0 | (0) |
| Prefer not to say | | 8 | (2.6) |

In meeting the criteria for inclusion, all 309 respondents had provided services to adults with an ID within the last ten years. The 265 respondents who answered the question about years of experience working with adults with an ID indicated that they had worked with adults with an ID for an average of 4.4 years (*SD* = 3.5; *n* = 265). Respondents who answered the question about the number of clients with an ID that they had served in the last ten years indicated that they had, on average, served 60.9 individuals with an ID (*SD* = 104.1; *n* = 259).

Eighty-three percent (*frequency* = 220) of those who responded to the question about level of contact with family caregivers (*n* = 265) indicated they had some level of contact with family caregivers of adults with an ID, and 45 respondents (17%) reported no contact with family caregivers. Also, 159 of these respondents (60%) reported that family caregivers were

present in music therapy sessions whereas 106 respondents (40%) reported that family caregivers were not present during music therapy sessions.

Participants' written comments indicated that the level of participation of family caregivers present in sessions varied. Some reported that family members did not participate in sessions but observed only. Reasons given for this included: waiting for their family member, being present in case of emergency, helping their family member transition into music therapy, and witnessing changes and development in their loved one. When caregivers did participate in sessions, respondents indicated that they often had specific roles within the session. These included learning skills and techniques for use outside of the music therapy context or helping their loved one to work on music therapy goals related to family interactions outside of the music therapy setting.

**Music Therapy Services Being Provided**

Respondents who indicated that family members were present during sessions were asked to indicate what kind of services they provided when family caregivers of adults with an ID were present in music therapy sessions. As respondents were asked to select all responses that applied, percentages were calculated according to the total number of respondents who participated in this survey ($n$ = 309). Table 2 provides an overview of these responses.

**Table 2**

*Music Therapy Services Provided When Family Members Present*

| Variable | *n* | *f* | % |
|---|---|---|---|
| | 309 | | |
| Individual sessions: Adult with an ID is primary client; family caregiver(s) present but not considered to be clients | | 114 | (36.9) |
| Group sessions: Adults with an ID are primary clients; family caregivers present but not considered to be clients | | 76 | (24.6) |
| Family sessions: One adult with an ID and one or more family members all participate as clients | | 27 | (8.7) |
| Family sessions: Several adults with an ID and their family members all participate as clients | | 13 | (4.2) |
| Individual sessions: Family caregiver is the primary (sole) client | | 11 | (3.6) |
| Group sessions: Family caregivers are the primary (only) clients | | 8 | (2.6) |
| Other | | 7 | (2.3) |
| N/A: Respondent has not worked in this context | | 80 | (25.9) |

*Note.* ID = intellectual disability.

Free response data (i.e., when respondents chose the *Other* category) indicated that other services being provided included: community groups that included family caregivers,

performance groups, and sibling sessions. Participants also indicated that they interacted with family caregivers in a wide variety of settings including day programs, hospitals, private practice, home visits, and hospice settings.

Participants' written responses indicated that family caregivers were involved in music therapy sessions as clients for various reasons. These included: it was inherent in their theoretical orientation (e.g., Community Music Therapy); they had additional training and professional roles that gave them the ability to do this type of work (e.g., family therapy or chaplaincy); and the professional setting in which services were being provided inherently included family members as clients (e.g., hospice). Some respondents indicated an interest in developing various types of music therapy services for family caregivers of adults with an ID, stating that it was an underserved population. However, some respondents also noted potential challenges involved in providing these services. One respondent indicated that it was difficult to include both adults with an ID and their family members in sessions as family caregivers sometimes attempt to dominate the sessions.

**Context A.** For sessions where family members were present but not considered as clients per se, respondents were asked to indicate (i.e., select all that apply) the music therapy approaches, goals, and music experiences that they used in this context. Table 3 provides an overview of these responses.

**Table 3**

*Context A: Music Therapy Approaches, Goals, and Music Experiences*

| Variable | *n* | *f* | % |
|---|---|---|---|
| | 309 | | |
| Music Therapy Approaches Used | | | |
| Orff Music Therapy | | 32 | (10.4) |
| Dalcroze Music Therapy | | 5 | (1.6) |
| Kodaly Music Therapy | | 7 | (2.3) |
| The Bonny Method of Guided Imagery and Music | | 7 | (2.3) |
| Nordoff-Robbins Music Therapy | | 49 | (15.9) |
| Psychodynamic Music Therapy | | 29 | (9.4) |
| Behavioral Music Therapy | | 115 | (37.2) |
| Music Therapy in Wellness | | 56 | (18.1) |
| Neurologic Music Therapy | | 45 | (14.6) |
| Biomedical Music Therapy | | 10 | (3.2) |
| Other | | 36 | (11.7) |
| N/A: Respondent has not worked in this context. | | 69 | (22.3) |
| Goals Addressed | | | |
| Communication | | 147 | (47.6) |
| Cognitive | | 122 | (39.5) |
| Motor | | 117 | (37.9) |
| Musical | | 72 | (23.3) |
| Emotional | | 117 | (37.9) |
| Social | | 145 | (46.9) |
| Other | | 11 | (3.9) |
| N/A: Respondent has not worked in this context. | | 61 | (19.7) |
| Music Experiences Provided | | | |
| Improvisational | | 114 | (36.9) |
| Re-creative | | 132 | (42.7) |
| Receptive | | 85 | (27.5) |
| Compositional | | 83 | (26.9) |
| Multi-arts | | 51 | (16.5) |
| Other | | 12 | (3.9) |
| N/A: Respondent has not worked in this context. | | 66 | (21.4) |

Participants' written responses indicated that other approaches used in Context A included client-centered music therapy, cognitive behavioral music therapy, community music therapy, dialectical behavior therapy, DIR/Floortime (Carpente, 2009), eclectic music therapy, humanistic music therapy, improvisational music therapy, spiritual care, music-centered music therapy, performance-based music therapy, psychotherapy, resource-oriented music therapy, and sensory integrative music therapy. Other goals addressed in Context A included health and wellness, reality orientation, self-esteem, spiritual, and strengthening relationships. For those respondents who indicated that they used other music experiences in Context A, they did not list experiences that went beyond those listed in the survey question. Instead they gave more specific

examples which included: song composition, movement and music, percussion improvisation, and group performances.

**Context B.** For sessions where family caregivers and the adults with an ID were present and both were considered as clients, respondents were asked to indicate (i.e., select all that apply) the music therapy approaches, goals, and music experiences that they used in this context. Table 4 provides an overview of these responses.

**Table 4**

*Context B: Music Therapy Approaches, Goals, and Music Experiences*

| Variable | *n* | *f* | % |
|---|---|---|---|
| | 309 | | |
| Music Therapy Approaches Used | | | |
| Orff Music Therapy | | 13 | (4.2) |
| Dalcroze Music Therapy | | 4 | (1.3) |
| Kodaly Music Therapy | | 3 | (1.0) |
| The Bonny Method of Guided Imagery and Music | | 3 | (1.0) |
| Nordoff-Robbins Music Therapy | | 14 | (4.5) |
| Psychodynamic Music Therapy | | 16 | (5.2) |
| Behavioral Music Therapy | | 42 | (13.6) |
| Music Therapy in Wellness | | 25 | (8.1) |
| Neurologic Music Therapy | | 15 | (4.9) |
| Biomedical Music Therapy | | 5 | (1.6) |
| Other | | 12 | (3.9) |
| N/A: Respondent has not worked in this context. | | 159 | (51.5) |
| Goals Addressed | | | |
| Communication | | 44 | (14.2) |
| Cognitive | | 29 | (9.4) |
| Motor | | 24 | (7.8) |
| Musical | | 21 | (6.8) |
| Emotional | | 38 | (12.3) |
| Social | | 47 | (15.2) |
| Other | | 4 | (1.3) |
| N/A: Respondent has not worked in this context. | | 168 | (54.4) |
| Music Experiences Provided | | | |
| Improvisational | | 33 | (10.7) |
| Re-creative | | 35 | (11.3) |
| Receptive | | 20 | (6.5) |
| Compositional | | 25 | (8.1) |
| Multi-arts | | 12 | (3.9) |
| Other | | 2 | (0.6) |
| N/A: Respondent has not worked in this context. | | 169 | (54.7) |

Free response data indicated that other approaches used in Context B included cognitive behavioral music therapy, community music therapy, creative music therapy, eclectic music therapy, improvisation-based music therapy, music therapy and spiritual care, and music-

centered music therapy. Other goals addressed in Context B were spiritual and strengthening relationships.

A few written responses indicated that communication goals were used in order to foster interactions between family caregivers and adults with an ID. One response indicated that emotional goals were used to help caregivers develop coping skills.

**Context C.** For sessions where family caregivers were the primary clients and their family members with an ID were not present, respondents were asked to indicate (i.e., select all that apply) music therapy approaches, goals, and music experiences that they used in this context. Table 5 provides an overview of these responses.

**Table 5**

*Context C: Music Therapy Approaches, Goals, and Music Experiences*

| Variable | *n* | *f* | % |
|---|---|---|---|
| | 309 | | |
| Music Therapy Approaches Used | | | |
| Orff Music Therapy | | 8 | (2.6) |
| Dalcroze Music Therapy | | 2 | (0.6) |
| Kodaly Music Therapy | | 2 | (0.6) |
| The Bonny Method of Guided Imagery and Music | | 6 | (1.9) |
| Nordoff-Robbins Music Therapy | | 6 | (1.9) |
| Psychodynamic Music Therapy | | 12 | (3.9) |
| Behavioral Music Therapy | | 25 | (8.1) |
| Music Therapy in Wellness | | 15 | (4.9) |
| Neurologic Music Therapy | | 8 | (2.6) |
| Biomedical Music Therapy | | 1 | (0.3) |
| Other | | 8 | (2.6) |
| N/A: Respondent has not worked in this context. | | 177 | (57.3) |
| Goals Addressed | | | |
| Communication | | 19 | (6.1) |
| Cognitive | | 10 | (3.2) |
| Motor | | 6 | (1.9) |
| Musical | | 8 | (2.6) |
| Emotional | | 20 | (6.5) |
| Social | | 16 | (5.2) |
| Other | | 1 | (0.3) |
| N/A: Respondent has not worked in this context. | | 192 | (62.1) |
| Music Experiences Provided | | | |
| Improvisational | | 16 | (5.2) |
| Re-creative | | 13 | (4.2) |
| Receptive | | 13 | (4.2) |
| Compositional | | 9 | (2.9) |
| Multi-arts | | 6 | (1.9) |
| Other | | 2 | (0.6) |
| N/A: Respondent has not worked in this context. | | 186 | (60.2) |

Free response data indicated that the other approaches used in Context C included community music therapy, music therapy and spiritual care, and music-centered music therapy. Other goals addressed in Context C included spiritual goals. Other music experiences provided in Context C included a specific example of how the Bonny Method of Guided Imagery in Music (one of the choices in the survey) was used. One participant indicated that there may have been barriers in marketing music therapy services directly to family caregivers directly but did not specify what those barriers included.

**Perceived Potential for Music Therapy Intervention with Family Caregivers**

**Context A.** All respondents, regardless of their level or type of experience with family caregivers of adults with an ID, were asked to choose two music therapy approaches and two music experiences they thought might be most beneficial in each of the three contexts outlined above. Table 6 provides an overview of their responses for music therapy sessions where family members are present but not considered to be clients per se (Context A).

**Table 6**

*Context A: Suggested Music Therapy Approaches and Music Experiences*

| Variable | *n* | *f* | % |
|---|---|---|---|
| | 309 | | |
| Suggested Music Therapy Approaches | | | |
| Orff Music Therapy | | 53 | (17.2) |
| Dalcroze Music Therapy | | 8 | (2.6) |
| Kodaly Music Therapy | | 3 | (1.0) |
| The Bonny Method of Guided Imagery and Music | | 7 | (2.3) |
| Nordoff-Robbins Music Therapy | | 77 | (24.9) |
| Psychodynamic Music Therapy | | 20 | (6.5) |
| Behavioral Music Therapy | | 102 | (33.0) |
| Music Therapy in Wellness | | 63 | (20.4) |
| Neurologic Music Therapy | | 58 | (18.8) |
| Biomedical Music Therapy | | 10 | (3.2) |
| Other | | 23 | (7.4) |
| Suggested Music Experiences | | | |
| Improvisational | | 127 | (41.1) |
| Re-creative | | 120 | (38.8) |
| Receptive | | 26 | (8.4) |
| Compositional | | 67 | (21.7) |
| Multi-arts | | 39 | (12.6) |
| Other | | 2 | (0.6) |

Free response data indicated other suggestions for approaches that could be used in Context A. These included community music therapy, developmental music therapy, DIR/Floortime (Carpente, 2009), eclectic music therapy, humanistic music therapy, integrated

therapy, and person-centered therapy. Participants' written responses suggested that behavioral music therapy was selected as a potential approach as it was something that participants had experience using within music therapy sessions. Some respondents indicated that caregivers could learn skills in behavioral music therapy contexts that they could use with their family members. Several respondents discussed the benefits of Nordoff-Robbins music therapy, the second most selected approach, as it is easily adapted for use with clients with an ID while also providing a supportive forum for communication and interactions between caregivers and clients.

Participants' written responses indicated that improvisational experiences were seen as opportunities for self-expression and interaction. Some respondents suggested that re-creative experiences provided opportunities for structure and experiences of success in the therapeutic environment while also providing common ground for social interactions. Specific examples of improvisational interventions included interactive improvised musical conversations, structured improvisations with blues or pentatonic scales, and turn-taking improvisations. Specific examples of re-creative interventions included adapted lessons and using familiar songs to facilitate choice-making which could also help demonstrate to the caregiver the new skills being developed by the client with an ID.

**Context B.** Table 7 provides an overview of respondents' suggestions pertaining to music therapy approaches and music experiences that could be used in music therapy sessions where family caregivers and the adults with an ID are present and both are considered as clients.

**Table 7**

*Context B: Suggested Music Therapy Approaches and Music Experiences*

| Variable | *n* | *f* | % |
|---|---|---|---|
| | 309 | | |
| Suggested Music Therapy Approaches | | | |
| Orff Music Therapy | | 65 | (21.0) |
| Dalcroze Music Therapy | | 6 | (1.9) |
| Kodaly Music Therapy | | 3 | (1.0) |
| The Bonny Method of Guided Imagery and Music | | 10 | (3.2) |
| Nordoff-Robbins Music Therapy | | 78 | (25.2) |
| Psychodynamic Music Therapy | | 34 | (11.0) |
| Behavioral Music Therapy | | 92 | (29.8) |
| Music Therapy in Wellness | | 78 | (25.2) |
| Neurologic Music Therapy | | 34 | (11.0) |
| Biomedical Music Therapy | | 5 | (1.6) |
| Other | | 20 | (6.5) |
| Suggested Music Experiences | | | |
| Improvisational | | 127 | (41.1) |
| Re-creative | | 101 | (32.7) |
| Receptive | | 28 | (9.1) |
| Compositional | | 59 | (19.1) |
| Multi-arts | | 39 | (12.6) |
| Other | | 4 | (1.3) |

Free response data contained other suggested approaches that could be used in Context B. These included: community music therapy, developmental music therapy, DIR/Floortime (Carpente, 2009), eclectic music therapy, group music therapy, improvisational music therapy, integrated music therapy, and sensory-integrative music therapy. Some participants' written comments indicated that the three most selected approaches (i.e, behavioral music therapy, music therapy in wellness, and Nordoff-Robbins music therapy) could all help to facilitate interactions, reinforce goals, and reduce stress. On the other hand, a few other respondents mentioned that behavioral music therapy might not create a meaningful change and that music therapy in wellness might not be well suited to this context.

Participants' written responses indicated that improvisational experiences would be beneficial for developing the relationship between family caregivers and their family member with an ID while at the same time providing each with opportunities for self-expression. Respondents suggested that re-creative experiences could provide structure to these sessions and help to create a therapeutic environment. Examples of improvisational interventions suggested for Context B included themed improvisations about issues and emotions, group drumming, and structured improvisations. Examples of re-creative interventions suggested for Context B

included instrument playing to facilitate interactions, performing pre-composed songs for an audience, and taking turns sharing and singing or playing preferred songs.

**Context C.** Table 8 provides an overview of respondents' suggestions pertaining to music therapy approaches and music experiences that could be used in music therapy sessions where family caregivers are the primary clients and their loved ones with an ID would not be present.

**Table 8**

*Context C: Suggested Music Therapy Approaches and Music Experiences*

| Variable | *n* | *f* | % |
|---|---|---|---|
| | 309 | | |
| Suggested Music Therapy Approaches | | | |
| Orff Music Therapy | | 32 | (10.4) |
| Dalcroze Music Therapy | | 3 | (1.0) |
| Kodaly Music Therapy | | 5 | (1.6) |
| The Bonny Method of Guided Imagery and Music | | 65 | (21.0) |
| Nordoff-Robbins Music Therapy | | 33 | (10.7) |
| Psychodynamic Music Therapy | | 72 | (23.3) |
| Behavioral Music Therapy | | 41 | (13.3) |
| Music Therapy in Wellness | | 117 | (37.9) |
| Neurologic Music Therapy | | 13 | (4.2) |
| Biomedical Music Therapy | | 7 | (2.3) |
| Other | | 13 | (4.2) |
| Suggested Music Experiences | | | |
| Improvisational | | 106 | (34.3) |
| Re-creative | | 52 | (16.8) |
| Receptive | | 52 | (16.8) |
| Compositional | | 107 | (34.6) |
| Multi-arts | | 40 | (12.9) |
| Other | | 5 | (1.6) |

Free response data indicated other suggestions for approaches that could be used in Context C. These included: cognitive behavioral music therapy, community music therapy, eclectic music therapy, integrated therapy, music-centered music therapy, resource-oriented music therapy, and verbal group therapy. Participants' written responses indicated that the music therapy in wellness approach was developmentally appropriate and beneficial or necessary for self-care. Psychodynamic music therapy was frequently suggested with respondents indicating that it had the potential to help family members in terms of emotional expression and working through challenges related to caregiving such as stress and guilt.

Other suggested music experiences included an example of a receptive lyric analysis experience and an explanation of how to use re-creative and multi-arts experiences. Participants'

written responses indicated that both compositional and improvisational experiences were beneficial for family caregivers' expression and self-care. Examples of compositional interventions suggested included thematic songwriting to: vent, reflect on needs, and process experiences. Examples of improvisational experiences included thematic improvisations to help process experiences and role-playing through improvisation.

## Chapter 5. Discussion

The purpose of this survey study was to investigate the extent to which professional music therapists in North America are working with family caregivers of adults with an ID, the nature of the work that they are doing, and their perspectives on the types of music therapy services that they feel would best serve this population.

A total of 381 music therapists responded (309 met the criteria for inclusion), suggesting some interest in this population as it seems unlikely that many of these individuals would have responded otherwise. More than half of the respondents (*frequency* = 190) indicated that family caregivers were present during individual (*frequency* = 114) and group music therapy sessions (*frequency* = 76) while a small number of respondents indicated that they had provided individual (*frequency* = 11) and group music therapy services (*frequency* = 8) to family caregivers as primary clients. Although only a small number of music therapists seem to be providing music therapy services for family caregivers themselves, they are often present during music therapy sessions with their loved ones. In these contexts, they are interacting with music therapists and may be receiving inadvertent benefits from these interactions. This, along with respondents' perspectives on this issue, suggests that there is potential to initiate more formal music therapy services that directly target the needs of family caregivers of adults with an ID.

This final chapter will discuss this study's findings. Limitations of the study as well as indications for music therapy practice and research will be presented.

### Current Music Therapy Practices with Family Caregivers

**Caregivers' interactions with music therapists.** Although this sample is likely not representative of the population of North American music therapists (i.e., random sampling was not used so as to give all music therapists who met the criteria for inclusion an opportunity to respond), these findings suggest that family caregivers of adults with an ID are in fact interacting with music therapists in various ways. As stated earlier, 83% of 265 respondents indicated that they had some type of contact with family caregivers. However, the free response data also revealed that the contexts within which this contact took place varied greatly. Possible implications for practice in relation to this point are discussed below.

**Music therapy services provided when family members were present.** A majority of respondents (60%, $n$ = 265) indicated that family caregivers were present in music therapy

sessions. The numbers (*frequency* = 190) suggested that this happened most often in group or individual contexts where family caregivers were present, but were not considered as clients. Although more research would be needed to verify why, this may be because family caregivers are providing support to their loved one during the sessions. Caregivers may also simply enjoy being a part of these sessions as they may like the music experiences in and of themselves or perhaps they have limited opportunities to interact with their loved one in mutually beneficial ways. In this researcher's professional experience, she noted that family members occasionally commented on how much they enjoyed observing their loved ones' music therapy sessions because they could relax and see their loved ones having positive experiences. However, participants' free response data revealed a wide continuum in terms of the level and types of family caregiver participation that occurred. It would be interesting to determine if these levels or types of involvement were formally or informally established or if they emerged organically over time as therapeutic processes progressed.

A small number of respondents (*frequency* = 40) provided music therapy services (families in group therapy or the family as an individual unit) to the family caregivers and adults with an ID where both were considered as clients. Participants' written responses indicated that this occurred for various reasons including: the setting where services took place (e.g., hospice) or the professional role (i.e., scope of practice) of the therapist (e.g., the music therapist also served as a family therapist, chaplain, etc.). This small number may be reflective of the fact that there have been few techniques or models established for family-based music therapy in general (McIntyre, 2009; Pasiali, 2010). Subsequently, it is likely that most music therapists have not received training on how to provide family-based music therapy services.

A small group of respondents (*frequency* = 19) indicated that they provided group and individual sessions directly to family caregivers as clients. It may be the case that family caregivers do not seek out services for themselves due to past negative experiences with the entire service system which cause them to be mistrustful of the system (Hines, Balandin, & Togher, 2014; Lunsky et al., 2014). One participant's comments also indicated that there were difficulties in directly marketing to family caregivers. Although a specific reason for difficulties with direct marketing to caregivers was not given by this participant, the literature indicates that there may be barriers for family caregivers to access support services (Brodarty, Thomson,

Thompson, & Fine, 2005; Greenwood, Habibi, Smith, & Manthorpe, 2015; Moriarty, Manthorpe, & Cornes, 2015; Ng, 2009; Rand & Malley, 2014). One possible barrier is that caregivers may be in denial of their own personal needs (Brodarty et al., 2005; Greenwood et al., 2015). Furthermore, time limitations may limit the time resources necessary for caregivers to seek out services for themselves (Moriarty et al., 2015; Ng, 2009). It seems that most state and provincial governments have limited funding for mental health type programs for family caregivers, and these caregivers may be unwilling or unable to pay for these services out of pocket (Hooyman & Gonyea, 1995). Finally, family members of adults with an ID may have a heightened awareness around the societal stigma that often occurs in relation to mental health support and may be hesitant to seek out this kind of support for themselves (Greenwood et al., 2015; Moriarty et al., 2015; Rand & Malley, 2014).

**Context A: Music therapy approaches, goals, and music experiences.** By far, the approach that respondents used most frequently when family caregivers were present (but not clients) was behavioral music therapy (*frequency* = 115). Communication (*frequency* = 147) and social goals (*frequency* = 145) were both targeted frequently which is consistent with what the literature indicates in relation to common goal areas for this population (Hooper, Wigram, Carson, & Lindsay, 2008a; Hooper, Wigram, Carson, & Lindsay, 2008b). These goal areas also make sense given that these family caregivers are sometimes learning skills to use outside of this music therapy context. The use of re-creative music experiences was indicated most frequently in Context A (*frequency* = 132). This makes sense in that behavioral music therapy (the approach cited as being used most often in this context) involves very structured procedures to influence changes in behavior (Madsen, 1999). The use of pre-composed music within re-creative music experiences automatically creates a predetermined structure that can actively engage clients while at the same time promote constructive changes in their behavior (Hooper et al., 2008a).

**Context B: Music therapy approaches, goals, and music experiences.** As mentioned earlier, fewer respondents had provided music therapy services with family caregivers and adults with an ID where both were considered clients. Again, the most highly reported approach being utilized was behavioral music therapy (*frequency* = 42). This was not surprising for similar reasons noted above in Context A. Again social (*frequency* = 47) and communication (*frequency* = 44) goals were targeted most often, but emotional goals (*frequency* = 38) were also more

frequently indicated by respondents when working in Context B. This may be because emotional goals within the context of relationship seem more relevant when both family caregivers and their loved ones are considered as clients. Participants' written responses indicated that when working with these families in a hospice setting, emotional goals are especially important for family caregivers as they process the emotions surrounding grief and loss (Magill, 2009; Stewart et al., 2005). Participants' written comments also indicated that emotional goals can be a good way for caregivers to develop general coping skills. Finally, both social and communication goals within this music therapy context can be helpful in developing secure, reciprocal relationships between caregivers and persons with an ID (Watson, 2014).

Similar to Context A, re-creative music experiences were reported most frequently in Context B (*frequency* = 35), closely followed by improvisational experiences (*frequency* = 33). Increased use of improvisational experiences in this context could be due to the fact that these experiences in general often focus on social and communication goals (Hooper et al., 2008a; Rasar, 2010; Watson, 2014). Multiple family members could be incorporated into these types of experiences.

**Context C: Music therapy approaches, goals, and music experiences.** Only a small number of music therapists (*frequency* = 19) reported working with family caregivers of adults with an ID where they were the sole (primary) client (i.e., the adult with an ID was not present). Again, behavioral music therapy was reported as being used most frequently (*frequency* = 25). Emotional goals (*frequency* = 20) were reported most often in this context. However, communication (*frequency* = 19) and social goals (*frequency* = 16) were reported only slightly less frequently. The literature indicates that emotional goals are often targeted in other caregiver populations who receive music therapy (e.g., those who provide care in end of life contexts; Klein & Silverman, 2012; Magill, 2009). In Context C, respondents indicated most frequently that they used improvisational experiences (*frequency* = 16) although re-creative (*frequency* = 13) and receptive (*frequency* = 13) experiences were indicated only slightly less frequently. These types of music experiences have been used with other caregiving populations and can be used to develop coping skills as well as facilitate relaxation and emotional insight related to the challenges of caregiving (Choi, 2010; Magill, 2009)

**Potential for Development of Music Therapy Programs or Interventions**

**Context A: Music therapy approaches and music experiences.** In selecting potential music therapy approaches for use when family caregivers were present in music therapy sessions (not as clients), respondents selected behavioral music therapy most frequently (*frequency* = 102) which mirrors what was most frequently selected by music therapists who are currently working in Context A. This could imply that respondents felt that the work that is actually happening is philosophically aligned with the work that could be happening in this context. Participants' written comments indicated that behavioral music therapy can also be used to teach family caregivers new skills which suggests that music therapists could consider more actively involving family caregivers when they attend sessions, even if they are not considered as clients.

In Context A respondents most frequently selected, improvisational (*frequency* = 127) and re-creative (*frequency* = 120) music experiences as those that could potentially be of benefit to family caregivers of adults with an ID. While these numbers are similar to those that applied to music therapy that is actually happening in this context, a higher number selected improvisational than re-creative experiences when suggesting what experiences could potentially be used. This may indicate that some respondents believed that improvisational experiences could be used in Context A more frequently than they are. There is a history of improvisational experiences and related approaches (e.g., Nordoff-Robbins music therapy) being used with persons who have an ID (Hooper et al., 2008a; Hooper et al., 2008b; Pavlicevic, O'Neil, Powell, Jones, & Sampathianaki, 2014) and it would interesting to better understand why they are not currently used more often.

**Context B: Music therapy approaches and music experiences.** In terms of potential music therapy approaches that could be used when family caregivers and adults with an ID are both considered clients, respondents most frequently suggested behavioral music therapy (*frequency* = 92). However, many also selected music therapy in wellness (*frequency* = 78) and Nordoff-Robbins music therapy (*frequency* = 78). Although these responses are similar to the approaches that respondents indicated are actually being used, wellness was emphasized more strongly as a potential approach that could be used. This may be because both family caregivers and care recipients may have many health issues especially related to stress. Written responses indicate that respondents may have recommended using the wellness approach as a way to

facilitate the development of better coping skills for both parties. Further exploration into why a wellness approach is not currently being used more frequently in this context seems warranted.

Similar to work that is actually being done to Context A and Context B, improvisational (*frequency* = 127) and re-creative experiences (*frequency* = 101) were selected most frequently as those that would potentially be of most benefit in Context B. This makes sense as these are both active experiences (Hooper et al., 2008a) that can be used to facilitate communication and interaction between family members (Rasar, 2010).

**Context C: Music therapy approaches and music experiences.** In terms of potential approaches and music experiences that could be used in Context C (family members are the sole/primary clients), respondents' choices were notably different from the other two contexts. In terms of approaches, respondents most frequently selected music therapy in wellness (*frequency* = 117). There was also a notable difference in the selections that respondents made in terms of the work that is actually happening in Context C versus the potential work that respondents indicated could potentially happen in Context C. For example, music therapy in wellness (*frequency* = 117), psychodynamic music therapy (*frequency* = 72), and the Bonny Method of Guided Imagery in Music (*frequency* = 65) were most selected potential approaches, but the main approach selected that is actually being used in Context C was behavioral music therapy. This difference may be due to the fact that far fewer music therapists reported actually working within this context so respondents' *real life* experiences may be limited. Participants' written responses also indicated that they selected potential approaches that require deeper reflection and more abstract thinking that may not be indicated for use in sessions when a person with an ID is part of the session. This suggests that while there are benefits in using music therapy in family-based therapy contexts that include adults with an ID, there is good rationale for providing these family caregivers with their own personal (individual or group) music therapy sessions. .

In terms of music experiences that could potentially be of benefit family caregivers in Context C, compositional experiences were selected most often (*frequency* = 107) followed by improvisational experiences (*frequency* = 106). Articles written about music therapy interventions for other caregiver populations suggest that composition is a very useful tool in helping caregivers develop insight into the challenges associated with care and deal with stress while also helping them develop new skills (Klein & Silverman, 2012; Magill, 2009). As such,

song writing interventions could fit well within the suggested wellness or psychodynamic approaches.

Although only a small number of music therapists seem to be providing services for family caregivers themselves (as sole/primary clients), family caregivers are often present during music therapy sessions, they are interacting with music therapists, and they may be receiving inadvertent benefits from these interactions. All of this information suggests that there is great potential to design and initiate more formalized music therapy services that directly target the multifaceted needs of family caregivers of adults with an ID.

**Limitations**

This study had several limitations. Because the overall population of music therapists is relatively small, there was no random sampling of participants, which may have created a self-selection bias in the responses. Participants were allowed to skip any question, which resulted in highly variable response rates to individual questions. The number of responses dropped as the survey progressed indicating that some respondents may have experienced response fatigue when completing the survey.

The survey originally defined a primary family caregiver as "any family member who provides a significant amount of care and support" (Appendix B, Question 7, para. 4). However, the word *significant* was not operationally defined in the survey itself and this may have affected how respondents considered this term when answering the questions.

Another limitation is that there may be music therapists working with family caregivers of adults with an ID who do not have experience working with persons with an ID (e.g., specializing in caregiver burn out). This possibility was overlooked when the criteria for inclusion were designed. Therefore, although this number is likely small, these potential participants' perspectives are missing from the results of this survey. Unfortunately, due to time constraints, further statistical analysis was not conducted. In particular, it might have been beneficial to have compared the responses of experienced music therapists with those who had little to no experience with family caregivers of adults with an ID—especially in terms of their suggestions for services that could potentially be provided in Contexts A, B, and C. Further data analysis will be conducted if this research is submitted for publication.

Respondents also mentioned or implied some limitations through their comments. Some indicated that the music therapy approach choices that were provided were very specialized. Some responses indicated some confusion around terminology. For example, creative music therapy was included as a free response (i.e., other) approach despite the fact that Nordoff-Robbins music therapy was provided as a choice—these two approaches are in fact, the same approach. Some respondents expressed difficulty in choosing approaches and music experiences for hypothetical clients. Some responses indicated some confusion about what was meant by the term *primary family caregiver* as some respondents made references to services provided for professional caregivers. All of these issues likely had an impact on the quality of the data and the subsequent conclusions that could be drawn from it.

**Implications for Future Practice**

In the free response sections, several respondents expressed an interest in working with this population. Because participants' written responses indicated that interactions with family caregivers of adults with an ID are happening in a wide variety of contexts, interventions will need to be designed that are easily adaptable. It would be helpful to develop resources for music therapists attempting to address the needs of family caregivers such as blog posts, case studies, and fact sheets which in turn may help to increase awareness of this population within the field of music therapy. Participants' written responses also indicate that there may be some confusion or lack of awareness pertaining to certain music therapy approaches. Therefore, more training and better organized information about different approaches that may be indicated for this population seems warranted. Subsequently, various public forums, which promote quality music therapy services targeting these family caregivers, are needed in order to increase these potential clients' awareness and encourage them to seek out these services as a viable alternative. Other fields that provide services to family caregivers (e.g., social work, mental health, etc.) have emphasized the use of outreach to help family caregivers find appropriate services that address their needs (Moriarty et al., 2015). Because a major barrier to accessing services for caregivers is a lack of awareness of available services (Brodarty et al., 2005; Greenwood et al., 2015), music therapists might consider using an outreach approach in contacting potential clients by partnering with local social service and peer support organizations (e.g., Canadian Caregiver Coalition, Alliance des femmes de la Francophonie canadienne, Family Caregiver Alliance, etc.) to develop

music therapy support and outreach programs for family caregivers. By working through these types of organizations, music therapists may better address the needs of family caregivers as the literature suggests that caregivers may feel more comfortable receiving services from caregiving peer support organizations as compared with traditional mental health providers (Rand & Malley, 2014).

The findings of this study suggest that family caregivers attend and sometimes participate in music therapy sessions despite the fact that they are not considered as clients. In these situations, the role of the family caregiver may be unclear which can potentially result in complicated ethical dilemmas (e.g., caregivers may have significant needs of their own and disrupt the intent of therapy session, privacy issues of the clients with an ID, etc.). The current researcher has experienced similar issues first hand in music therapy sessions that took place in chronic care settings where professional caregivers were present and, at times, re-directed sessions in ways that were not in the best interest of the client. Further consideration on how to best approach therapy and define roles in these complex contexts in a respectful way is an ethical imperative for all who are involved in these sessions.

A community music therapy approach could help to provide a supportive and inclusive environment for caregivers. This approach was not offered as a choice in the survey questions due as it is a developing approach that was not included in *Introduction to Approaches in Music Therapy*, the textbook from which inspired the approaches included in the survey (Darrow, 2008). Despite this, several respondents included community music therapy in the free response (i.e, other) sections, especially in response to the questions about music therapy approaches used in Scenario A. In community music therapy, one considers the continuum between an individual and the greater community, and a family group could be considered as a microcosm within the community (Andsell, 2002). It has been suggested that some community music therapy groups could be used not only to build community but to address issues such as societal stigma by encouraging self-advocacy (Curtis & Mercado, 2004; Snow et al., 2008). While these writings have primarily focused on peer groups of adults with an ID, this same idea could be applied to help empower family caregivers who may also experience stigma.

The findings of this survey also indicate that some music therapists are providing services to families as a unit that include family caregivers. However, as mentioned earlier, music

therapists may not be receiving training to provide family-based music therapy services. Training programs could be developed that help music therapists develop the skills necessary to work with families. The availability of these types of programs may help to increase the amount of music therapy services offered to families as a whole.

Although only a small number of respondents are providing direct therapy to family caregivers of persons with an ID, several respondents expressed interest in offering more services to this population. The literature suggests that music therapy may be beneficial for family caregivers at large particularly in helping them develop skills related to caregiving (Nicholson et al., 2008; Pasiali, 2010; Thompson, 2012; Williams et al., 2012), improving relationships with care recipients (Archer, 2004; Bull, 2008; Decuir, 1991; Hammar, et al., 2011; Loth, 2008; Oldfield, 2006; Oldfield, 2011; Pasiali, 2010; Thompson, 2012), and coping with the challenges associated with providing care (Choi, 2010; Dvorak, 2012; Hammar et al., 2011; Klein & Silverman, 2012; Magill, 2009; Narme et al., 2014; Stewart et al., 2005; Tung, 2014). This suggests that family caregivers for persons with an ID may benefit from further access to music therapy services addressing the areas mentioned above.

In terms of service characteristics that may limit access to therapy sessions, music therapists must take into account that caregiving can be quite time consuming (Brodarty et al., 2005; Greenwood et al., 2015; Ng, 2009). Therefore, music therapists should consider providing services to family caregivers in evenings and on weekends when family caregivers may have more time available. Family caregivers may also be struggling financially (Brodarty et al., 2005; Greenwood et al., 2015; Ng, 2009). Therefore, music therapists that wish to work with population could consider finding external sources of funding such as grants to support music therapy programming (Ng, 2009).

**Implications for Future Research**

As there is limited music therapy research pertaining to family caregivers of adults with an ID, further research is warranted. The current study further supports this notion. As noted above, many music therapists may not have a clear understanding of the approaches that work best with family caregivers of persons with an ID. Therefore, research that further investigates the experiences and needs of family caregivers of adults with an ID is clearly needed. How family caregivers can use music as a part of their caregiving and daily lives would help to

develop resources and tools for caregivers. Music therapists could help to develop these resources and train caregivers.

Some respondents indicated that they considered family caregivers' presence in the therapy sessions to have little effect on the overall structure of the session. However, little is known about how their presence affects music therapy sessions and the therapeutic process itself. Written comments suggested that there can be both benefits and drawbacks to having family caregivers present, and that the role they play in the session varies greatly. Greater understanding of how family caregivers' presence impacts the music therapy sessions and the potential roles that they could have in the sessions would allow therapists to better adapt sessions and determine the most appropriate times for family caregivers to attend.

The fact that the potential approaches and music experiences selected in Context C varied from the potential approaches selected for Contexts A and B suggests that music therapy provided to family caregivers as primary clients may involve targeting different goals. This is not surprising. However, the fact that only a few respondents reported working with family caregivers in this way and that little has been published on this topic indicates that more information is needed to better understand how to create music therapy services that will best address the needs of this population. In chronic care, a study explored the ways caregivers used music as part of their lived experience (O'Callaghan et al., 2011). Results indicated that some caregivers did use music to cope with the stressors related to caregiving, to enhance their connection with their care recipients, and to decrease burden (O'Callaghan et al., 2011). It was also noted that some of the caregivers interviewed recommended that expanded music program services (e.g., music libraries, resources for caregivers to use music, shared music support groups, etc.) provided in an age-appropriate manner could be beneficial in reducing caregiver burden. Similar research into how family caregivers of adults with an ID use music in their lives might yield similar information which could be used to develop both therapeutic interventions and personal self-care resources for these family caregivers.

Participants' comments did mention that appropriate music therapy assessments must be developed that address the particular needs of caregivers. The literature has indicated that long term caregiving is a developmental process that changes over time (Haveman et al., 1997; Talley

& Montgomery, 2013). Further research into assessment tools related to caregiving is warranted, and could help music therapists to better address the needs of this population.

**Closing Remarks**

As this study has suggested, family caregivers of adults with an ID are interacting with music therapists and, at times, are receiving some music therapy services for themselves. Due to a lack of music therapy research pertaining to this population, little is known about the needs of this population or how music therapy intervention specifically might effectively address these needs. This survey study has highlighted some of the possible needs and the potential for development of services. It is hoped that this study will inspire music therapists to conduct further research and develop high quality interventions so that family caregivers of adults with an ID will have increased access to the broad spectrum of services and support that they need.

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## Appendix A

## Invitation to Participate in a Music Therapy Survey

Dear Colleague,

My name is Karli Purscell, and I am a graduate music therapy student at Concordia University under the direction of Dr. Laurel Young in the Department of Creative Arts Therapies.

You are being invited to complete an online survey as part of a research study that I am conducting to fulfill the requirements of a thesis in the MA in Creative Arts Therapies program at Concordia University in Montreal, Quebec. You were contacted to participate in this study because you are an accredited member of the Canadian Association for Music Therapy (MTA) and/or a Board Certified Music Therapist (MT-BC) of the Certification Board for Music Therapists. In order to participate in this survey, you must have experience as a music therapist working with adults with intellectual disabilities within the past 10 years; however, you do not necessarily need to have professional experience working with family caregivers.

The purpose of this study is to better understand how music therapy may be used with family members who are caring for adults with intellectual disabilities. The survey will include 28 questions, with space for optional, additional comments, and should take no longer than 30 minutes to complete.

You are free to choose not to participate in this study or withdraw from the study at any time with no penalty. Your responses will be completely anonymous. The results of this study may be used in reports, presentations or publications.

To access the survey, please follow the link below:
https://www.surveymonkey.com/s/QTR659T

If you have any questions about this research study, please contact the researcher or research advisor at:

Principle Investigator:
Karli Purscell, MT-BC
e-mail: purscellk@gmail.com
Phone: (438)930-5941

Faculty Research Supervisor:
Laurel Young, Phd, MTA
e-mail: laurel.young@concordia.ca
Phone: (514)848-2424 ext.4682

If you have any questions about your rights as a subject/participant in this research, or if you feel you have been placed at risk, please contact:
David McLauchlan
Research Ethics Manager
Office of Research
Concordia University
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Thank you for your consideration,
Karli Purscell

## Appendix B

## Survey

1. Indicate your music therapy professional credentials. (answer required)*
    a. MT-BC
    b. MTA
    c. Both MT-BC and MTA
    d. Neither
    * (If d. is chosen, the survey will close.)

2. Over the past 10 years, have you provided music therapy services to adults with intellectual disabilities? (answer required)*
    a. Yes
    b. No
    * (If b. is chosen, the survey will close):

3. State your age in years.
   Currently, I am ________ years of age.

4. What is your gender?
    a. Prefer not to specify
    b. Male
    c. Female
    d. Other ______________________

5. What is your highest level of music therapy education?
    a. Undergraduate degree
    b. Equivalency Diploma (e.g. Post graduate certificate/diploma)
    c. Master's degree
    d. Doctorate/PhD

6. State the approximate number of years you have been practicing as a professional music therapist.
   I have been practicing as a professional music therapist for approximately ___years.

7. Indicate the region in which you currently provide music therapy services.
    a. Great Lakes region: Illinois, Indiana, Michigan, Minnesota, Ohio, Wisconsin
    b. Mid-Atlantic region: Delaware, District of Columbia, Maryland, New Jersey, New York, Pennsylvania, Virginia, West Virginia
    c. Midwestern region: Colorado, Iowa, Kansas, Missouri, Montana, Nebraska, North Dakota, South Dakota, Wyoming
    d. New England region: Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, Vermont

e. Southeastern region: Alabama, Arkansas, Florida, Georgia, Kentucky, Louisiana, Mississippi, North Carolina, South Carolina, Tennessee
f. Southwestern region: New Mexico, Oklahoma, Texas
g. Western region: Alaska, Arizona, California, Hawaii, Idaho, Nevada, Oregon, Utah, Washington
h. Atlantic Provinces: Newfoundland/Labrador, Prince Edward Island, New Brunswick, Nova Scotia
i. Ontario (Canada)
j. Quebec
k. Prairie Provinces: Alberta, Saskatchewan, Manitoba
l. British Columbia
m. Canadian territories: Yukon, The Northwest Territories, Nunavut
n. Prefer not to answer

*The following questions are seeking to find out information with regard to the clinical work that you do/have done with adults who have intellectual disabilities and, more specifically, with their primary family caregivers. Some of the multiple choice questions will contain an optional "Additional Comments" section where you may provide additional information should you wish to explain or comment upon your answer.*

"The Diagnostic and Statistical Manual of Mental Disorders" defines **intellectual disability** as "a disorder with onset during the developmental period that includes both intellectual and adaptive functioning deficits in conceptual, social, and practical domains" (American Psychiatric Association, 2013, [np]). This study is focused on **adults with intellectual disabilities** who are 21 years of age or older and who meet the diagnostic criteria for an intellectual disability.

A **primary family caregiver** is being defined as any family member who provides a significant amount of the care and support to an adult relative with intellectual disabilities within either a home or an institutional environment. This may include, but is not limited to: a parent, grandparent, or sibling.

Please keep these definitions in mind when answering the following questions:

8. Over the last 10 years, for what total amount of time have you been working as a music therapist with adults who have intellectual disabilities? Please provide your best estimate for the number of years that you have worked with this population.

   Over of the last 10 years, I have worked as a music therapist with adults with intellectual disabilities for an approximate total of ____years.

9. Over the last 10 years, approximately how many clients with intellectual disabilities have you served as a music therapist? Please provide your best estimate.

Over the last 10 years, I have worked with approximately ___ clients who have intellectual disabilities.

10. Over the last 10 years in your role as a music therapist, do you or have you had any contact whatsoever with family caregivers of adults with intellectual disabilities?
    a. Yes
    b. No

11. Over the past 10 years, have you ever provided music therapy services where family caregivers of adults with intellectual disabilities were present during music therapy sessions?
    a. Yes
    b. No

12. If you answered yes to #11, please indicate what kinds of services you have provided when family members who are caring for adults with intellectual disabilities were present during music therapy sessions. Select all that apply.
    a. Individual MT sessions where the adult with an ID is the primary client and one or more family members are present during the session but not considered to be clients
    b. Group MT sessions where adults with IDs are the primary clients and family members are present the session but not considered to be clients
    c. Family MT sessions where one adult with an ID and one or more of his/her family members all participate in the sessions as clients.
    d. Family MT sessions where several adults with IDs and their family members all participate in the sessions as clients
    e. Individual MT sessions for a family member who is caring for an adult with an ID but the adult with ID is NOT involved (i.e., not present) in the session.
    f. Group MT sessions for family members who are caring for adults with IDs but the adults with IDs are not involved (i.e., not present) in the sessions.
    g. Other types of MT sessions that involve family members of adults with ID. Please describe:
    h. n/a (answered "no" to #11)

    **Additional Comments explain your answer:**

13. Which music therapy approaches do you use/have you used in your work with adults with intellectual disabilities where family members are present (i.e., family members participate in some capacity, but are not considered to be clients per se)? Please select all that apply.
    a. Orff Music Therapy
    b. Dalcroze Music Therapy
    c. Kodaly Music Therapy
    d. The Bonny Method of Guided Imagery and Music

e. Nordoff-Robbins Music Therapy
f. Psychodynamic Music Therapy
g. Behavioral Music Therapy
h. Music Therapy in Wellness
i. Neurologic Music Therapy
j. Biomedical Music Therapy
k. Other: specify
l. n/a – I do not work in this context

**Additional Comments explain your answer:**

14. Which music therapy approaches do you use/have you used in your work in family music therapy contexts where both adults with intellectual disabilities and family caregivers are present and are all considered to be clients? Please select all that apply.
    a. Orff Music Therapy
    b. Dalcroze Music Therapy
    c. Kodaly Music Therapy
    d. The Bonny Method of Guided Imagery and Music
    e. Nordoff-Robbins Music Therapy
    f. Psychodynamic Music Therapy
    g. Behavioral Music Therapy
    h. Music Therapy in Wellness
    i. Neurologic Music Therapy
    j. Biomedical Music Therapy
    k. Other: specify
    l. n/a – I do not work in this context

**Additional Comments explain your answer:**

15. Which music therapy approaches do you use/have you used in your work with family caregivers of adults with ID who attend music therapy on their own as clients (i.e., the adult(s) with ID are not present)? Please select all that apply.
    a. Orff Music Therapy
    b. Dalcroze Music Therapy
    c. Kodaly Music Therapy
    d. The Bonny Method of Guided Imagery and Music
    e. Nordoff-Robbins Music Therapy
    f. Psychodynamic Music Therapy
    g. Behavioral Music Therapy
    h. Music Therapy in Wellness
    i. Neurologic Music Therapy
    j. Biomedical Music Therapy
    k. Other: specify
    l. n/a – I do not work in this context

**Additional Comments explain your answer:**

16. What goal areas do you typically focus on when providing music therapy services to adults with intellectual disabilities where family caregivers are present (i.e., the family caregivers are not considered to be clients per se). Please select all that apply.
    a. Communication
    b. Cognitive
    c. Motor
    d. Musical
    e. Emotional
    f. Social
    g. Other: Specify
    h. n/a – I do not work in this context

**Additional Comments explain your answer:**

17. What goal areas do you typically focus on when providing family music therapy services where adults with intellectual disabilities and family caregivers are all present and considered to be clients? Check all that apply
    a. Communication
    b. Cognitive
    c. Motor
    d. Musical
    e. Emotional
    f. Social
    g. Other: Specify
    h. n/a – I do not work in this context

**Additional Comments explain your answer:**

18. What goal areas do you typically focus on when providing music therapy services where the family caregivers of adults with ID are considered to be the clients (i.e. the adults with an ID are not present)? Check all that apply
    a. Communication
    b. Academic/Cognitive
    c. Motor
    d. Musical
    e. Emotional
    f. Social
    g. Other: Specify
    h. n/a – I do not work in this context

**Additional Comments explain your answer:**

19. What types of music experiences do you use when providing music therapy services to adults with intellectual disabilities where family caregivers are present (i.e., the family caregivers are not considered to be clients per se). Check all that apply.
    a. Improvisational (therapist and/or client(s) improvise music)
    b. Re-creative (therapist and client(s) sing/play pre-composed music)
    c. Receptive (client(s) listens to live or recorded music)
    d. Compositional (therapist and client(s) write music/songs)
    e. Multi-arts (other artistic material incorporated into session)
    f. Other: Specify
    g. n/a – I do not work in this context

    **Additional Comments explain your answer:**

20. What types of music experiences do you use when providing family music therapy services where adults with intellectual disabilities and family caregivers are present and all considered to be clients? Check all that apply.
    a. Improvisational (therapist and/or client(s) improvise music)
    b. Re-creative (therapist and client(s) sing/play pre-composed music)
    c. Receptive (client(s) listens to live or recorded music)
    d. Compositional (therapist and client(s) write music/songs)
    e. Multi-arts (other artistic material incorporated into session)
    f. Other: Specify
    g. n/a – I do not work in this context

    **Additional Comments explain your answer:**

21. What types of music experiences do you use when providing music therapy services where the family caregivers of adults with ID are considered to be the clients (i.e., the adults with an ID are not present)? Check all that apply.
    a. Improvisational (therapist and/or client(s) improvise music)
    b. Re-creative (therapist and client(s) sing/play pre-composed music)
    c. Receptive (client(s) listens to live or recorded music)
    d. Compositional (therapist and client(s) write music/songs)
    e. Multi-arts (other artistic material incorporated into session)
    f. Other: Specify
    g. n/a – I do not work in this context

    **Additional Comments explain your answer:**

22. Based on your knowledge and experience **(even if you have not worked in this context)** please select **two** music therapy approaches that you feel might be of the most benefit when providing music therapy services to adults with intellectual disabilities where

family caregivers are present (i.e., the family caregivers are not considered to be clients per se).

a. Orff Music Therapy
b. Dalcroze Music Therapy
c. Kodaly Music Therapy
d. The Bonny Method of Guided Imagery and Music
e. Nordoff-Robbins Music Therapy
f. Psychodynamic Music Therapy
g. Behavioral Music Therapy
h. Music Therapy in Wellness
i. Neurologic Music Therapy
j. Biomedical Music Therapy
k. Other: specify

**Why did you select these approaches?**

23. Based on your knowledge and experience **(even if you have not worked in this context)** please select **two** music therapy approaches that you feel might be of the most benefit when providing family music therapy services where adults with intellectual disabilities and family caregivers are present and all are considered to be clients.
    a. Orff Music Therapy
    b. Dalcroze Music Therapy
    c. Kodaly Music Therapy
    d. The Bonny Method of Guided Imagery and Music
    e. Nordoff-Robbins Music Therapy
    f. Psychodynamic Music Therapy
    g. Behavioral Music Therapy
    h. Music Therapy in Wellness
    i. Neurologic Music Therapy
    j. Biomedical Music Therapy
    k. Other: specify

    **Why did you select these approaches?**

24. Based on your knowledge and experience **(even if you have not worked in this context)** please select two music therapy approaches that you feel might be of the most benefit when providing music therapy services where the family caregivers of adults with ID are considered to be the clients (i.e. the adults with an ID are not present).
    a. Orff Music Therapy
    b. Dalcroze Music Therapy
    c. Kodaly Music Therapy
    d. The Bonny Method of Guided Imagery and Music
    e. Nordoff-Robbins Music Therapy
    f. Psychodynamic Music Therapy

g. Behavioral Music Therapy
h. Music Therapy in Wellness
i. Neurologic Music Therapy
j. Biomedical Music Therapy
k. Other: specify

**Why did you select these approaches?**

25. Based on your knowledge and experience **(even if you have not worked in this context)** please select **two** types of music experiences that you feel might be of the most benefit when providing music therapy services to adults with intellectual disabilities where family caregivers are present (i.e., the family caregivers are not considered to be clients per se).
    a. Improvisational (therapist and/or client(s) improvise music)
    b. Re-creative (therapist and client(s) sing/play pre-composed music)
    c. Receptive (client(s) listens to live or recorded music)
    d. Compositional (therapist and client(s) write music/songs)
    e. Multi-arts (other artistic material incorporated into session)
    f. Other: Specify
    g. n/a – I do not work in this context

    **Why did you select these experiences?**

    **Can you provide examples of specific interventions that would fall under these music experience categories that you feel would be particularly beneficial?**

26. Based on your knowledge and experience **(even if you have not worked in this context)** please select **two** types of music experiences that you feel might be of the most benefit when providing family music therapy services where adults with intellectual disabilities and family caregivers are all present and considered to be clients.
    a. Improvisational (therapist and/or client(s) improvise music)
    b. Re-creative (therapist and client(s) sing/play pre-composed music)
    c. Receptive (client(s) listens to live or recorded music)
    d. Compositional (therapist and client(s) write music/songs)
    e. Multi-arts (other artistic material incorporated into session)
    f. Other: Specify
    g. n/a – I do not work in this context

    **Why did you select these experiences?**

    **Can you provide examples of specific interventions that would fall under these music experience categories that you feel would be particularly beneficial?**

27. Based on your knowledge and experience **(even if you have not worked in this context)** please select **two** types of music experiences that you feel might be of the most benefit when providing music therapy services where the family caregivers of adults with ID are considered to be the clients (i.e., the adults with an ID are not present).
    a. Improvisational (therapist and/or client(s) improvise music)
    b. Re-creative (therapist and client(s) sing/play pre-composed music)
    c. Receptive (client(s) listens to live or recorded music)
    d. Compositional (therapist and client(s) write music/songs)
    e. Multi-arts (other artistic material incorporated into session)
    f. Other: Specify
    g. n/a – I do not work in this context

    **Why did you select these experiences?**

    **Can you provide examples of specific interventions that would fall under these music experience categories that you feel would be particularly beneficial?**

28. Please share any additional thoughts that you have on the use of music therapy or potential for the use of music therapy with family members who are the primary family caregivers of adults with intellectual disabilities.

**THANK YOU FOR YOUR TIME!**

**Appendix C**

**Consent Form**

**CONSENT TO PARTICIPATE IN "The potential for music therapy intervention with family caregivers of adults with intellectual disabilities: A survey study"**

I understand that I have been asked to participate in a research project being conducted by Karli Purscell of the Creative Arts Therapies Department of Concordia University, (438) 930-5941, purscellk@gmail.com, under the supervision of Dr. Laurel Young of the Creative Arts Therapies Department of Concordia University, (514) 848-2424 ext.4682, laurel.young@concordia.ca.

**A. PURPOSE**

I have been informed that the purpose of this research is to better understand how music therapy can be used with families who are caring for adults with intellectual disabilities.

**B. PROCEDURES**

- I understand that I am being asked to complete a web-based survey that contains 28 questions.
- I understand that I will be asked open-ended and close-ended questions as part of the survey.
- I understand that I am not to include my name or other identifying information in any of my responses.
- I understand that, after the first two questions, I may skip questions that I do not wish to answer.
- I understand that my responses will be completely anonymous, and my e-mail address and IP information will not be stored with my responses.
- I understand that the data from all survey responses will be stored in a secure, password-protected location and all printed materials will be stored in a locked filing cabinet for up to five years after the completion of the survey.
- I understand that only the researcher, thesis supervisor, and statistical consultant (if needed) will have access to the survey data.
- I understand that I am free to withdraw my consent and discontinue my participation in the survey at any time without negative consequences.

**C. RISKS AND BENEFITS**

- I understand that my responses will help to increase knowledge about music therapy practices with family caregivers of adults with intellectual disabilities, which could lead to further development of music therapy interventions/programs for this population.

- I understand that there are no known risks related to completing this survey.
- I understand that I am free to choose not to participate in this study or withdraw from the study at any time with no penalty.

**D. CONDITIONS OF PARTICIPATION**

- I understand that my participation in this study is anonymous (i.e., the researcher will not know, and will not be able to disclose my identity) and voluntary.
- I understand that the data from this study will be published in a thesis. I understand that the completed thesis will be stored as an electronic copy that will be located in Spectrum, an open-access internet database. The database can be located at this address: http://spectrum.library.concordia.ca/.
- I understand that following completion of the thesis, the Investigator may submit the results for publication and/or disseminate the results through presentations.

By checking the box below, I indicate that I have: Carefully studied the above and understand this agreement. I freely consent and voluntarily agree to participate in this study.

☐ I freely consent

If at any time you have questions about the proposed research, please contact the study's Principal Investigator or Faculty Research Supervisor.


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If at any time you have questions about your rights as a research participant, please contact David McLauchlan, the Research Ethics Manager at Concordia University, 514.848.2424 ext. 7481, david.mclauchlan@concordia.ca.