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A Survey of Music Therapists Regarding the Efficacy of Music Therapy in the Treatment of Children and Adolescents with Williams Syndrome

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A SURVEY OF MUSIC THERAPISTS REGARDING THE EFFICACY OF
MUSIC THERAPY IN THE TREATMENT OF CHILDREN AND
ADOLESCENTS WITH WILLIAMS SYNDROME

by

Mayumi Hata

A Thesis
Submitted to the
Faculty of The Graduate College
in partial fulfillment of the
requirements for the
Degree of Master of Music
School of Music

Western Michigan University
Kalamazoo, Michigan
July 2006

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2006

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I dedicate this work to my former clients with Williams syndrome who mindfully taught me joy and appreciation towards our life and music. I wish to thank them for allowing me into their worlds and broadening my view of reality with their perspectives on life.

I also wish to express deep appreciation to my friends who have supported me emotionally. In addition, I wish to thank my professors and mentors for their assistance in this project and wisdom in the profession of music therapy.

Lastly, there exist no words to express how thankful I am to have had strong support of my family throughout this long education process.

Mayumi Hata

A SURVEY OF MUSIC THERAPISTS REGARDING THE EFFICACY OF MUSIC THERAPY IN THE TREATMENT OF CHILDREN AND ADOLESCENTS WITH WILLIAMS SYNDROME

Mayumi Hata, M.M.

Western Michigan University, 2006

The purpose of this study was to determine music therapist' perception of the efficacy of music therapy interventions for clients with Williams syndrome. By surveying music therapists who have clinical experience with individuals with Williams syndrome, this study attempted to gather following information: (a) music therapists' perception of the efficacy of music therapy (b) predominant technique or approach (c) predominant goals (d) collaboration with other professionals and (e) the referral sources for music therapy. The results indicated that music therapists lack information and experience working with the Williams syndrome population. However, many of the participants who had worked with individuals with Williams syndrome saw music therapy as an effective tool to support this population.

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CHAPTER I

INTRODUCTION

Williams syndrome (WS) is a rare genetic disorder that occurs in approximately 1 in 7,500 live births when a small amount of genetic material is “lost” on one of an individual’s chromosome #7. The negative effects of WS vary between individuals but often include cardiac disorders, low birth weight, developmental delays, overly friendly relation patters, learning disabilities, feeding difficulties, perceptual/spatial difficulties, small stature, small and widely spaced teeth, and/ or poor fine motor skills. There are also effects which tend to be positive that include excellent long-term memory, excellent memory of faces, very endearing personality, unusually compassionate attitude, very talkative personality, excellent vocabulary, and/or strong passion for music (Monkaba, 2000, Stromme, Bjornstad, & Ramstad, 2002).

Based on my clinical experiences working with individuals with WS, there seems to be substantial benefit of music therapy for individuals with WS. However, there appears to be very limited clinical research in the extant literature substantiating the efficacy of music therapy for individuals with WS. Because of the wide range of musical abilities that exists among individuals with WS (Don, 1996; Lenhoff, 1996; Lenhoff, 1998a; Lenhoff, 1998b; Stambaugh, 1996), additional research is needed to

address and explore the effects of music therapy for this population.

The purpose of this study is to determine music therapists' perception of the efficacy of music therapy interventions for clients with Williams syndrome. By surveying music therapists who have clinical experience with people with Williams syndrome, the findings from this study may help the music therapy profession to better understand (a) whether music therapists see music therapy as a effective therapeutic intervention for individuals with WS, (b) if there is a predominant technique or approach that is widely utilized or whether most music therapists draw from several different approaches when working with this population, (c) the predominant goals addressed by music therapy interventions when working with individuals with WS, (d) if music therapist collaborate with other professionals to better serve individuals with WS, and (e) the referral sources for music therapy .

CHAPTER II

REVIEW OF RELATED LITERATURE

History of Williams Syndrome (WS)

Williams syndrome (WS) was discovered independently by Fanconi (1952) and Williams, a British cardiologist (Williams, Barrett-Boyes, & Lowe, 1961). The disorder was also called Williams-Beuran syndrome, as well as Infantile Hypercalcemia. However, nothing was known of the genetics of WS at that time. The first meeting of the Williams syndrome Association was held in San Diego in 1984, with several families attending. At that time there were only 60 identified cases of WS in the country. Little had been published on WS other than a few studies of IQ, which were inconclusive. Early research efforts looked at the possible contribution of high levels of calcium in the blood to the syndrome and attempted to find the gene associated with WS based on the hypothesis that it might be related to a calcitonin gene which is related to peptide. (Mervis, Robinson, Bertrand, Morris, Klein-Tasman & Armstrong, 2000; Einfeld, & Florio, 1997; Morris, & Mervis, 1999; Mervis, 2003).

In the 1980's, Bellugi began researching Williams syndrome at the Salk Institute, specifically the cognitive and brain bases of WS contrasted with Down's Syndrome (DS) (Bellugi & George. 2001). In 1993, it was discovered that the gene for

elastin was part of the microdeletion in WS. In 1990's WS clinics, local organizations, regional and national family meetings, and family newsletters were established resulting in more information becoming available to the public regarding WS. Between 1994 and 1995, Bellugi and her colleagues investigated WS as a genetically based syndrome with its well defined phenotype across cognitive, neuroanatomical, neurophysiological, and molecular genetic levels. This was in contrast to earlier studies for the investigation of mental retardation (Mervis, Robinson, Bertrand, Morris, Klein-Tasman & Armstrong, 2000; Einfeld, & Florio, 1997; Morris & Mervis, 1999; Mervis, 2003).

Since 1993, it has been learned that WS is caused by the deletion of one copy of a small set of genes on chromosome 7 (also called long arm of chromosome 7, band 7q11.23), which includes the genes which code for elastin, LIM1 kinase, Frizzled, WSCR 1, and Syntaxin 1 A among others (Korenberg, Chen, Lai et al., 1997; Ewart et al., 1993). In 2001, it was determined that the syndrome occurs in approximately 1 in 30,000 births (Bellugi, & George, 2001). More recent research in Europe indicates WS is now found in approximately 1 in 7,500 births (Stromme, Bjornstad, & Ramstad, 2002). Some of the frequent physical manifestations of WS include a specific heart defect (a narrowing of the aorta), a defect in the production of elastin, and hypercalcemia (Bellugi, & George, 2001). Facial features of individuals with WS are

quite distinctive, and have been described as “pixie-like” and “elfin.” People with WS often look more like each other than they do to people in their own families.

Today special schools and music camps for WS have started worldwide. Publications and TV programs as well as articles in the international press about WS became available.

The Cognitive Profiles of Williams Syndrome: Patterns of Strength and Weakness

Bellugi, Lichtenberger, Jones, Las and Gorge (2001) described WS as a rare genetically based disorder that produces a constellation of distinctive cognitive, neuroanatomical and electrophysiological features. The distinctive cognitive profile of individuals with WS includes relative strength in language and facial processing and profound impairment in spatial cognition. Bellugi and her colleagues also found that the overall cognitive ability (IQ) of individuals with WS is typically in the mild-to moderate range of mental retardation, the peaks and valleys within different cognitive domains. They investigated major dissociations among and within diverse cognitive functions: selectively spared grammatical capacity in the face of marked cognitive deficits, dissociations within language (grammar, semantics) as well as within other domains of cognition (impaired spatial cognition, remarkably spared face processing).

Mervis and colleagues established specific cognitive profiles associated with

WS. In their study, the cognitive strengths and weaknesses of individuals with WS were correlated with language, auditory rote memory, and visuospatial construction (e.g., block design and drawing). Overall level of intellectual ability varied across individuals with WS ranging from severe mental retardation to average intelligence. In the cognitive area, individuals with WS were likely to have better auditory rote memory ability and language abilities, but lower visuospatial constructive abilities (Mervis, Robinson, Bertrand, Morris, Klein-Tasman, Armstrong, 2000). The lack of visuospatial constructive abilities and configural abilities may be due to abnormal neuronal development (Gagliardi, Frigerio, Burt, Cazzaniga, Perrett, & Borgatti, 2003). Moreover, Farran and colleagues suggested that a relationship exists between the impaired spatial relations in WS and impaired comprehension of spatial language to classify spatial relations such as “in,” “on,” and “behind” in WS. (Farran, Jarrold, & Gathercole, 2003). Even though individuals with WS had better language skills, words related to spatial cognition were a problem area in their comprehensive understanding.

Lenhoff (1998a) provided more positive approaches to define cognitive characteristics of individuals with WS. According to Lenhoff, researchers are now finding that individuals with WS also share a number of abilities that are remarkable considering their other cognitive and physical problems. For example, although they

have extreme difficulties with simple addition and subtraction, spatial relations, logical reasoning, and abstract ideas, they show a high level of language development for individuals with cognitive impairments. As a group, many show a great love, appreciation, and talent for music. They have a condition called “hyperacusis,” allowing them to hear the faintest of sounds. They are “people-oriented” and aim to please. They have extremely warm and kind personalities and show a great deal of empathy in understanding the feelings of others (Lenhoff, 1998a).

According to Gagliardi and colleagues (2003), individuals with WS excel in face recognition and show both a remarkable concern for social stimuli and a linguistic capacity for emotionally referenced language. Based on their research with the Animated Full Facial Expression Comprehension Test (AFFECT), a new test of emotional expression perception, the expression recognition performance of individuals with WS did not correlate with age, but was instead found to correlate with IQ. This is compared to earlier findings, replicated in this study, that face recognition performance on the Benton test correlates with age and not IQ. The results of the Benton test have been explained in terms of individuals with WS being good at face recognition. Since a piecemeal strategy can be used, this strategy is improved with practice which would explain the correlation with age. The results indicated that even though individuals with

WS had remarkable ability to recognize faces, there had poor expression recognition abilities. Gagliardi and colleagues (2003) proposed that this may be due to a lack of configural ability since changes in the configuration of the face were an important part of expressions. Furthermore, they pointed out that these reduced configural abilities may be due to abnormal neuronal development and are thus fixed from an early age.

Individuals with WS may also have visuo-spatial difficulties. Farran, Jarrold, and Gathercole (2003) studied bias of divided attention, selective attention and drawing process in individuals with WS. The visuo-spatial abilities of individuals with WS have consistently been shown to be generally weak. From the results of identification tasks, the WS group experienced equal interference from global to local as from local to global levels, and did not show an advantage of one level over another. In the drawing task, individuals with WS were significantly better at drawing the local form in comparison to the global figure, whereas the typically developing control group did not show a bias towards either level. Through these results Farran and colleagues concluded that there were no local biases observed in stimulus identification in WS in either selective or divided attention. However, there was some local bias observed in the drawing process in individuals with WS. The author also suggests that spatial relations are impaired in individuals with WS. This is supported by recent evidence that has

shown that the comprehension of spatial language used to classify spatial relations such as “in,” “on,” and “behind” is impaired in WS. These results imply that the bias in drawing is not necessarily related to a bias at the more perceptual level as have been previously assumed. Instead, Farran and colleagues believes that the local bias observed in the drawing of individuals with WS results from a problem with adhering to the spatial relations when integrating the parts of an image.

Hypersociability and Behavioral Characteristics: The Social and Affective Phenotype of Williams Syndrome

Studies have shown that people with WS display extensive anxiety and have behavioral problems, as do individuals with other disorders (VanLieshout, DeMeyer, Curfs, & Fryns, 1998; Einfeld, Tonge, & Florio, 1997). However, Jones, Bellugi, Lai, Chiles, Reilly, Lincoln, and Adolphs (2001) cite a growing body of evidence (from clinical and laboratory studies, parental report, and from their own observation of several hundred subjects with WS) that individuals with WS may be unusually sociable, friendly, and empathic, also known as hypersociability. Based on this evidence, Bellugi and colleagues examined relationships between cognition, genotype and brain neurobiology. They were interested in unusual social phenotype in WS that includes an overfriendly and engaging personality and investigated the neural and genetic bases of social behavior in WS. They stated that the abnormal profile of excessively social

behavior represents an important component of the phenotype that may distinguish WS from other developmental disorders. The profile of hypersociability was observed across a wide range of ages in WS (Jones, Bellugi, Lai, Chiles, Reilly, Alan, & Adolphs, 2001).

According to Bellugi and her colleagues (2001), people with WS made extensive, and even excessive, use of expressive linguistic devices to engage and involve their audience in both narrative and interview situations. It was also indicated in the study that WS children, beginning at an early age, used evaluative devices to engage and maintain their listeners' attention. The subject with WS also used significantly more evaluative devices than other subject groups, including people with Down's syndrome or normal controls. Children with WS used a preponderance of social engagement devices in contrast to normal control children. Those findings suggest that WS children exploit their developing language abilities for social purposes and have a strong drive toward social interaction that makes up an important and distinctive part of the WS behavioral phenotype. The social drive appears to influence other cognitive domains, including language, and evidence of it can be detected even in simple narrative and storytelling tasks.

Bellugi et al.(Bellugi, & George, 2001) also studied the early development of

the social nature of WS and found the social behavior of infants with WS was characterized by a strong attraction to social interaction that may interfere with their focus on cognitively driven tasks. These findings suggest that many aspects of the expressive and social nature of people with WS are present very early on, and that children with WS may have an attraction to social interaction, which is apparent even in infancy. Social interaction in individuals with WS is developmentally pervasive and is detected in children even before they can talk. The social behavior of individuals with WS also includes an apparent lack of fear of strangers and an overfriendliness with strangers and a remarkable ability to remember the faces and names of individuals that they meet, even for people that they have met only once years earlier (Bellugi & George, 2001). The authors studied the increased tendency of WS individuals to approach and engage in interactions with strangers. Their findings expanded and replicated the data from a prior study (Bellugi, Adolphs, Cassady & Chiles, 1999), and demonstrated that adolescents and adults with WS consistently judge unfamiliar individuals as abnormally approachable, consistent with their interest in approaching strangers and engaging them in real life. These findings support observation that overfriendliness, as targeted in this study, is characteristic of WS individuals during real world social interaction. The strong drive toward social interaction is quantifiable through both objective tasks, such

as those measuring subjective interest in approaching other people, as well as through parental report.

Bellugi and George (2001) also compared the social phenotypes of individuals diagnosed with Williams syndrome, Down's syndrome, and Autism. Based on the contrasting nature of the social phenotypes, the authors stated that the profile of social phenotypes in individuals with WS consisted of excessive interest in others and a lack of inhibition toward approaching other individuals. WS subjects were generally overly social and exhibited a tendency towards hypersociability compared with the individuals with DS and Autism. They also stated that specific differences in sociability existed between individuals with WS and those with other disorders, notably those with Autism. WS children seek out social interaction and eye contact and generally do it in a polite and friendly manner. In contrast, the cardinal feature of Autism is a profound deficiency in social knowledge, affective expression, and communication. The autistic child avoids eye contact and is poor at discriminating facial expressions. The hypersocial drive of subjects with WS appears to strongly distinguish WS from other disorders, including Autism and DS, as well as from normally developing peers. Bellugi and George (2001) concluded that hypersociability is a salient aspect of behavior in WS. The social behavior of subjects with WS is quantifiable and highly unusual relative to other

disorders.

Based on their findings and similarity/differences of the behavioral patterns in clients with the focal bilateral damage to the amygdala in their brain, Bellugi and George (2001) believe there may be links between aspects of abnormal social behavior in WS, and possible dysfunction in the amygdala and other limbic regions. Neuroanatomical contrasts between subjects with WS and Autism may suggest that areas of the cerebellum may play a role in the sociability differences between these two disorders. As the neocerebellar vermis appears to be disproportionately enlarged in individuals with WS. It apparently disproportionately small in individuals with Autism and may be one important substrate of the social deficiencies in the disorder.

In describing behavioral and affective characteristics associated with WS, Morris and Mervis have observed that individuals with WS have greater anxiety, hyperactivity, preoccupations, and inappropriate interpersonal relationships. Other characteristics include short attention span, selective eating habits, overly attention-seeking, being inappropriately happy, and wandering aimlessly. Another defining characteristic is that the children with WS are significantly less likely to repeat words or phrases over and over (Morris, & Mervis, 1999; Einfeld & Florio, 1997).

Einfeld, Tonge and Florio (1997) assessed behavioral and emotional

disturbance in 70 children and adolescents with WS. According to their study, individuals with WS were more likely to be diagnosed with psychiatric disorders. In addition to problems with anxiety, hyperactivity, preoccupations, and inappropriate interpersonal relationship, they also found significantly higher rates of other individual symptoms such as sleep disturbance, hyperacusis and heightened sensitivity to sound. The authors stated that children with WS are more anxious, over-affectionate, and overactive and have shorter attention spans than typical developing children.

According to Scheiber (2000), most individuals with WS suffer from more anxiety than the rest of the population. A common fear among children with WS is hyper-reaction to noises such as sirens, thunder, fireworks, vacuum cleaners, and/or bursting balloons. As mentioned previously, individuals with WS may have difficulty in spatial awareness and it may cause fear towards specific factors. For example, a poor sense of balance can cause anxiety about things like roller coasters, elevators, and/or flying on a plane. In more extreme cases anxiety can create a feeling of being on the edge and restless, a persistent uneasiness and worry, and may result in panic and phobias that restrict participation in ordinary activities. Individuals with WS are more likely to be anxious about upcoming events, sudden changes in schedules, arguments between others, and/or hearing news of natural disasters. In addition, individuals with

WS tend to have strong memories of frightening experiences, memories that return vividly over a long period of time.

Levine, Wharton, and Miranda (1999) believe that such anxiety can be treated effectively. The nature of the anxiety in individuals with WS often takes the form of both generalized anxiety and simple phobias. For individuals with WS, the sources for the most common type of phobias are those related to hyperacusis (i.e., sirens, alarms, fireworks, thunder, appliances, lawn mowers, and other people's sudden loud coughing or laughter). Although anxiety is more common in girls than boys in the general population, there is not a gender difference for individuals with WS. Levine and her colleagues report that behavioral strategies, auditory and visualization relaxation techniques, social stories, role play, pretend play, and medications can be effective tools to treat anxiety and phobia in individuals with WS. Even though medication is one of the treatment options, the authors caution that medication should never be the first measure used to treat anxiety. Rather, suggest starting with therapeutic approaches, and then using medication in combination with therapeutic approaches if necessary.

Neurophysiological Markers of Face Processing in Williams Syndrome

Brain activity with event-related brain potential (ERP) has been linked to face-processing abilities, which are typically spared in individuals with WS (Mills,

Alvarez, George, Appelbaum, Bellugi & Neville, 2001.) The authors' research suggests that adults with WS, like normal children, do not employ markedly different brain systems for recognizing upright and inverted faces, as do normal adults. Their findings indicate that individuals with WS pay increased attention to faces in WS when compared to normal controls. In contrast, abnormalities in the early ERP patterns indicate that index face perception may be specific to WS. Mills and colleagues believe the abnormal N100/N200 complex might be an electrophysiological marker for abnormal face perception in WS. For example, it may be linked to subtle structural abnormalities, or abnormal orientation of specific sulci, both of which are common among all individuals with WS. The results may be linked to increased attention to faces in subjects with WS and might be specific to the disorder. The results were consistent with earlier ERP studies of language processing in WS, which suggested abnormal cerebral specialization for spared cognitive functions in individuals with WS. For future research, Mills and colleagues are planning to examine whether the variability in the amplitudes and scalp distributions of N100/N200 complex can be linked to variability in neurological and genetic profiles of individuals with WS.

Neuroanatomy of Williams Syndrome: A High-Resolution Magnetic Resonance Imaging (MRI) Study

Reiss, Eliez, Schmitt, Straus, Lai, Jones and Bellugi (2001) studied the correlation between neurobiological features in individuals with WS by using high-resolution neuroimaging similar to MRI. The results showed that subjects with WS had decreased overall brain and cerebral volumes, relative preservation of cerebellar and superior temporal gyrus (STG) volumes, and disproportionate volume reduction of the brainstem. The authors suggested that the pattern of cerebral lobe proportions in WS may be altered compared to normal controls with a greater ratio of frontal to posterior (parietal+occipital) tissue. They assessed the tissue composition and stated that, relative to controls, individuals with WS have relative preservation of cerebral gray matter volume and disproportionate reduction in cerebral white matter volume. However, within the cerebral gray matter tissue compartment, the right occipital lobe was noted to have excess volume loss.

One brain area found to be preserved in size in a subject with WS (Reiss et al.), as well as in past imaging investigations of this condition (Hickok et al., 1995a; Hickok et al., 1995b), is the superior temporal region. This region of the brain is thought to be important in the perception and processing of music (Liegeois-Chauvel, Peretz, Babai, Laguitton, & Chauvel, 1998; Zatorre, Evans, & Meyer, 1994), as well as its well-known

function in auditory and language processing (Demonet et al., 1992; Price et al., 1992; Schollosser et al., 1998). It is especially interesting that the gray matter volume of this region appears most preserved in individuals with WS, given their relative cognitive strength in both of the domains of cognitive processing and function. However, it is not clear if this relatively larger gray matter volume of the superior temporal region in WS clients is preserved from birth or attributable to consistently greater use of these cognitive skills over time resulting in larger cortical representation and corresponding increased neuropil. Research of the longitudinal structural and functional imaging studies of young children with WS will likely to help resolve this question (Reiss, Eliez, Schmitt, Straus, Lai, Jones & Bellugi, 2001).

Based on the neuroanatomical findings regarding aberrant brain development, the findings of Reiss and his colleagues appear to concur with the well-known visuospatial difficulties ascribed to WS subjects which suggest a possible neuroanatomical correlate. This also agrees with the known neurobehavioral profile of WS, in which relative preservation of frontal and temporal lobe function such as language and affect are found. Given the emerging evidence of a role for the posterior cerebellum in social and emotional behavior, the significantly increased size of the posterior vermis could be related to the hypersociability and positive affective behavior

frequently observed in individuals with WS.

Special Musical Talent and Williams Syndrome

The relation between clients with WS and special musical talent is another issue that has been investigated by researchers. Don, Schellenberg, and Rourke (1996) identified the following observed musical characteristics of WS: 1) individuals with WS tend to have greater attention span for listening to and participating in musical activities, 2) many seem to have absolute and relative pitch, 3) many seem to be able to learn complex drum beats, such as 7/4, in a short session, 4) individuals with WS tend to have excellent sense of timing, 5) many are able to retain complex music, 6) individuals with WS who learn to sing in foreign languages have near perfect accents, and 7) many of them seem to lack stage fright.

In their research, Lenhoff, Perales, & Hickok (2001) discussed a high incidence of Absolute Pitch (AP) in individuals with WS. Absolute pitch (AP), the capacity to recognize, name and produce the pitch of a musical note without a reference pitch, is reported to occur in 1 out of 10,000 persons in western populations, usually those trained in music before age 6. Of the five individuals who had WS that Lenhoff and his colleagues tested, all possessed near ceiling levels of absolute pitch despite their limited cognitive abilities. Based on the subjects' musical training and their learning style which

primary through listening, the authors believe that the normal critical period of ages 3-6 for acquiring AP may be extended somewhat in individuals with WS (Lenhoff, Perales, & Hickok, 2001). This study suggests that the prevalence of AP in the population of individuals with WS may be greater than that found in the general population of the western world.

Rancer (2004) contends that AP or relative pitch may cause different learning styles in music. She encourages music educators and music therapists to consider different approaches if individuals with WS have AP and/or relative pitch. Rancer further stated that individuals with any degree of perfect pitch learn differently than those without it. According to her, if music is taught using conventional methods, students in the perfect pitch spectrum may become unmotivated and their talents could be left undeveloped. However, when these students are encouraged appropriately, musical talent may blossom in dramatic ways. When a student with perfect or relative pitch reads a simple song or plays a melodious piece of music for the first time, he or she involuntarily processes it in his or her auditory memory. The piece is captured, much like a tape recording. Once this process has occurred, the visual component of the musical piece can be removed and the student can play the same piece of music without any reference to the notes. Based on her experience, Rancer also provided a list of

behaviors and instructions to test AP and relative pitch.

When teaching skills for individuals with WS, Braden and Obrzut recommend that educational professionals emphasize children's strengths instead of re-mediating their weaknesses. From a musical point of view, Reis and her colleagues (2003) recommend a similar approach as Braden and Obrzut. Based on their experiences in a summer program for individuals with WS, they used talent development to educate individuals with WS. This program, Music & Minds, focused on individual learning styles, prior experiences, patterns of talent development, and educational needs. In order to develop programs for this population that include appropriate curriculum and instruction in musical, the authors recommended gathering information about the preferences, interests, learning styles, and music abilities in persons with WS. For music therapists and music educators, knowledge about how music can be used to teach academic areas is crucial. The love and affinity that this population has for music can be used to help address other deficit areas (Reis, Schader, Milne, & Stephens, 2003).

However, other researchers have found limitations in the musical ability of individuals with WS (Hopyan, Dennis, Weksberg, & Cytrynbaum, 2001). Musicality in individuals with WS is not so much an analytic skill in the formal aspects of music as it is a strong engagement with music as a means of expression, play, and perhaps,

improvisation. Because of the limitation in understanding of formal elements of music in individuals with WS, the authors suggest that, at least in the initial stages, musical instruction should be focused less on the acquisition of analytic skill than on the development of musical expressiveness (Hopyan, Dennis, Weksberg, & Cytrynbaum, 2001).

In reporting her experiences of teaching music to individuals with WS, Stambaugh (1996) stressed the selection of instruments. Since the purpose of the program was to expose these students with WS to a great deal of music, a primary goal was to determine what talents the students already had and what instruments they enjoyed so they could search for another teacher when they returned home. She found percussion instruments and piano were popular for all ages while guitar, autoharp, and trumpet were good for adults and teenagers. Clarinet and trombone were difficult dependent on the students' previous experiences (Stambaugh, 1996). Because motor limitations vary in individuals with WS, that may affect the type of musical instruments they can play. Lenhoff (1998a) made additional recommendations depending on the category of motor limitations.

Music Therapy and Individuals with Williams Syndrome

As indicated above, the special musical talents associated with WS may make music therapy an important intervention for individuals with WS. Based on the grouping mechanism of the organization of musical information (Deutsch, 1982), musical mnemonics may be useful aids for individuals with WS to retain information (Gfeller, 1983). Generally, music has benefits on attentional capacity, memory, and distractibility (Morton, Kershner, & Siegel, 1990). As an example of the application of those therapeutic uses of music, music in a talent development approach focusing on strengths, interests, and learning style preferences was found to enhance all participants' understanding of mathematics and to provide opportunities for the further development of their abilities, especially their music potential (Reis, Schader, Milne, & Stephens, 2003).

Based on the anecdotal reports of musical ability in WS and experiences with his own child with WS, Lenhoff (1998a) suggested four generalizations to teaching music to individual with WS: 1) One-on-One teaching is preferred, 2) Children with WS learn best through hearing, 3) Musical notation gets in the way, and 4) Motor limitation may affect the kind of musical instrument played. Although very young individuals with WS enjoy singing and striking rhythm instruments in a group setting, older individuals

with WS learn better in one-on-one settings. Lenhoff also pointed out that a strong motivation for individuals with WS to learn music is to please someone. They seem to need a great deal of reinforcement, with praise offered at every improvement and criticism kept at a minimum.

In the second category, Lenhoff(1998a) mentioned that individuals with WS learn music best through hearing. Therefore recording lessons in a cassette tape, with the student practicing daily while listening to the recorded lessons, was very successful for individuals with WS.

In third category, even though some individuals with WS may be capable of reading musical notation, Lenhoff (1998a) stated that the cognitive processing of the information involved in reading musical notes interferes with the desire to produce music in individuals with WS.

In the last category, Lenhoff (1998a) pointed out the motor problems in the individuals with WS may limit their choice of instruments. Structure of the mouth and lips, difficulty in fine motor movement in fingers, unusual gait, and/or scoliosis may limit instruments choices and their ability to participate in rhythmic dance movements. Even though individuals with WS (including females) are often reported to have low or hoarse voices, there are a number of excellent singers who have WS.

Based on the characteristics and differences in musical learning style in individuals with WS, Coleman (1998) suggested that music therapy and adapted music lessons may be two different types of options when pursuing musical experiences. According to Coleman, adapted music lessons should focus on teaching musical skills, such as proficiency on an instrument or appreciation and understanding of musical styles. On the other hand, music therapy also focuses on non-musical goals by using music and music-related strategies. She mentioned that learning to play an instrument requires (a) the ability to follow simple instructions, (b) some degree of fine motor control and coordination, and (c) the ability to store and recall information from one lesson to another. Therefore, children with cognitive deficits and/or multiple disabilities who desire adapted music lessons may be best served by a music therapist who is trained in creating successful experiences for clients with special needs. Coleman states that the most important thing in both adapted music lessons and music therapy is that children with WS to have fun with music. One of the benefits of music therapy as a therapeutic tool for children is that, whatever the goal, it is almost always fun for them.

Current Musical Opportunities for Individuals with Williams Syndrome

To enhance the connection between music and individuals with WS, the Williams Syndrome Music Camp was founded in 1994 at Belvoir Terrace in Lenox,

Massachusetts, offering the first place where people with WS could focus fully on their passion for music (Scheiber, 2000). In 2002, the music camp changed placement from Massachusetts to Michigan. The Williams syndrome Music and Enrichment Camp at Indian Trails (Whispering Trails Camp) was initiated to provide an appropriate summer enrichment opportunity for teens and young adults with WS. The camp offers two different activity programs. One was music based and focused on nurturing the innate musicality that is present in many individuals with WS through individual instrumental/vocal lessons, theater, chorus, and band. The other program included traditional camp activities (e.g., swimming, basketball, dance, archery, arts and crafts, boating, and/or hiking) lead by activity/occupational therapists.

For younger campers with WS, 2005 was the fifth year for the music therapy based camp had existed at Indian Trails (Whispering Trails Camp). This particular camp was designed to provide a variety of musical experiences for younger children with WS in a relaxed and natural setting. Children ages 6-11 participated in classes that enhanced existing musical abilities and interest, as well as provided opportunities for the development of new musical skills. Non-musical goals, such as fine and gross motor skills and social interaction, were also addressed.

Music interventions for the youngest campers, ages six to seven, included

music and movement, instrumental experiences, and group singing. Music interventions for the older children, ages between 8 to 11, included music and movement, percussion ensemble, tone chime choir, choir, and drum circle. They also had opportunities for piano/ percussion/ ukulele/ voice improvisation sessions with an instructor in addition to group classes. The camp experience also included camper performances, evening campfires, opportunities for swimming, and other outdoor activities.

Parents had opportunities to learn more about age-appropriate music enrichment for their children (from music therapy to private music instruction and school programs) as well as time to get together for informal networking. Parents learned about the possible benefits of music to their child's development.

Summary and Need of the Study

According to the professional literature Williams syndrome (WS) is a rare genetic disorder that occurs in approximately 1 in 7,500 live births when a small amount of genetic material is "lost" on one of an individual's chromosome #7s. The negative effects of WS vary between individuals but often include cardiac disorders, low birth weight, developmental delays, overly friendly relation patterns, learning disabilities, feeding difficulties, perceptual/ spatial difficulties, small stature, small and widely spaced teeth, and/or poor fine motor skills. There are also effects which tend to be

positive that include excellent long-term memory, excellent memory of faces, very endearing personality, unusually compassionate attitude, very talkative personality, excellent vocabulary, and/or a strong passion for music (Monkaba, 2000, Stromme, Bjornstad, & Ramstad, 2002).

Based on my clinical experiences working with individuals with WS, there seems to be substantial benefit in providing music therapy for individuals with WS. However, there appears to be very limited clinical research in the extant literature substantiating the efficacy of music therapy for individuals with WS. Because of the wide range of musical abilities that exists among individuals with WS (Don, 1996; Lenhoff, 1996; Lenhoff, 1998a; Lenhoff, 1998b, Stambaugh 1996), additional research is needed to address and explore the effects of music therapy for this population.

Purpose/ Research Questions

The purpose of this study is to determine music therapists' perceptions of the efficacy of music therapy interventions for clients with WS. By surveying music therapists who have clinical experience with people with WS, the study attempted to answer the following questions:

- 1) What are the current demographics of music therapists working with individuals with WS?

- 2) Were the educational experiences regarding WS provided in the degree program of the respondents? If yes, what aspects of the information regarding WS was taught? Have educational experiences in the degree programs made any difference in the interventions and goals used in the music therapy sessions with individuals with Williams syndrome?
- 3) Are there differences in the settings/structures of the music therapy sessions for individuals with WS?
- 4) Is there a predominant technique or approach in intervention that is widely utilized or do most music therapists draw from several different approaches when working with this population?
- 5) Are there predominant goals addressed by music therapy interventions working with individuals with WS?
- 6) Do music therapists collaborate with other professionals to better serve individuals with WS? If so who are they?
- 7) Where do referrals for music therapy come from?

Statement of Hypothesis

- 1) There will be no difference in the demographic information (credential/professional designation, educational level, AMTA region) of music

therapists who work with individuals with WS.

- 2) A. There will be no difference in techniques/interventions used in music therapy with individuals with WS based on the educational experiences regarding WS that music therapists received in their degree programs.

B. There will be no difference in goals addressed by music therapy interventions when working with individuals with WS based on the educational experiences regarding WS that music therapists received in their degree programs.

- 3) A. There will be no differences in the settings of the music therapy sessions for individuals with WS.

B. There will be no differences in the structure (individual or group session, inclusion, family- included session) of the music therapy sessions for individuals with WS.

- 4) There will be no difference in techniques/interventions used in music therapy with individuals with WS based on music therapists' amount of experiences with individuals with WS.

- 5) There will be no difference in goals addressed by music therapy interventions when working with individuals with WS based on music therapists' amount of

experiences with individuals with WS.

- 6) There will be no difference between music therapists' perceptions of types of professionals whom music therapists collaborate with to better serve individuals with WS.
- 7) There will be no difference between music therapists' perceptions of referral sources between referral sources from parents and from other referral sources.

Assumptions

This study assumes that the music therapists who indicated they worked with individuals with WS had sufficient experience to determine the needs of young children with Williams syndrome, the efficacy of music therapy interventions, and the importance of using music as a therapeutic tool for this population.

Delimitations

The participants in this study will be limited to music therapists who are members of the American Music Therapy Association and who have indicated they work with individuals with WS.

CHAPTER III

METHODOLOGY

Participants

The initial population for this study was current American Music Therapy Association (AMTA) members/music therapists who currently work in Child/Adolescent Treatment Center, Children's Day Care/Preschool, Early Intervention Program, Private Music Therapy Agency, School (K-12), and/or Self Employed/ Private Practice settings. Permission from AMTA was obtained to use the list of names and e-mail addresses from the 2005 Member Sourcebook published by the AMTA. Of these music therapists, 742 had listed emails and were invited via email to participate in this study. However, the initial invitation failed in transmission to 106 of these 742 music therapists (possibly due to email blocking technology or address changes) leaving a total of 636 potential participants. The demographic information of these participants was obtained in a section of the survey and is described later in the results section of this paper.

Instruments

In reviewing the music therapy literature relating to individuals with Williams syndrome (WS), it was determined that there was a lack of information about the

effectiveness of providing music therapy services to individuals with WS. As a result, a researcher-designed survey was created with the purpose of describing the demographics of the music therapists working with individuals with WS and current music therapy services being offered to individuals with WS. Survey questions consisted of yes/no, ranking format, open answer, and checklists. Music therapy models/approaches were selected from relevant literature (Darrow, 2004) and added to the instrument to gather information about current effective practices. The survey consisting of 23 questions plus comments was divided into 7 sections: 1) demographic information, 2) educational training regarding WS, 3) music therapy settings/effectiveness of music therapy for individuals with WS, 4) music therapy techniques/interventions/models/approaches for individuals with Williams syndrome, 5) music therapy goals for individuals with WS, 6) collaboration and team approach, and 7) referrals for music therapy. Prior to inviting the potential respondents to complete the survey, a pilot study was conducted in an attempt to ensure the items on the questionnaire were clear, concise, and complete as possible. Four currently practicing music therapists were selected to receive the survey. They were asked to provide feedback regarding suggested revisions and the length of time required to complete the survey. Based upon the therapists' comments, the wording of some questions was

changed but the length of the questionnaire was kept the same. After all corrections were made, the researcher adapted the final version of the questionnaires into an Internet web page using an online survey company, SurveyMonkey.com®.

Informed Consent Process

This research project was reviewed and approved by the Western Michigan University Human Subject Institutional Review Board (see Appendix A).

Procedure

After obtaining approval of this study by the Western Michigan University Human Subject Institutional Review Board, the 636 music therapists identified by the AMTA sourcebook were contacted via an email consent letter (see Appendix C) containing a hyperlink to the online survey. As indicated in the cover letter, subjects were considered to have granted their permission to participate in the study by completing the survey. The web page was made available to the participants for two weeks. After the first week, a reminder email was sent to the 514 music therapists who had not responded to the survey at that time. At the end of the second week, the data was downloaded using SurveyMonkey.com®'s software to the researcher's personal computer to which only she had access. The data received was only reviewed by the researcher. Access to the data required the researcher's username and a password.

SurveyMonkey.com® makes replies anonymous and unable to be traced to the sender's email address. The results were graphed using the Microsoft Excel® and Minitab® software and described in narrative form.

Limitations

Using an online survey format rather than the traditional paper survey format excluded those music therapists with no computer access and unlisted or no email addresses. However, considering the accessibility of computers and the reported response speed, high response rate and cost efficiency of online surveys (Sheehan, 2001), this format was deemed acceptable. In addition, the use of the AMTA sourcebook for selection of participants may have excluded credentialed music therapists who were not members of AMTA, and may have included music therapists who had very little experience with individuals with Williams syndrome. However, the demographics section of this survey study incorporated questions about the extent of experience with this population in an effort to address this issue.

CHAPTER IV

RESULTS

Of the 636 survey links distributed by email, 171 completed surveys were submitted online, yielding a 29% response rate for Demographic information and Educational experiences. Of the 171 surveys that were completed and submitted online, 75 respondents indicated having working experiences with individuals with Williams syndrome. This resulted in a response rate of 12% from the sections regarding music therapy settings/effectiveness of music therapy for individuals with WS through the section related to the referrals for music therapy. It should be noted that there is a possibility that more than 636 music therapists received the survey hyperlink due to participants forwarding the email invitation to other music therapists. The results of each question as well as cross tabulations of questions are presented below.

Demographic Information

-Research Question 1: What are the current demographics of music therapists working with individuals with WS?

-Hypothesis 1: There will be no difference in the demographic information of music therapists who work with individuals with WS

The first section of the survey asked for basic demographic information about the participants.

Question 1: What are your credentials/ Professional Designations (Select all that apply)?

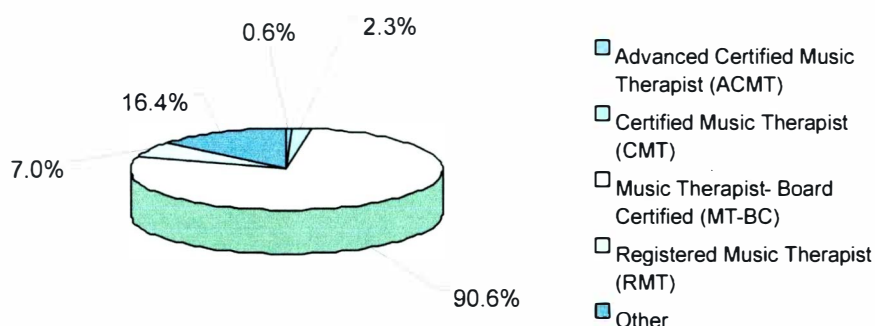


Figure 1. Credentials/Professional Designations

As shown in Figure 1, 90.6% of the respondents (n=171) reported they were Music Therapist-Board Certified (MT-BC). Seven percent or 12 respondents were Registered Music Therapist (RMT), and 16.4% reported that they were Certified Music Therapist (CMT). Only one respondent was an Advanced Certified Music Therapist (ACMT). Less than three percent of the respondents reported other credentials which included: Neurologic Music Therapist, Music Therapist UK certified, Licensed Mental Health Counselor (LMHC), Licensed Creative Arts Therapist in New York State, Fellow of the Association for Music and Imagery, Educational specialist, Developmental Therapist, Speech Language Pathologist, and/or Music Education license. Therefore, the majority of participants in this survey (90.6%) were Music Therapist- Board Certified.

Question 2: What is your highest level of education completed (Select all that apply)?

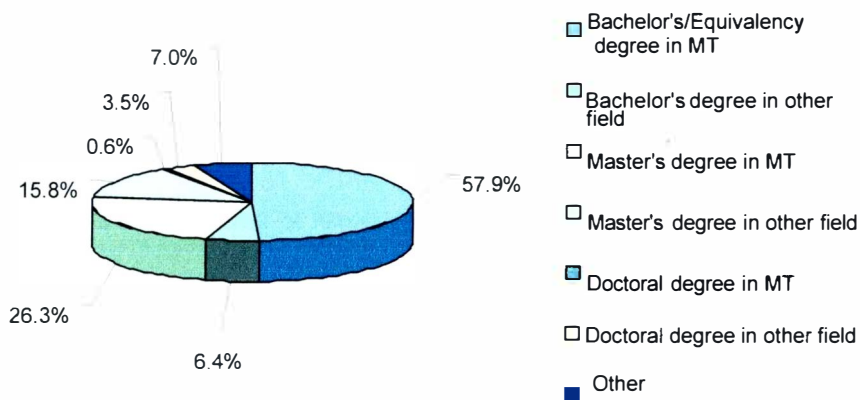


Figure 2. Educational Levels

As shown in Figure 2, 57.9% of the total respondents (n=171) answered that they had a bachelor's degree in music therapy. Twenty-six point three percent of the respondents had a master's degree in music therapy. Six point four percent of respondents answered that they had a bachelor's degree in a field other than music therapy, and 15.8% reported having master's degree in a field other than music therapy. Only 0.6% or 1 respondent who participated in this survey held a doctoral degree in music therapy and 3.5% or 6 respondents answered that they had doctoral degrees in the fields other than music therapy. Seven percent of the respondents indicated that they had other educational degrees including an advanced certificate in educational

administration and leadership, three honorary doctorates, nine graduate credits, adult school credential, community college instructors credential, post graduate diploma related in music therapy, additional coursework beyond masters level, and/or certification in adaptive music education. Therefore, more than half of the participants (57.9%) in this study had at least a bachelor's degree or an equivalent degree in music therapy.

Question 3: AMTA region in which you work

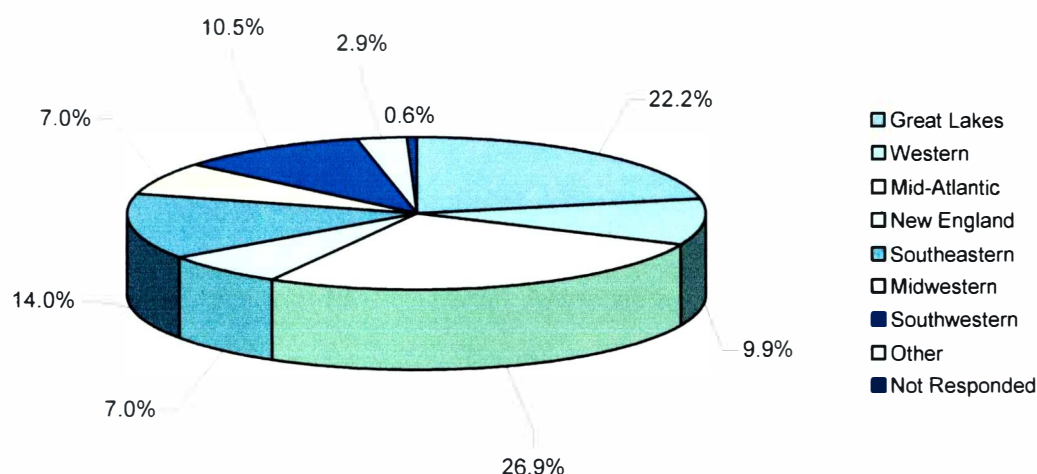


Figure 3. AMTA Region

Figure 3 portrays the geographical distribution of the 171 respondents (including one participant who did not answer this question) across the United States of America and other countries. Although the majority of the participants were fairly evenly distributed across the United States, the two AMTA regions most represented in

this survey were the Mid-Atlantic (27.1%) and the Great Lakes (22.4%) regions. Fourteen point one percent of respondents worked in the Southeastern region, 10.6% worked in the Southwestern region, ten percent of respondents worked in the Western region and 7.1% in the New England region and the Midwestern region. Two point nine percent of the respondents indicated that they worked outside of the United States (Israel, Japan, United Kingdom, Scotland, Puerto Rico, or Mexico.)

Based on the responses to the questions of the survey regarding demographic information, the majority of participants (90.6%) were Music Therapist Board Certified (MT-BC), hold at least a bachelor or an equivalent degree in music therapy (57.9%), and/or were working in the United States of America, especially in Great Lakes or Mid Atlantic region of American Music Therapy Association.

A Chi square test was run to compare the differences between demographic information between each participant. There were significant differences found between participants' credentials ($p=0.001$), the levels of education indicated ($p=0.001$), and regional areas where the participants currently work ($p=0.001$). Therefore, hypothesis one was rejected indicating that there were significant differences in the demographic information of music therapists who participated in this study.

Educational Experiences Regarding Williams Syndrome

-Research Question2: Were the educational experiences regarding WS provided in the degree program of the respondents'? If yes, what aspects of the information regarding WS was taught? Have educational experiences in the degree programs made any difference in the interventions and goals used in the music therapy sessions with individuals with WS?

-Hypothesis 2-1: There will be no difference in techniques/interventions used in music therapy with individuals with WS based on the educational experiences regarding WS that music therapists received in their degree programs.

-Hypothesis 2-2: There will be no difference in goals addressed by music therapy interventions when working with individuals with WS based on the educational experiences regarding WS that music therapists received in their degree programs.

Question 4: Did you learn about Williams syndrome (WS) in your education program (undergraduate, equivalency, graduate programs)?

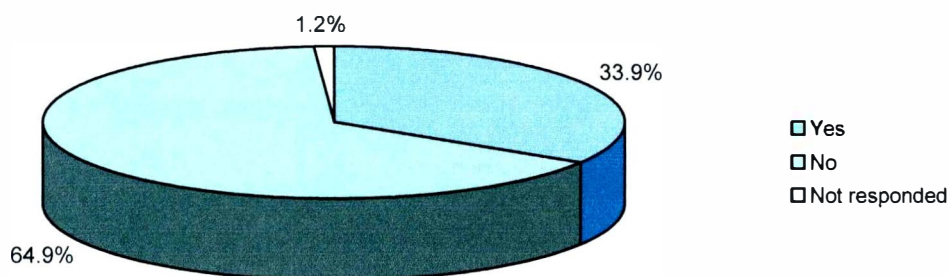


Figure 4. Educational Experiences Regarding Williams Syndrome

As indicated in Figure 4, 33.9% of the respondents (n=171, including two

participants who did not answer this question) answered that they learned about WS in their degree programs while 64.9% of the respondents indicated that they had not learned about WS during their degree program.

Question 5: What aspect of WS did you learn in your educational program (Select all that apply)?

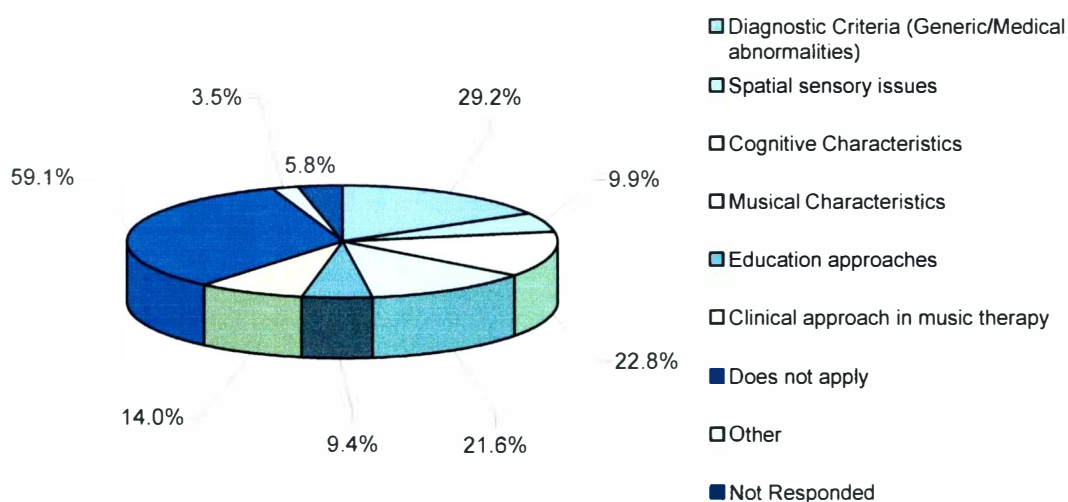


Figure 5: Aspects of Educational Information Received

As indicated in Figure 5 a total of 35.1% reported learning about WS in their educational program. Twenty-nine point two percent or 50 respondents answered that they received information about diagnostic criteria/generic or medical abnormalities associated with WS (n=171, including ten participants who did not answer this

question). Twenty-two point eight percent of the respondents received information about cognitive characteristics of WS, 21.6% received information about musical characteristics of WS, 9.9% received information about spatial sensory issues in WS, 9.4% received information about educational approaches, and 14.0% received information about clinical approaches in music therapy. However, 59.1% of the respondents indicated that this question did not apply to them.

Question 6: In what context was this information presented to you?

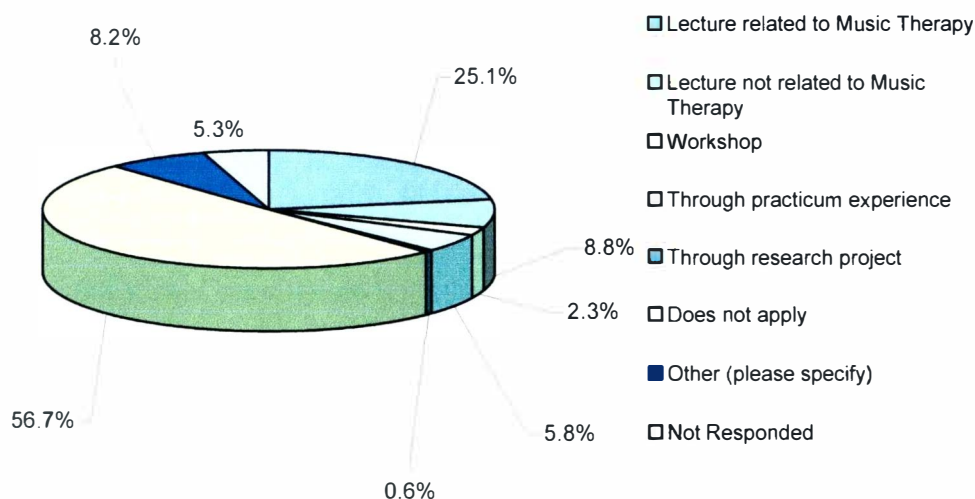


Figure 6. Context of the Educational Experiences Regarding Williams Syndrome

As shown in Figure 6 a total of 38% reported having educational experiences related to WS. Twenty-five point one percent of the respondents (n=171, including

nine participants who did not answer this question) answered that they received information about WS in a lecture related to music therapy. Eight point eight percent of the respondents received information about WS in a lecture not related to music therapy, 5.8% received information through practicum experiences, 2.3% received information in a workshop and 0.6% received information through their research project. Eight point two respondents indicated that they received information in other contexts including video, through employment opportunities in the public school, from journals and other reading materials, from clients, assisting in a summer camp for individuals with WS, from internship experiences, and/or a from class textbook. However, 56.7% of the respondents indicated that this question did not apply for them.

As shown in Figure 4, only 33.9% of the respondents indicated that they received any educational experiences regarding WS during their degree program. This means that almost two thirds of the respondents reported not receiving information regarding WS in their degree programs. According to the answers provided by the respondents who received training about WS in the degree program, diagnostic criteria (generic/medical abnormalities), cognitive characteristics and musical characteristics or WS were the three most frequently reported areas of information provided in their education.

An ANOVA test was run to examine differences between educational experiences in the degree programs and technique/intervention and/or goals addressed by music therapy. There were no significant differences in the techniques/interventions used by the music therapists based on the therapists' educational experiences received in degree programs. Also, there were no significant differences in the goals addressed by music therapists based on their educational experiences received through degree programs. Therefore, hypothesis 2-1 and 2-2 failed to reject indicating there were no significant differences in techniques/interventions and/or goals addressed by music therapy based on the educational experiences received in degree programs.

Music Therapy Settings/Effectiveness of Music Therapy for Individuals with Williams Syndrome

-Research Question 3: Are there differences in the settings/structures of the music therapy sessions for individuals with WS?

-Hypothesis 3-1: There will be no differences in the settings of the music therapy sessions for individuals with WS.

-Hypothesis 3-2: There will be no differences in the structure of the music therapy sessions for individuals with WS.

Question 7: Have you worked with individuals with Williams syndrome?

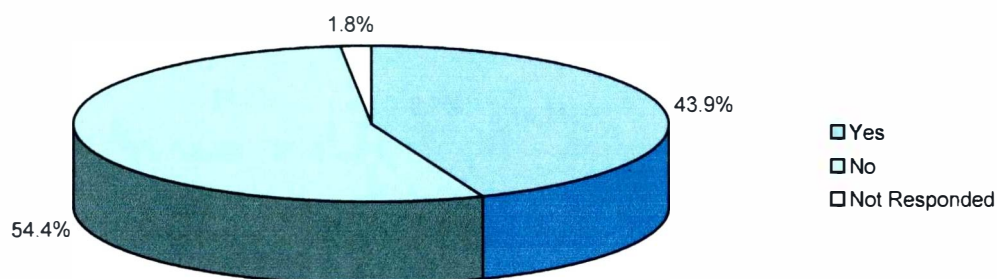


Figure 7. Experiences with Individuals with Williams Syndrome

As indicated in Figure 7, 43.9% or 75 respondents (n=171, including three participants who did not answer this question) indicated that they had experience working with individuals with WS. Fifty-four point four percent or 93 respondents answered that they did not have experience working with individuals with WS. Therefore, 43.9% or 75 respondents who had experience with individuals with WS were eligible to participate in the rest of survey Section 3 through 7.

Question 8: In what type of facility/program have you worked with this population?

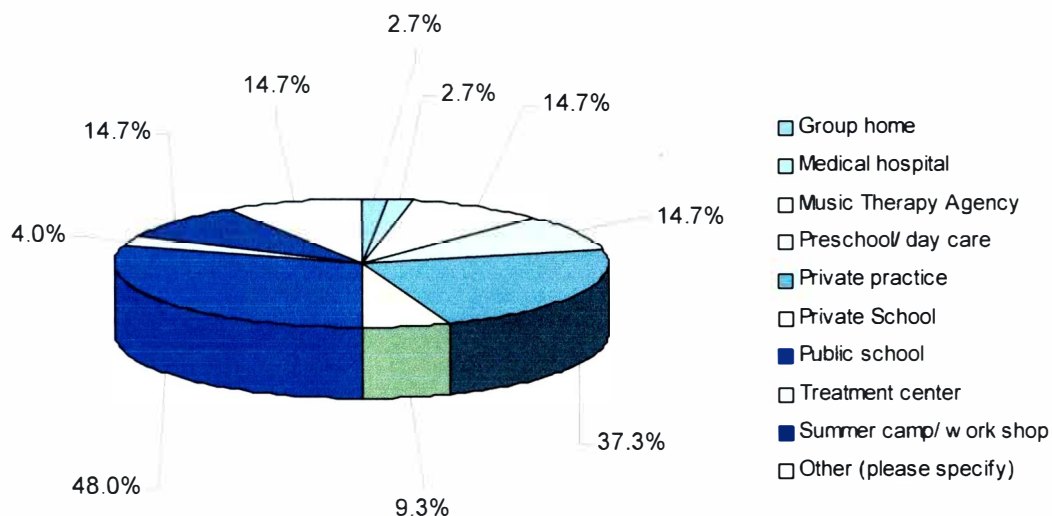


Figure 8. Facilities where Music Therapists have Worked with Individuals with Williams Syndrome

As shown in Figure 8, 48.0% of the respondents (n=75) indicated that they had worked with individuals with WS in the public school setting and 9.3% answered that they had worked with this population in the private schools. Out of 75 respondents, 37.3% indicated they had worked with individuals with WS in their private practice. Fourteen point seven percent of the respondents had worked with individuals with WS in a pre school/day care, music therapy agency, and/or summer camp or workshop settings. Two point seven percent of the respondents indicated that they worked with

this population in a group home and/or medical hospital setting, and 4.0% indicated that they had worked with this population in a treatment center. Fourteen point seven percent of the respondents identified other settings which included: students' homes, community music schools, county board of mental retardation and early intervention and early childhood classes, early intervention, after school activity centers for children with disabilities, residential state schools, and/or on-campus music therapy clinics. Even though the music therapy settings for individuals with WS vary, more than a half of the music therapy services for this population were provided in the public/private school settings.

Question 9: What is the length of your experience with clients with Williams syndrome?

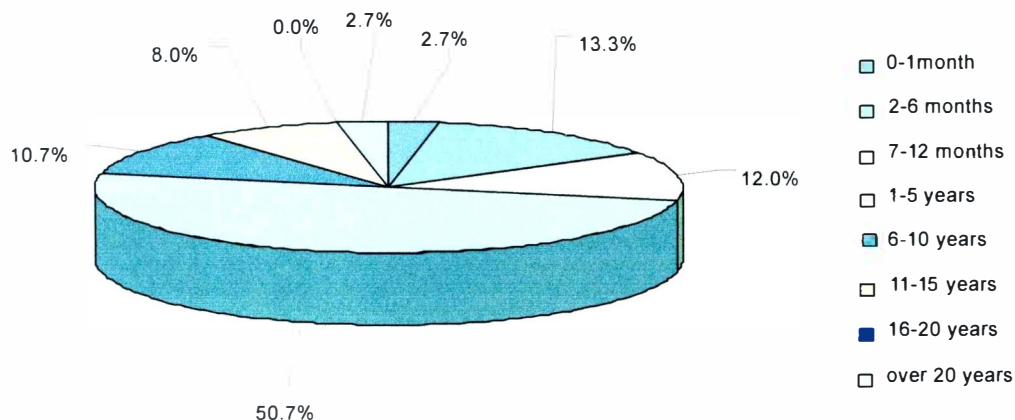


Figure 9. Length of Experience with Individuals with Williams Syndrome

As indicated in Figure 9, 50.7% of the respondents (n=75) answered that the length of their experience with individuals with WS was 1 year to 5 years. Thirteen point three of respondents indicated that they worked with this population for 2 to 6 months, and 12% of respondents for 7 to 12 months. Ten point seven percent of the respondents worked with this population for 6 to 10 years while 8 % or 6 respondents indicated that they worked with this population for 11 to 15 years. Only 2.7% or 2 respondents indicated that they worked with this population either less than one month or over 20 years. As the results are shown here, nearly a half of the respondents had 5 years or less experience with individuals with WS.

Question 10: As a music therapist, how many clients with WS have you worked with?

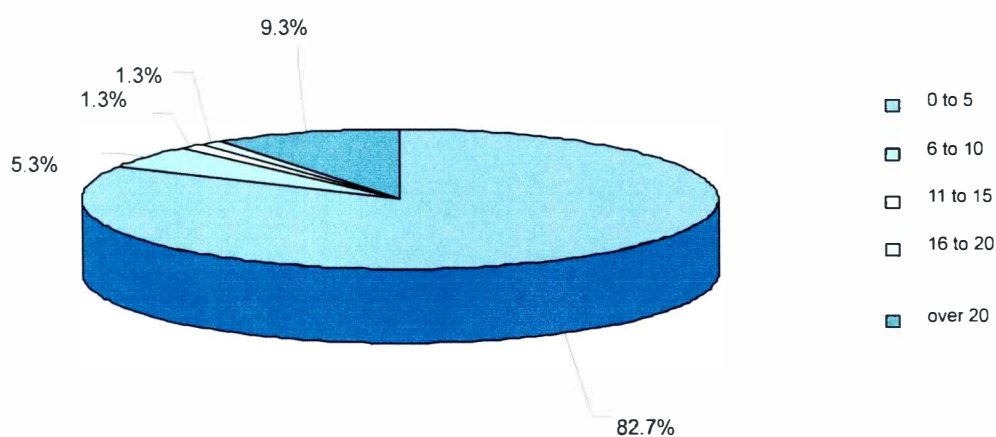


Figure 10. Numbers of Clients with Williams Syndrome in the Past

As shown in Figure 10, 82.7% of the respondents (n=75) indicated that they worked with only 0 to 5 individuals with WS. Five point three percent of the respondents answered that they had clinical experience with 6 to 10 individuals with WS, and 1.3% of the respondents indicated that they had experience with either 11 to 15 or 16 to 20 individuals with WS. Nine point three percent or 7 respondents had experience with more than 20 individuals with WS. When the researcher analyzed other aspects of the seven respondents, all of them had experience working with this population in summer camp/work shop settings as indicated in the question 8. Therefore, summer camp/work shop settings may provide more opportunities to work with large numbers of individuals with WS. As a result, the majority of the respondents (82.7%) had experience working with no more than 1 to 5 individuals with WS.

Question 11: How many clients with WS are you presently working with?

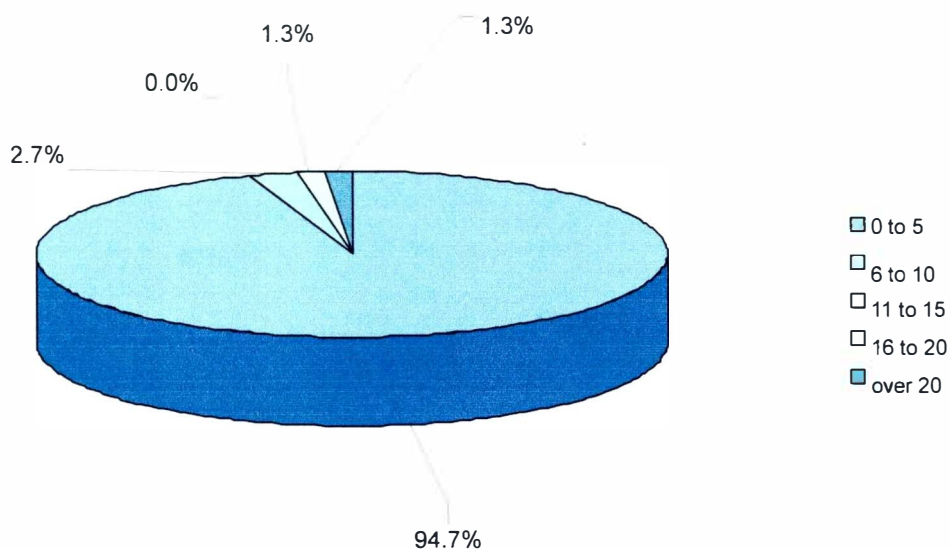


Figure 11. Numbers of Clients with Williams Syndrome in Respondents' Current Music Therapy Practice

As indicated in Figure 11, 94.7% of the respondents (n=75) indicated that they are currently working with 0 to 5 individuals with WS. Two point seven percent of the respondents are working with 6 to 10 individuals, and 1.3% of the respondents reported working with 16 to 20 or over 20 individuals at the present time.

Question 12: Select the top two age ranges of individuals with Williams syndrome you have most often worked with.

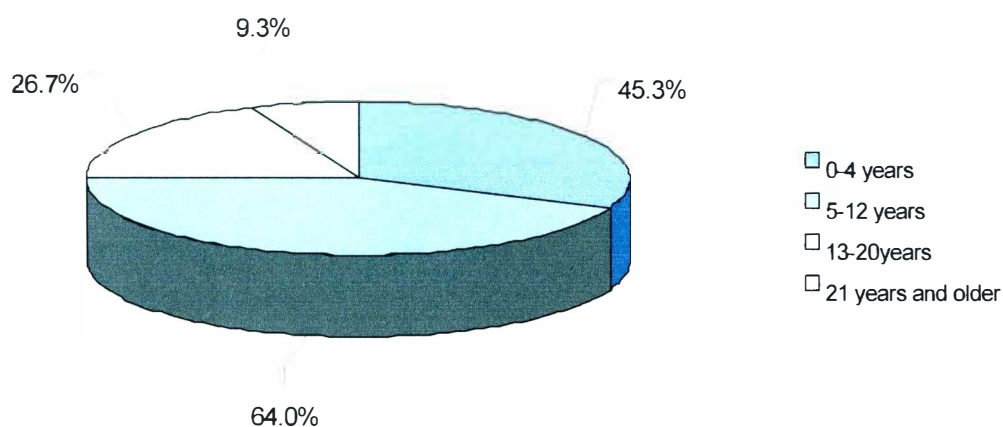


Figure 12. Age Range of the Individuals with Williams Syndrome Receiving Music Therapy

As indicated in the Figure 12, 64% of the individuals with WS receiving music therapy sessions were between 5 to 12 years old. Forty-five point three percent were between 0 to 4 years old and 26.7% of the individuals were between 13 to 20 years old. Only 9.3% fell into 21 years old or older category. Even though it was not statistically significant ($p=0.112$), the distribution of age ranges may have a correlation with the school settings where the majority of the music therapy services were provided (as

indicated in question 8) (n=75).

Question 13: Please indicate the music therapy treatment setting you have used with clients with WS

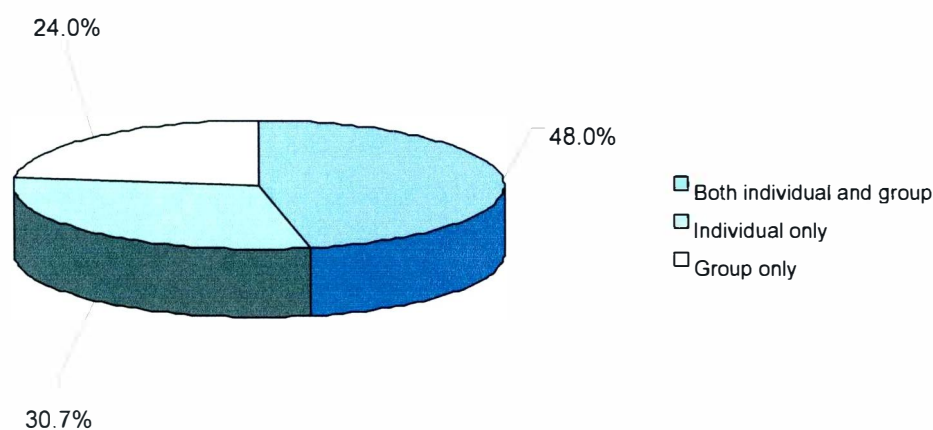


Figure 13. Individual or Group Session

As indicated in Figure 13, 48% of the music therapy sessions with individuals with WS were provided in both individual and group sessions (n=75). Thirty point seven percent of the session for this population were provided in individual sessions only and 24% of the music therapy programs for this population were provided in the group sessions.

Question 14: Approximately what percentage of your clients with Williams syndrome are involved in music therapy sessions with typically developing peers?

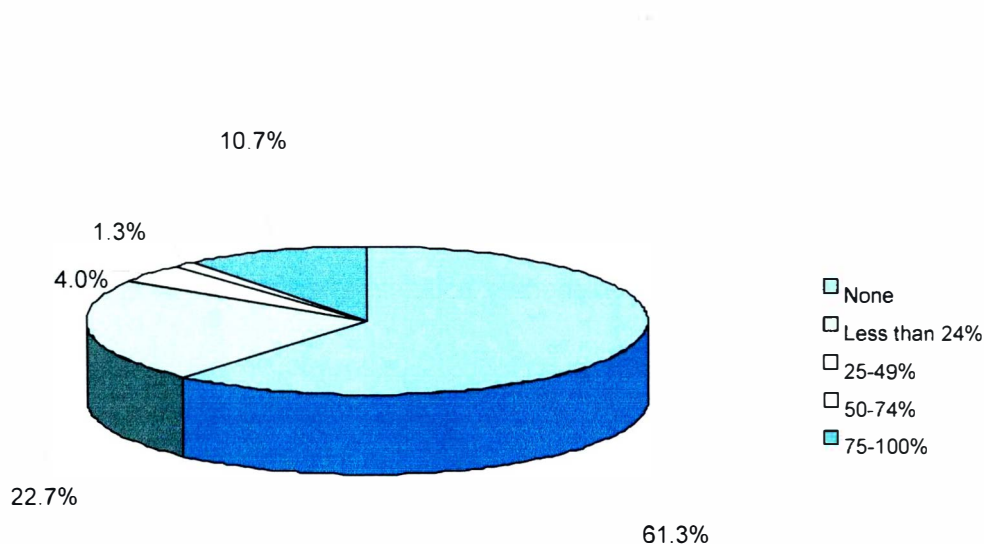


Figure 14. Inclusion Levels

As shown in Figure 14, 61.3% of the music therapy sessions for individuals with WS did not involve typically developing peers ($n=75$). Twenty-two point seven percent of the respondents indicated that less than 24% of their music therapy sessions with individuals with WS involved typically developing peers, 4% or 3 respondents answered that 25% to 49% of the music therapy sessions with clients with WS involved typically developing peers, and only 1.3% or 1 respondent answered that 50-74% of the

music therapy sessions with this population involved typically developing peers. Eight respondents or 10.7% of the respondents indicated that their music therapy sessions with this population involved typically developing peers more than 75% of the time. Therefore, the majority (61.3%) of the music therapy sessions with individuals with WS did not involve typically developing peers.

Question 15: Approximately what percentage of your clients diagnosed with Williams syndrome were involved in family-included sessions on a regular basis?

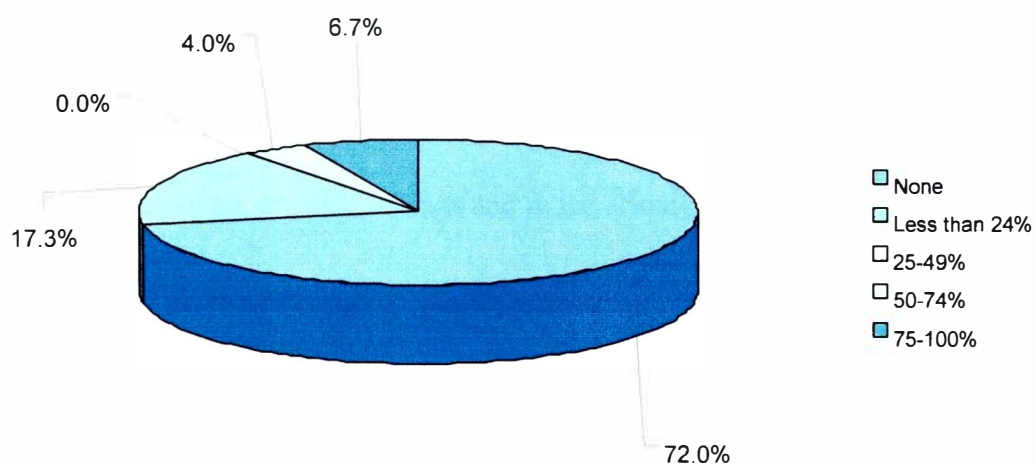


Figure 15. Levels of Family-included Sessions

As indicated in Figure 15, 72% of the respondents (n=75) indicated that

individuals with WS were not involved in family- included sessions on a regular basis. For the purpose of this survey, “regular basis” was defined as “at least one family member is involved in the child’s session for at least once a month for more than three months.” Seventeen point three percent of the respondents indicated that less than 24% of their clients with WS were involved in the family-included sessions on a regular basis, and 4% or 3 respondents indicated that 50-74% of the music therapy sessions with individuals with WS were involved in the family-included session. Six point seven percent or five respondents answered that 75 to 100 percent of their clients with WS were involved with family-included sessions. Out of five respondents who indicated more than 75% of their sessions with individuals with WS were involved with family-included sessions, three respondents identified themselves as working in the private practice settings and in the school or pre-school settings.

Based on the response to question seven, 43.9% or 75 out of 171 respondents answered that they had worked with individuals with WS (see Figure 7). This result may indicated that nearly a half of music therapists in this survey who classified themselves as working in Child/ Adolescent Treatment Center, Children’s Day Care/Preschool, Early Intervention Program, Private Music Therapy Agency, School (K-12), and/or Self Employed/ Private Practice settings encountered WS population. Experiences of the

participants were very similar as 50.7% of the participants (n=75) had one to five years of the experiences, 82.7% of the participants (n=75) had 0 to 5 clients with WS in the past, and 94.7% of the participants (n=75) had 0 to 5 clients with WS in current practice.

Chi square tests were run to examine if there are differences in the settings and structures of the music therapy sessions for individuals with WS. According to the responses for question eight, more than a half of the music therapy services for this population were provided in the public/private school settings. There were significant differences between settings found and hypothesis 3-1 was rejected ($p=0.001$).

There were also significant differences found in most of the structures of the music therapy sessions for individuals with WS. Age ranges of individuals with WS in music therapy sessions varied from 5 to 12 years as a top age ranges served by music therapists (64%, n=75). There were significant differences found between age-ranges of individuals with WS served in the music therapy ($p=0.001$). Even though it was not statistically significant ($p=0.112$), the distribution of the age-ranges may have correlation with the school settings where the majority of the music therapy services provided (as indicated in question 8). Nearly a half of the participants used both individual and group sessions for individuals with WS (48%, n=75). There were

significant differences found between the use of individual/group sessions with individuals with WS($p=0.035$). There were significant differences found in the use of inclusion and family-included sessions (both $p=0.001$). Inclusion with typically developing peers were not common as 61.3% of the respondents ($n=75$) indicated none of their clients were in the inclusion settings when receiving music therapy services. Family-included sessions were also in the minority with 72% of the respondents($n=75$) indicating that none of their clients with WS were involved in family-included sessions. Based on those findings, there were significant differences between the structures of the music therapy sessions for individuals with WS.

Music Therapy:Techniques/Interventions/Models/Approaches for Individuals

with Williams Syndrome

-Research Question 4: Are there predominant techniques or approaches in intervention that are widely utilized or do most music therapists draw from several different approaches when working with this population?

-Hypothesis 4: There will be no differences in techniques/interventions used in music therapy with individuals with WS based on music therapists' amount of experiences with individuals with WS.

Question 16: Please select the three most frequently used interventions in your work with clients with WS.

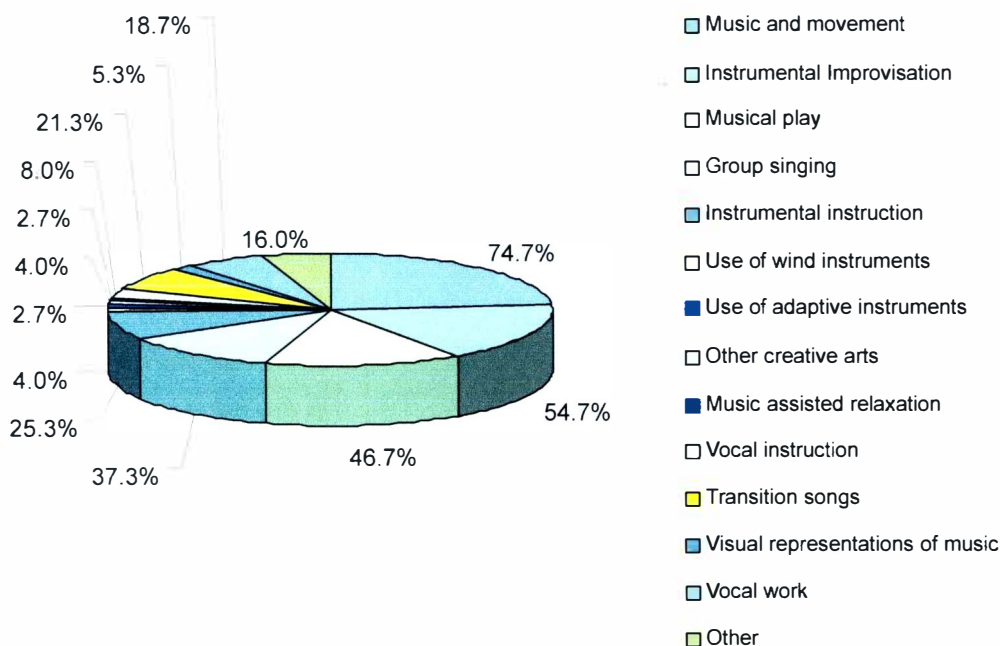


Figure 16. Frequently Used Interventions

As shown in the Figure 16, 74.7% of the respondents (n=75) indicated that music and movement was one of the most frequently used intervention with individuals with WS. Fifty-four point seven percent of the respondents used instrumental improvisation and 46.7% of the respondents used musical play with this population. Thirty-seven point three percent of the respondents indicated that group singing was a frequently used intervention and 25.3% answered that instrumental

instruction was frequently used with this population. Transition songs were used by 21.3% of the respondents and vocal work was mentioned by 18.7% of the respondents as a frequently used intervention. Vocal instruction was used with 8% of the respondents and visual representations of music was used by 5.3% of the respondents. Wind instruments, adaptive instruments, other creative arts, and music assisted relaxation were used by less than 5% of the respondents. Sixteen percent of the respondents listed specific interventions other than those listed in the survey questionnaire including: drum circle activities, interventions incorporated in the academic work specified in IEP, music leading, song writing incorporating cognitive tasks, vocal play, song writing to support academic subjects, performance, and/or social stories/songs.

Question 17: In general, which one of the following styles do you use in the majority of your sessions working with this population?

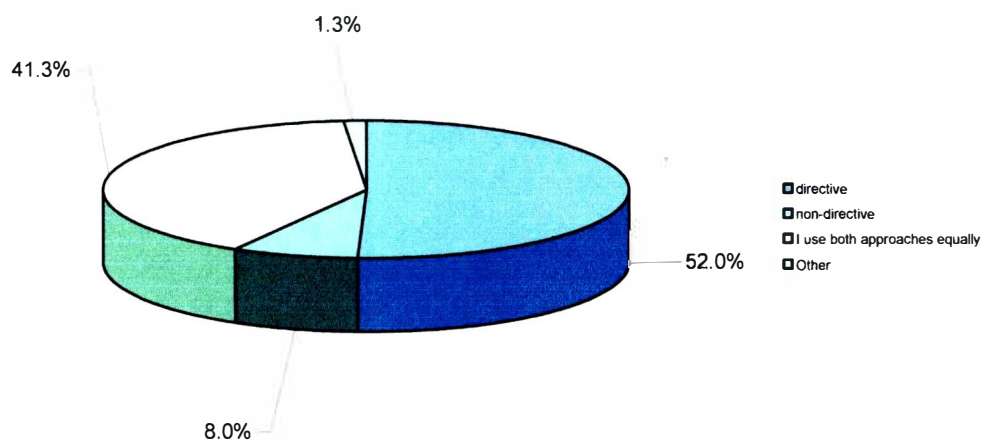


Figure 17: Session Style: Directive/Non-directive

As indicated in Figure 17, 52% of respondents used a directive style to facilitate music therapy sessions with individuals with WS (n=75). Eight percent of the respondents reported that they used a non-directive style to facilitate the sessions and 41.3% stated that they used both directive and non-directive style equally. One point three percent or one respondent selected other and stated that it always depends on each individual how to decide the structure for the session. It was also stated that even though structure is important, expression was key for the successful session with this population.

Question 18: What models/ approaches have you used in your work with clients with Williams syndrome

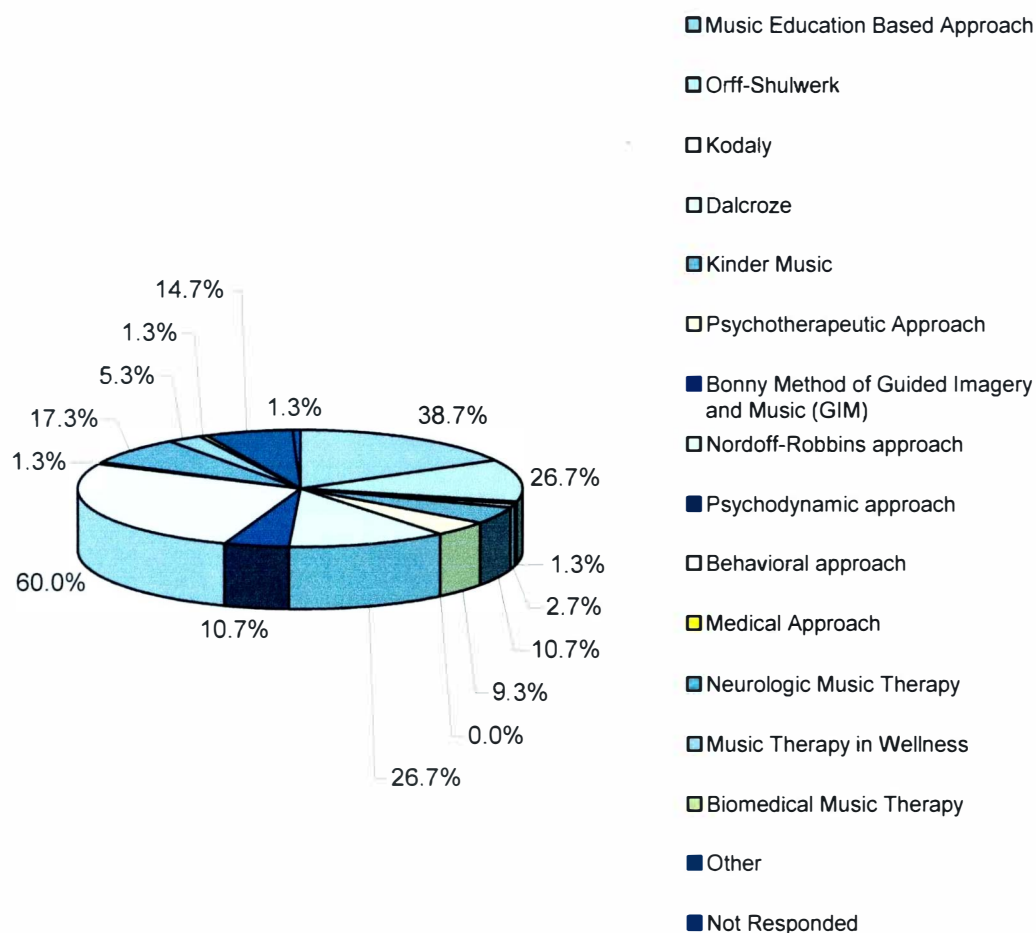


Figure 18: Models/Approaches

As shown in Figure 18, 60.0% of the respondents answered that they used a behavioral approach in their music therapy sessions with individuals with WS (n=75, including four of the respondents who did not answer this question.). Thirty-eight point seven percent of the respondents indicated that a music education based approach was

used in their session and 26.7% of the respondents used an Orff-Shulwerk or Nordoff-Robbins approach. Seventeen point three percent of respondents used a neurologic music therapy approach and 10.7% respondents used a Kinder music or psychodynamic approach. Nine point three percent of the respondents used a psychotherapeutic approach and 5.3% claimed to use a music therapy in wellness approach. Other approaches were used by less than 5% of the respondents including: Kodaly approach, Dalcroze approach, Medical approach, and Biomedical music therapy approach. No respondents reported using the Bonny Method of Guided Imagery and Music with this population. Fourteen point seven percent respondents indicated that they used different approaches than listed in the survey which included: academic task focused approach, Arthur Hull approach (group drumming), IEP based approach, instrumental instruction based approach, attachment-related approach, community music therapy approach, improvisational music therapy approach, and/or keyboard instruction based approach using books by John Schaum, Alfred, Jay Stewart and Betty Glasscock.

Question 19: Which of the following do you employ in the majority of your work with the Williams syndrome population (Select all that apply)?

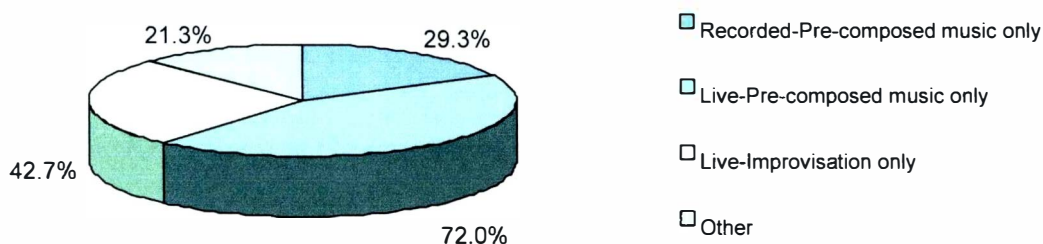


Figure 19. Music Structures

As indicated in Figure 19, most music therapists (72%) used live-pre-composed music in their music therapy sessions with individuals with WS (n=75). Forty-two point seven percent of the respondents indicated that live-improvised music was used and 29.3% of the respondents used recorded-pre-composed music. All participants who commented in “other” category used all three musical structures depending on the clients and session goals and/or structures. When observing what combination of the structures selected by the respondents, only 2 respondents used only recorded-pre-composed music, 19 respondents used only live-pre-composed music, and

only 1 respondent used only live-improvisation. Nine respondents used recorded and live pre-composed music, 4 respondents used recorded-pre-composed music and live-improvisation and 18 respondents used live-pre-composed music and live-improvisation. Twenty-one of the respondents answered that they used all three music structures in their music therapy with individuals with WS.

An ANOVA test was run to examine the differences in techniques/interventions used in music therapy with individuals with WS based on music therapists' amount of experiences with this population. . There was no significant difference found ($p=0.586$) in the length of the experience with this population. However, more than half of the participants ($n=75$) selected music and movement (74.7%) and instrumental improvisation (54.7%) as one of the interventions/techniques often used with this population. Therefore, these results may indicate that there are trends in techniques/interventions used in music therapy with this population.

Although not statistically significant, some trends were found in the models/approaches and music styles used with this population. In the models/approaches, a behavioral approach was selected by 60% of the respondents, and a music education based approach was selected by 38.7% of the respondents ($n=75$). It is noted that Orff-Shulwerk was also used often (26.7%), compared with other specific

music education based approaches (Kodaly[1.3%], Dalcroze[2.7%] and/or Kinder music[10.7%]). The Nordoff-Robins approach was used by 26.7% of the respondents.

Music Therapy Goals for Individuals with Williams Syndrome

-Research question 5: Are there predominant goals addressed by music therapy interventions working with individuals with WS?

-Hypothesis 5: There will be no difference in goals addressed by music therapy interventions when working with individuals with WS based on music therapists' amount of experiences with individuals with WS

Question 20: Please select the three domains/ goal areas where you have observed the MOST progress in music therapy sessions with clients with Williams syndrome.

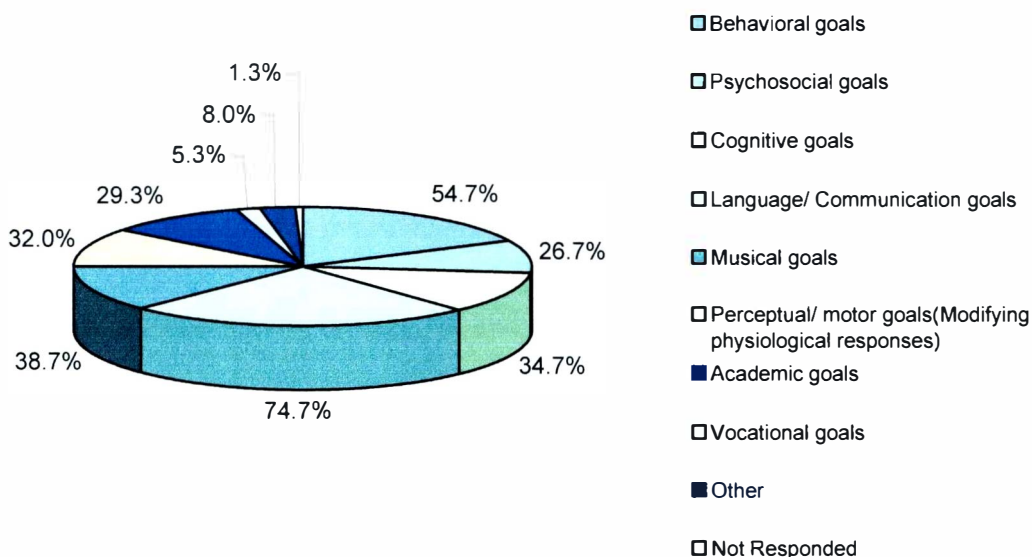


Figure 20. Most Progressed Domains/Goals

As shown in Figure 20, the most progressed domain/goal selected by 74.7% of

the respondents was language/communication goals (n=75, including one respondent who did not answer this question). Following that was behavioral goals selected by 54.7% of the respondents and then musical goals selected by 38.7% of the respondents. Thirty-four point seven percent of the respondents ranked cognitive goals among the top 3 domains/goal areas and 32% of the respondents selected perceptual/motor goals/modifying physiological responses. Twenty-nine point three respondents selected academic goals while 26.7% chose psychosocial goals among the top 3 domain/goal areas. Only 5.3% of the respondents indicated that vocational goals were among the top 3 domain/goal areas. Eight percent of the respondents listed domains/goals other than those provided in the question. They included interpersonal goals, fine motor skills, speech volume and tone, and/or emotional/self-esteem goals. Other comments indicated the observed benefits of music therapy for individuals with WS, one respondent stated that "Rhythm has played a huge part in much of the academic content the student has been able to retain." Another added that "Client's fine motor skills have improved to the point where a raise was granted at the work place."

Question 21: Please select the three domains/goal areas in which you have observed the LEAST progress in music therapy sessions with clients with Williams syndrome

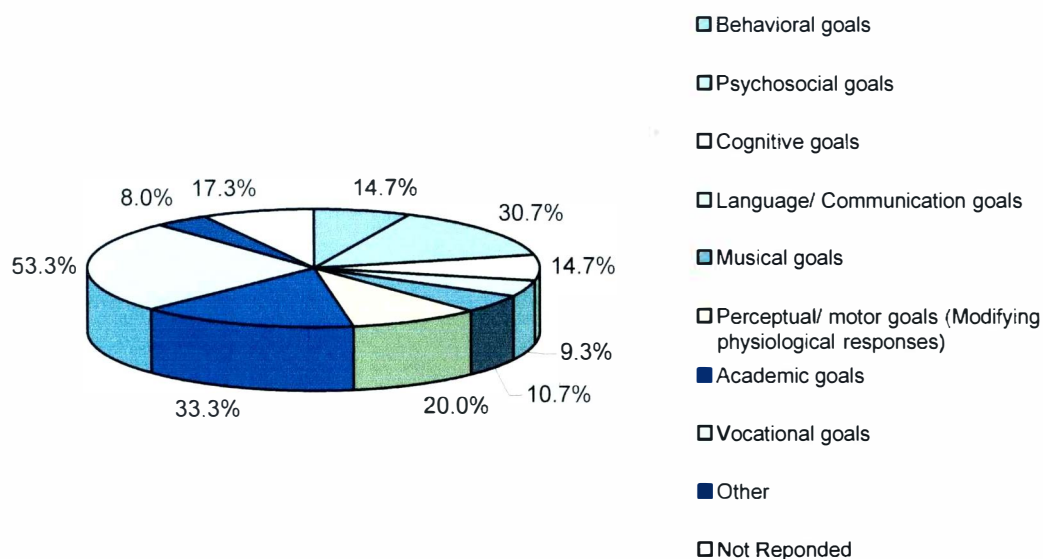


Figure 21. Least Progressed Domains/Goals

As can be seen in Figure 21, 53.3% of the respondents (n=75, including 13 respondents who did not answer this question.) selected vocational goals as the least progressed domains/goals addressed in the music therapy setting with individuals with WS. This was followed by academic goals at 33.3%, psychosocial goals at 30.7%, and perceptual motor goals/modifying physical responses at 20%. Fourteen point seven percent of respondents indicated that behavioral or cognitive goals progressed the least, 10.7% of the respondents indicated that musical goals were least progressed, and 9.3%

answered that language/communication goals were least progressed. Other domains/goals mentioned by some of the respondents as least progressed included: letter identification, naming skills, Individualized Educational Plan(IEP) related goals, and pre-vocational skills (reading, etc.). Some respondents commented that music therapy did not address vocational and cognitive goals. Thirteen of the respondents did not answer this question.

Two ANOVA tests were run to compare the differences in goals addressed by music therapy interventions when working with individuals with WS based on music therapists' amount of experience with individuals with WS. No differences were found for either the most progressed ($p=0.73$) or the least progressed goals ($p=0.64$). Therefore, hypothesis five was rejected. However, the data did indicate some trends in the goals reported by music therapists when working with individuals with WS. Language/communication goals and behavioral goals were mentioned by more than a half of respondents as being the domain/goal areas where respondents observed the most progress with this population. Vocational and academic goals were selected as domain/goal areas where they observed the least progress.

Collaboration and Team Approach

-Research Question 6: Do music therapists collaborate with other professionals to better serve individuals with WS? If so who are they?

-Hypothesis 6: There will be no difference between music therapists' perceptions of types of professionals whom music therapists collaborate with to better serve individuals with WS

Question 22: Please indicate any and all other professionals that you collaborate with

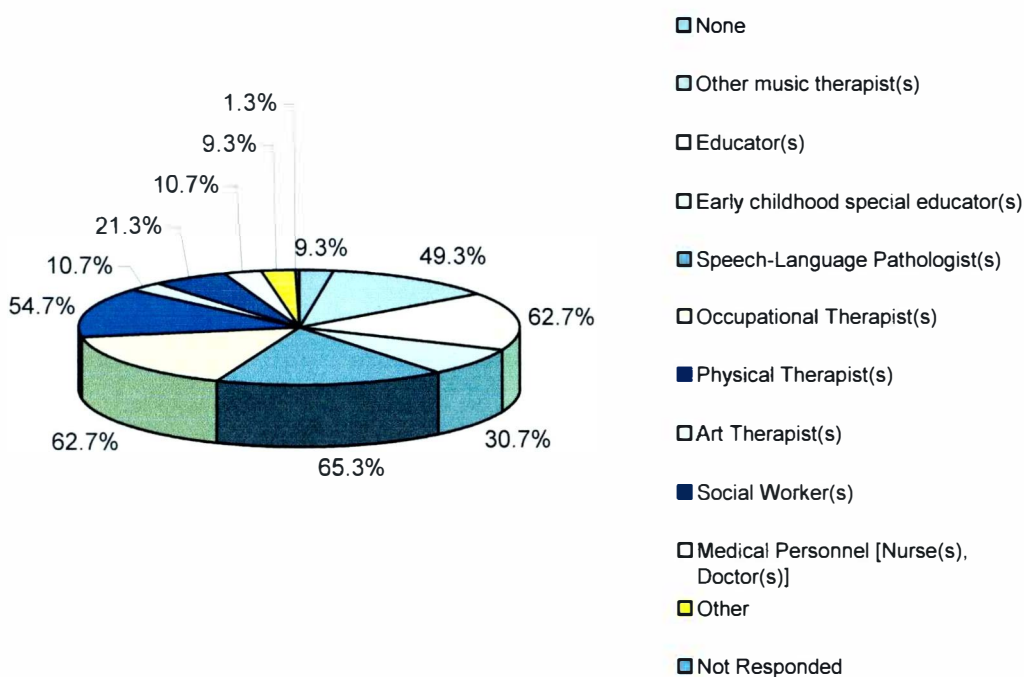


Figure 22. Collaborating Professionals

As shown in Figure 22, 65.3% of the respondents (n=75, including one respondent who did not answer this question) indicated that they collaborated with speech-language pathologist(s), 62.7% indicated that they collaborated with educator(s)

and/or occupational therapist(s), 54.7% of the respondents collaborated with physical therapist(s), and 30.7% of the respondents collaborated with early childhood special educator(s). Twenty-one point three percent of the respondents collaborated with social worker(s) and 10.7% of the respondents answered that they collaborated with either an art therapist and/or medical personnel [nurse(s) or physician(s).] Nine point three percent of the respondents indicated that they do not collaborate with any other professionals. Other professionals that respondents mentioned they collaborated with included: parent(s), psychologist(s), psychiatrist(s), recreation therapist(s), adapted physical education specialist(s), dance/movement specialist(s), and/or neurologist(s).

Question 23: Approximately what percentage of your sessions involves co-treatment with other professionals

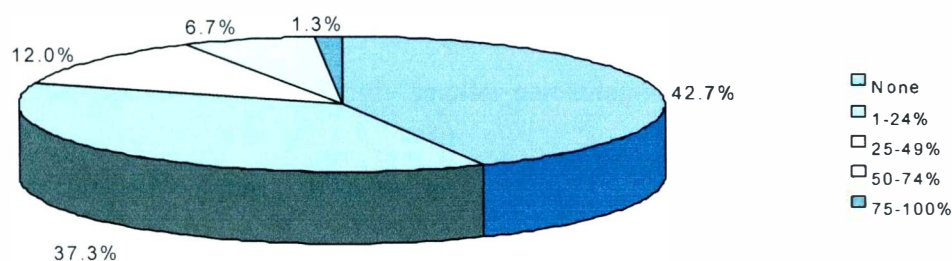


Figure 23. Collaboration in Music Therapy Sessions

As shown in Figure 23, 42.7% of the respondents (n=75) indicated that they do not collaborate with other professional(s) in the music therapy session. Thirty-seven point three percent of the respondents indicated that 1 to 24% of their sessions with individuals with WS included collaboration with other professional(s), 12% of the respondents indicated that 25 to 49% percent of the sessions with this population included collaboration with other professional(s), 6.7% of the respondents indicated that 50-74% of their music therapy sessions with this population included collaboration with other professional(s), and 1.3% of the respondents indicated that 75 to 100% of their music therapy sessions with this population included collaboration with other professional(s).

As shown in Figure 22 and 23, music therapists collaborate with other professionals to better serve individuals with WS. More than 60% of the respondents indicated that they collaborate with speech-language pathologists, educators, and/or occupational therapists. However, a slightly smaller percentage (57.3%) reported being involved in co-treatment with other professionals.

A Chi-square test was run to test the differences between music therapists' perceptions of type of professionals whom music therapists collaborate with to better serve individuals with WS. There were significant differences in the music therapists'

perceptions of type of professionals to collaborate with ($p=0.001$).

Referrals for Music Therapy

-Research Question 7: Where do referrals for music therapy come from?

-Hypothesis 7: There will be no difference between music therapists' perceptions of referral sources between those from parents and those from other referral sources.

Question 24: How involved do you believe each of the following groups are in requesting music therapy for individuals with WS?

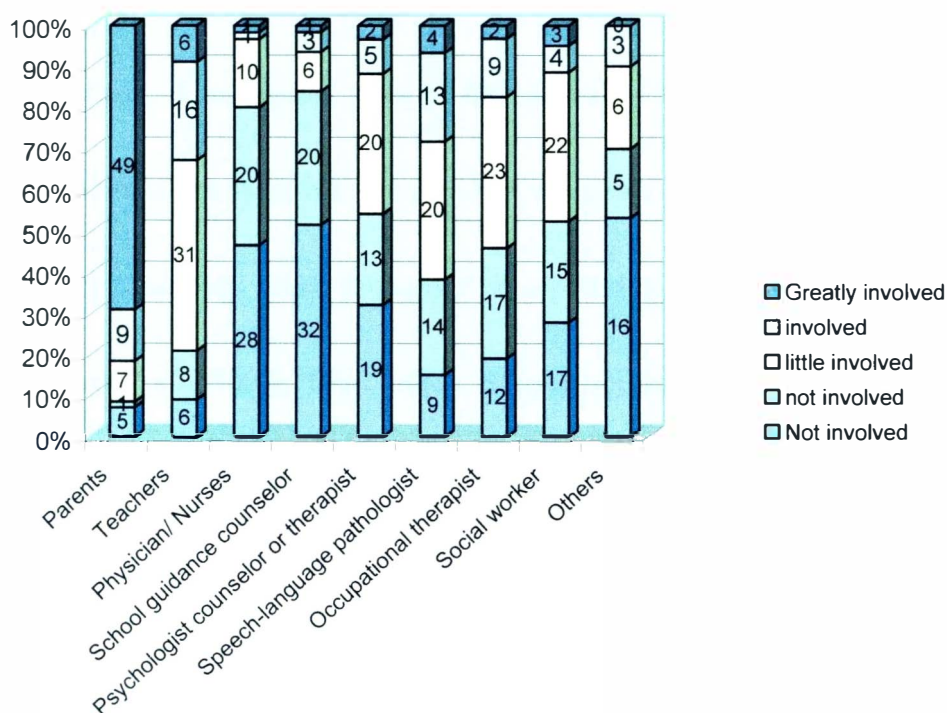


Figure 24. Referral Involvement

As shown in Figure 24, 49 respondents (65%, $n=75$, including two of the

respondents who did not answer this question.) indicated that parents were greatly involved in requesting music therapy for individuals with WS. The other professionals who were selected as “greatly involved” made up less than 10% indicating that parent(s)’ involvement in the referral process for individuals with WS is greater. Teachers, psychologist/counselor/therapist, speech-language pathologist, occupational therapist and social workers were rated as “involved” by 33 to 46 percent of the respondents. Physician/ nurses, school guidance counselor and other professionals were rated as “not involved” by 47 to 53% of the respondents.

Based on the findings, it seems that most of the referrals for music therapy come from the parents of individuals with WS. An ANOVA test and a Tukey-test were run to examine the differences between music therapists’ perceptions of referral sources between those from parents and those from other referral sources. There were significant differences in the referral sources between those from parents and those from other referral ($p=0.001$).

Free Comments

Question 25: Please provide any additional comments that you feel would be relevant to this survey (open ended free comments.)

Thirty-eight respondents wrote open-ended comments relevant to the survey.

Categories of those comments included general experience with individuals with WS (5), clinical experience (8), assessments (2), educational training issues (3), request for more information regarding WS (10), general comments regarding WS and music therapy (10), and/or input regarding survey structures (3). A listing of all of the comments made by respondents is available in appendix F.

CHAPTER V

SUMMARY AND DISCUSSIONS

Based on the results of demographic information, it was found that there were significant differences in the demographic information of music therapists who participated in this study. Location, credentials, and educational levels completed varied among the respondents. These results also indicate that individuals with WS are located throughout the United States and any music therapist may have the opportunity to work with individuals with this disability.

The results from the questions regarding educational experiences indicated that nearly 75% of the respondents did not receive training about WS during the completion of their degree programs. However, that does not necessarily mean that those who did not receive information about WS within their education do not know about this disability. Several respondents commented that they learned about WS from resources outside of their degree programs. The statistical analysis revealed that there were no significant differences in technique/intervention and/or goals addressed by music therapy based on the educational experiences received in degree programs. It may be beneficial for future studies to examine what specific outside resources were used by music therapists to learn about WS, and what updated resources are currently available

for them.

Respondents indicated that the information provided about WS within degree programs was mainly about the diagnostic criteria (generic/medical abnormalities), cognitive characteristics and musical characteristics of WS. In one of the open ended questions, a respondent pointed out that music therapy students today may be more highly educated in specific areas of treatment issues dealing with individuals with WS than students were 20 years ago. This also could depend upon the degree program where one was trained and the particular philosophical model of the degree program. The respondents also mentioned that those differences could be largely a result of curricular changes in music therapy training as a result of the competencies identified by AMTA.

Even though many of the respondents requested information about WS, one commented that whether or not a client has WS should not necessarily be a determining factor in deciding the music therapy caseload. According to this respondent the music therapy caseload should be determined by the clients' age and severity of impairment (Severe and Moderate Cognitive Impairment). This comment does not state that information about WS is not necessary to provide better services for individuals with WS. Another comment expressed an opposing philosophy in music therapy; namely that

it is vitally important to differentiate between general client-group proclivities and tendencies and the personal needs and histories of individuals. As described in the extant literature, individuals with WS use different cognitive patterns to process musical, spatial, and communication related input because of their neuronal characteristics. Therefore, having information about the diagnosis of WS may help music therapists to develop suitable approaches in music therapy to better serve this population. Related to the educational issue, there were many open-ended comments requesting more information regarding WS. Of the 38 comments provided as a response to question 25, 10 respondents either requested information or indicated a lack of information regarding WS. Many suggested that information about WS be included with university music therapy courses, AMTA conference sessions, and/or continuing educational opportunities. Most of the respondents expressed an interest in exploring WS yet indicated there was a lack of information about WS and music therapy. One commented that continuing education should be included not only about WS, but also updated information about endocrinology issues.

The results from the questions regarding music therapy settings/effectiveness of music therapy for individuals with WS present the current picture of music therapy services for individuals with WS. According to the results from this section, 45% of

music therapists encountered someone with WS, particularly those music therapists who reported working in Child/Adolescent Treatment Centers, Children's Day Cares/Pre-schools, Early Intervention Programs, Private Music Therapy Agencies, Schools (K-12), and/or Self Employed/ Private Practice settings. Music therapists' experiences were very similar in the length of practice with this population and the number of the clients with WS they have served. More than half of the respondents had only 1 to 5 years of experience with this population and more than 80% of the respondents worked only with 1 to 5 clients. Even though more than a half of the music therapy services for this population were provided in the public/private school settings, significant differences between settings were found ($p=0.001$).

There were also significant differences found in most of the structure of the music therapy sessions for individuals with WS. Age ranges of individuals with WS in music therapy sessions varied from 5 to 12 ($n=75$). There were significant differences found between age ranges of individuals with WS ($p=0.001$). Even though it was not statistically significant ($p=0.112$), the distribution of the age range may correlate to the school settings where the majority of the music therapy services were provided. Nearly half of the participants provided both individual and group sessions for individuals with WS (48%, $n=75$) and there were significant differences found between the use of

individual/group sessions with individuals with WS ($p=0.035$). There were significant differences found in the use of inclusion and family-included sessions (both $p=0.001$). Inclusion with typically developing peers was not as popular. More than half (61.3%, $n=75$) of the respondents indicated none of their clients were in the inclusion setting when receiving music therapy services. An even larger number (72% of the respondents [$n=75$]) indicated none of their clients with WS were involved in family-included sessions. Based on those findings, there were significant differences found between the structures of the music therapy sessions for individuals with WS.

The results from the section regarding music therapy techniques/interventions/models/approaches for individuals with WS revealed that there were no significant differences between techniques/interventions used in music therapy with this population based on music therapists' amount of experiences with this population ($p=0.586$). More than half of the participants ($n=75$) selected music and movement (74.7%) and instrumental improvisation (54.7%) as one of the interventions/techniques often used with this population. There were some comments supporting the importance of repetition, use of rhythm, and multi-sensory approaches when providing music therapy services for this population.

Although not statistically significant, there were some trends found in the

models/approaches and music styles used with this population. In regards to the models/approaches used, a behavioral approach was selected by 60% of the respondents and a music education based approach was selected by 38.7% of the respondents (n=75). It is noted that Orff-Shulwerk was used more often (26.7%), than other specific music education based approaches, including Kodaly (1.3%), Dalcroze (2.7%) and/or Kinder music (10.7%). The Nordoff-Robins approach was also used by 26.7% of the respondents.

The results from the section regarding music therapy goals for individuals with WS indicated that there was no correlation between goals addressed by music therapy interventions when working with individuals with WS and music therapists' amount of experience with individuals with WS ($p=0.73$ for most progressed goals and $p=0.64$ for least progressed goals.) However, language/communication goals and behavioral goals were mentioned by more than half of respondents as being the domain/goal area where they had observed the most progress with this population. Vocational and academic goals were indicated as the areas where they had observed the least progress with this population.

However, some respondents did indicate that they addressed academic goals and vocational goals successfully in their client(s) with WS. One commented that her

experiences to adjust academic goals for the student and concluded that retention seemed better within the structure of musical interventions. Moreover, this respondent commented that the assessment showed an increase in attentiveness to difficult academic tasks, higher retention of some concept and continuous effects on the objectives stated in the IEP.

Another respondent also stated that music was more than a motivator for this population. The respondent indicated that advanced clients were able to tell teachers that they needed to sing it or bring it to music therapy when confused about a task/skill. Another also commented that rhythm had played a huge part in much of the academic content that the student had been able to retain. These comments characterize how widely music therapy may be utilized for this population.

Although vocational goals were not reported as a major goal area addressed in music therapy, one respondent described a successful program to address vocational goals through music therapy. According to her comment, a client benefited from a program arranged through his school vocational training to gain experience assisting music therapists. She concluded that the goals within this vocational training, pertaining to task focus and attention to detail, were continually being achieved. Also, another respondent commented that as a result of music therapy interventions a client had

received a raise at work due to improvement in the fine motor skills. These statements regarding academic and vocational goals suggest that music therapy may be able to support individuals with WS in their academic and vocational areas.

As shown in the results of the sections related to collaboration and team approach, most music therapists collaborate with other professionals to better serve individuals with WS. More than 60% of the respondents indicated that they collaborate with speech-language pathologists, educators, and/or occupational therapists. There were significant differences in the music therapists' perceptions of types of professionals to collaborate with ($p=0.001$). However, co-treatment is not a popular way to collaborate with those professionals, as 42.7% of the respondents indicated that they do not provide co-treatment with other professionals for individuals with WS. Conversely, one of the respondents commented that co-treatment has proved essential in addressing and impacting IEP goals or treatment goals, based on her experience with this population.

The results from the section related to the referrals for music therapy indicated that most of the referrals for music therapy seemed to come from parents. There were significant differences in the referral sources between those from parents and those from other referral sources ($p=0.001$.) A respondent commented that most of their referrals

were parental by word-of-mouth and paid privately. In the school setting it seems more collaboration took place in the referral process. One respondent indicated that the classroom teacher of a student made the initial request for a music therapy assessment to help the student retain academic content. Observations by all other professionals involved with this student (parent, OT, ST, classroom teacher, case manager for the campus) also supported this referral and confirmed that this student was a strong auditory learner and highly motivated by music.

A complete listing of the comments stated by the respondents who worked with this population is available in Appendix F. These comments indicate that music therapists who worked with this population have observed the efficacy of music therapy for this population. Because many parents request music therapy for their children, it would seem that parents have also observed the efficacy of music therapy for this population. Despite these findings, the results also indicate that there is a lack of clinical information/research of the effectiveness of music therapy with individuals with WS. Furthermore, the data from this study as well as additional comments provided by the respondents suggest that music therapy practice with this population may have a wider application to support this population in real life settings (academic, vocational settings) than was previously thought.

CHAPTER VI

CONCLUSIONS AND RECOMMENDATIONS

The results from this survey indicate that music therapists are integrating diverse treatment models into their clinical work with people with WS. However, one could also interpret the varied range of treatment methods and theoretical influences reported by music therapists to be reflective of the lack of specific interventions based on outcomes research. Additional research is needed to clarify what treatment methods are the most effective with this specific population.

This study described the current techniques and approaches used with individuals with WS. One might assume that the use of a particular intervention/goal is the best or most effective technique in practice. However, as it was indicated in the opposing results and comments from the respondents, this assumption could be false. It is hoped that future research will provide more detailed information regarding the intervention/goals addressed with individuals with WS.

Also, one might assume that the small percentage of respondents who reported receiving information about WS in their degree programs will increase due to changes in music therapy curricula reflecting the AMTA competencies and expanding research base on WS. Given that over half of the respondents reported that they have not

received information regarding WS in their degree programs and there is a great possibility some may eventually work with this population, there is a growing need for information regarding the educational and informational needs of WS. It is this author's opinion that information regarding WS needs to be provided to all music therapists in the field as well as future music therapists in the current degree programs.

In addition, this type of population-specific survey could be conducted in other countries in order to unify and further define the practice of music therapy with these individuals, as well as with the other clinical populations. As the research regarding WS was just started in the past two decades, it is important to continue developing research bases to define the profession's practices with individuals with WS.

Appendix A

Protocol Clearance From the Human Subjects
Institutional Review Board

WESTERN MICHIGAN UNIVERSITY



Human Subjects Institutional Review Board

Date: January 13, 2006

To: Brian Wilson, Principal Investigator
Mayumi Hata, Student Investigator for thesis

From: Mary Lagerwey, Ph.D., Chair

Mary Lagerwey

Re: HSIRB Project Number: 05-12-07

This letter will serve as confirmation that your research project entitled "A Survey of Music Therapists Regarding the Efficacy of Music Therapy in the Treatment of Children and Adolescents with Williams Syndrome" has been approved under the exempt category of review by the Human Subjects Institutional Review Board. The conditions and duration of this approval are specified in the Policies of Western Michigan University. You may now begin to implement the research as described in the application.

Please note that you may only conduct this research exactly in the form it was approved. You must seek specific board approval for any changes in this project. You must also seek reapproval if the project extends beyond the termination date noted below. In addition if there are any unanticipated adverse reactions or unanticipated events associated with the conduct of this research, you should immediately suspend the project and contact the Chair of the HSIRB for consultation.

The Board wishes you success in the pursuit of your research goals.

Approval Termination: January 13, 2007

Appendix B

A Survey of Music Therapists Regarding the Efficacy of Music Therapy in the Treatment of Children and Adolescents with Williams Syndrome

**“A survey of music therapists regarding the efficacy of music therapy in the treatment of
children and adolescents with Williams syndrome”**

Survey Question

1) Demographic Information

1-1 What are your credentials/ Professional Designations (Select all that apply)?

☐ Advanced Certified Music Therapist (ACMT)

☐ Certified Music Therapist (CMT)

☐ Music Therapist- Board Certified (MT-BC)

☐ Registered Music Therapist (RMT)

☐ Other (please specify) _____

1-2 What is your highest level of education completed (Please select all that apply)?

☐ Bachelor's degree (or its equivalency degree) in music therapy

☐ Bachelor's degree in other field

☐ Master's degree in music therapy

☐ Master's degree in other field

☐ Doctoral degree in music therapy

☐ Doctoral degree in other field

☐ Other (please specify) _____

1-3 AMTA region in which you work

☐ Great Lakes

☐ Western

☐ Mid-Atlantic

☐ New England

☐ Southeastern

☐ Midwestern

☐ Southwestern

☐ Outside of the US (please specify) _____

2) Educational training regarding Williams syndrome(WS)

2-1 Did you learn about Williams syndrome(WS) in your educational program? (undergraduate, equivalency, graduate programs)

☐ Yes

☐ No

If yes, please answer the following questions. If no, please proceed to question 8-1

2-2 What aspect of WS did you learn in your educational program? (Select all that apply)

☐ Diagnostic Criteria (Generic/Medical abnormalities)

☐ Spatial sensory issues

☐ Cognitive Characteristics

☐ Musical Characteristics

☐ Education approaches

☐ Clinical approach in music therapy

☐ Others

☐ Do not apply

2-3 In what context was this information presented to you?

☐ Lecture related to Music Therapy

☐ Lecture not related to Music Therapy

☐ Workshop

☐ Through practicum experience

☐ Through research project

☐ Others

☐ Do not apply

(If you have not worked with individuals with WS, please proceed to the question 8-1)*

3) Music Therapy settings/ Effectiveness of music therapy for individuals with Williams syndrome

3-1 In what type of facility/ program have you worked with this population (Select ALL that apply, If you are self employed, please select all facility/programs you are working with)

☐ Group home

☐ Inpatient Psychiatric Unit

☐ Mental health center

☐ Medical hospital

☐ Music Therapy Agency

☐ Nursing home/ assisted living facility

☐ Preschool/ day care

- ☐ Private practice
☐ Private School
☐ Public school
☐ Treatment center
☐ Summer camp/ work shop
☐ Other _____ (please specify) _____

3-2 What is the length of your experience with clients with Williams syndrome (i.e., total length of time you have worked with individuals with Williams syndrome, not with each client)?

- ☐ 0-1month
☐ 2-6 months
☐ 7-12 month s
☐ 1-5 years
☐ 6-10 years
☐ 11-15 years
☐ 16-20 years
☐ over 20 years

3-3 As a music therapist, how many clients with WS have you worked with?(NOT including current clients)

- ☐ 0-5
☐ 6-10
☐ 11-15
☐ 16-20
☐ over 20

3-4 How many clients with WS are you presently working with?

- ☐ 0-5
☐ 6-10
☐ 11-15
☐ 16-20
☐ over 20

3-5 Select the top two age ranges of individuals with Williams syndrome you most often worked with.

- ☐ 0-4 years
☐ 5-12 years
☐ 13-20years
☐ 21 years and older

3-6 Please indicate the music therapy treatment setting you have used with clients with WS

☐ Both individual and group

☐ Individual only

☐ Group only

3-7 Approximately what percentage of your clients with Williams syndrome are involved in music therapy sessions with typically developing peers?

☐ None

☐ Less than 24%

☐ 25-49%

☐ 50-74%

☐ 75-100%

3-8 Approximately what percentage of your clients diagnosed with Williams syndrome are involved in family-included sessions on a regular basis (at least one family member is involved in the child's sessions)?

(For the purpose of this question, regular basis defined as at least once a month for more than 3 month.)

☐ None

☐ Less than 24%

☐ 25-49%

☐ 50-74%

☐ 75-100%

4) Music therapy technique/interventions/models/approaches for individuals with WS

4-1 Please select **the three** most frequently used interventions in your work with clients with WS

☐ Music and movement

☐ Instrumental Improvisation

☐ Musical play

☐ Group singing

☐ Instrumental instruction

☐ Use of wind instruments (i.e. kazoo, recorder)

☐ Use of adaptive instruments

☐ Other creative arts (i.e., visual arts)

☐ Music assisted relaxation

☐ Vocal instruction

☐ Transition songs

- ☐ Visual representations of music
- ☐ Vocal work
- ☐ Other (Please specify) _____

4-2 In general, which one of the following styles do you use in the majority of your session work with this population?

- ☐ A directive, structured approach
- ☐ A non-directive, free or open-structured approach
- ☐ I use both approaches equally
- ☐ Other (Please specify) _____

4-3 What models/approaches have you used in your work with clients with Williams syndrome (Select all that apply)

- ☐ Music Education Based Approach
 - ☐ Orff-shulwerk
 - ☐ Kodaly
 - ☐ Dalcroze
 - ☐ Kinder Music
- ☐ Psychotherapeutic Approach
 - ☐ Bonny Method of Guided Imagery and Music (GIM)
 - ☐ Nordoff-Robbins approach
 - ☐ Psychodynamic approach
 - ☐ Behavioral approach
- ☐ Medical Approach
 - ☐ Neurologic Music Therapy
 - ☐ Music Therapy in Wellness
 - ☐ Biomedical Music Therapy
- ☐ Other (Please specify) _____

4-4 Which of the following do you employ in the majority of your work with the Williams syndrome population? (Select all that apply)

- ☐ 1. Recorded-Pre-composed music only
- ☐ 2. Live-Pre-composed music only
- ☐ 3. Live-Improvisation only

5) Music therapy goals for individuals with Williams syndrome

5-1 Please select the **three** domains/goal areas where you have observed the most progress in music therapy sessions with clients with Williams syndrome

- ☐ Behavioral goals
- ☐ Psychosocial goals
- ☐ Cognitive goals
- ☐ Language/ Communication goals
- ☐ Musical goals
- ☐ Perceptual/ motor goals
- ☐ Academic goals
- ☐ Vocational goals
- ☐ Other (Please specify) _____

5-2 Please select the **three** domains/goal areas you have observed the least progress in music therapy sessions with clients with Williams syndrome

- ☐ Behavioral goals
- ☐ Psychosocial goals
- ☐ Cognitive goals
- ☐ Language/ Communication goals
- ☐ Musical goals
- ☐ Perceptual/ motor goals (Modifying physiological responses)
- ☐ Academic goals
- ☐ Vocational goals
- ☐ Other (Please specify): _____

6) ***Collaboration and team approach**

*Collaboration: Collaboration refers to work together with another person or group in order to achieve common goals. In this survey, collaboration includes but is not limited to consultation or interdisciplinary team approach to facilitate interventions together.

6-1 Please indicate any and **all** other professionals that you collaborate with

- ☐ None
- ☐ Other music therapist(s)
- ☐ Educator(s)
- ☐ Early childhood special educator(s)
- ☐ Speech-Language Pathologist(s)
- ☐ Occupational Therapist(s)
- ☐ Physical Therapist(s)

- ☐ Art Therapist(s)
☐ Social Worker(s)
☐ Medical Personnel (Nurse(s), Physician(s))
☐ Others(Please specify)

6-2 Approximately what percentage of your sessions involves co-treatment with other professionals?

- ☐ None
☐ 1-24%
☐ 25-49%
☐ 50-74%
☐ 75-100%

7) Referrals for music therapy

7-1 How involved do you believe each of the following groups are in requesting music therapy for individuals with WS?

	Not involved		involved		greatly involved
Parents	1	2	3	4	5
Teachers	1	2	3	4	5
Physician /Nurses	1	2	3	4	5
School guidance counselor	1	2	3	4	5
Psychologist, counselor or therapist	1	2	3	4	5
Speech-language pathologist	1	2	3	4	5
Occupational therapist	1	2	3	4	5
Social worker	1	2	3	4	5
Other (please specify) _____	1	2	3	4	5

8) Additional Comments

8-1 Please provide any additional comments that you feel would be relevant to this survey. Your time and feedback are appreciated.

If you are done with survey, please click "Submit" at the bottom of this survey. Thank you for your participation

Appendix C

Invitation for Survey/Explanatory of Consent E-mail

Western Michigan University, Department of Music Therapy

Principal Investigator: Brian Wilson, MM, MT-BC

Student Investigator: Mayumi Hata, BA, MT-BC, NMT

A survey of music therapists regarding the efficacy of music therapy in the treatment
of children and adolescents with Williams syndrome

Dear Music Therapist who is working in early intervention, school settings and related fields:

In order (1) to better understand the music therapist's perception of the efficacy of music therapy in the treatment of individuals with Williams syndrome, (b) to provide information regarding the techniques, approaches, goals in intervention in the treatment of individuals with Williams syndrome, and (e) to provide information regarding the collaboration and referral sources in the treatment of individuals with Williams syndrome, I have created an online survey project as my Master's thesis through Western Michigan University. As a fellow music therapist working with individuals with Williams syndrome, I have a vested interest in exploring and helping to define the efficacy of music therapy in the treatment of individuals with Williams syndrome.

Upon approval of the study by the Human Subjects Institutional Review Board (HSIRB), the American Music Therapy Association provided me with your name and contact information.

Your participation in this study may aid in providing a precise picture of the efficacy of music therapy, characteristics of setting and interventions for individuals with Williams syndrome, and music therapy training information necessary working with this population. The researcher plans to make the results of this study available to the music therapy community.

To be eligible for this survey, you should be:

- (1) A board certified music therapist or its equivalent, AND
- (2) Working in the areas of early intervention, a school setting, and/or related field,
AND

You do **NOT** need to have experiences working with individuals with Williams syndrome to participate in the first part of the study

To participate, simply click on the link of the website address below, to access the secure survey web page and follow the instructions to complete the survey. This site will be available to you until January 31st, 2006 and will take approximately 15 minutes of your time. You can decline to participate, stop participating at any time, or refuse to answer any question without repercussions or penalty.

Link to the Survey:

<http://www.surveymonkey.com/s.asp?u=171071678103>

All of the information collected from you is confidential meaning that your e-mail and responses will be kept confidential. SurveyMonkey.com®, the company through which this survey was created, guarantees the security and confidentiality of responses and e-mail addresses. SurveyMonkey.com® makes replies anonymous and unable to be traced to the sender's email address.

In the comment sections in the survey, please do not identify yourself or anyone else to keep your information confidential.

This consent document has been approved for use for one year by the Human Subjects Institutional Review Board (HSIRB) as indicated on January 13th, 2006. Do not participate after January 13th, 2007. Submitting the survey indicates consent to use your answers for this research.

If you wish to obtain the results of this study, have any questions, or should any problems arise during this study please contact the researcher, Mayumi Hata, MT-BC at mayumi.hata@wmich.edu, telephone (269-779-6648), or Brian Wilson, MM, MT-BC, Chair of the Music Therapy Department at WMU and the study advisor at 269-387-4679. You may also contact the Chair, Human Subjects Institutional Review Board at hsirb@wmich.edu, telephone (269-387-8293), or the Vice President for Research (269-387-8298) if questions or problems arise during the course of the study.

I appreciate your time in completing this survey and I thank you in advance for your prompt response.

Cordially,

Mayumi Hata, MT-BC

Appendix D

Reminder/ Follow-up E-mail

Western Michigan University, Department of Music Therapy

Principal Investigator: Brian Wilson, MM, MT-BC

Student Investigator: Mayumi Hata, BA, MT-BC, NMT

A survey of music therapists regarding the efficacy of music therapy in the treatment
of children and adolescents with Williams syndrome

Dear Music Therapist who is working in early intervention, school settings and related fields:

This is a reminder of the letter inviting you to participate in a research project entitled “A survey of music therapists regarding the efficacy of music therapy in the treatment of children and adolescents with Williams syndrome”.

In order (1) to better understand the music therapist’s perception of the efficacy of music therapy in the treatment of individuals with Williams syndrome, (b) to provide information regarding the techniques, approaches, goals in intervention in the treatment of individuals with Williams syndrome, and (c) to provide information regarding the collaboration and referral sources in the treatment of individuals with Williams syndrome, I have created an online survey project as my Master’s thesis through Western Michigan University. As a fellow music therapist working with individuals with Williams syndrome, I have a vested interest in exploring and helping to define the efficacy of music therapy in the treatment of individuals with Williams syndrome.

Upon approval of the study by the Human Subjects Institutional Review Board (HSIRB), the American Music Therapy Association provided me with your name and contact information.

Your participation in this study may aid in providing a precise picture of the efficacy of music therapy, characteristics of setting and interventions for individuals with Williams syndrome, and music therapy training information necessary working with this population. The researcher plans to make the results of this study available to the music therapy community.

To be eligible for this survey, you should be:

- (1) A board certified music therapist or its equivalent, AND
- (2) Working in the areas of early intervention, a school setting, and/or related field, AND

You do **NOT** need to have experiences working with individuals with Williams syndrome to participate in the first part of the study

To participate, simply click on the link of the website address below, to access the secure survey web page and follow the instructions to complete the survey. This site will be available to you until January 31st, 2006 and will take approximately 15 minutes of your time. You can decline to participate, stop participating at any time, or refuse to answer any question without repercussions or penalty.

Link to the Survey:

<http://www.surveymonkey.com/s.asp?u=171071678103>

All of the information collected from you is confidential meaning that your e-mail and responses will be kept confidential. SurveyMonkey.com®, the company through which this survey was created, guarantees the security and confidentiality of responses and e-mail addresses. SurveyMonkey.com® makes replies anonymous and unable to be traced to the sender's email address.

In the comments sections in the survey, please do not identify yourself or anyone else to keep your information confidential.

This consent document has been approved for use for one year by the Human Subjects Institutional Review Board (HSIRB) as indicated on January 13th, 2006. Do not participate after January 13th 2007. Submitting the survey indicates consent to use your answers for this research.

If you wish to obtain the results of this study, have any questions, or should any problems arise during this study please contact the researcher, Mayumi Hata, MT-BC at mayumi.hata@wmich.edu, telephone (269-779-6648), or Brian Wilson, MM, MT-BC, Chair of the Music Therapy Department at WMU and the study advisor at 269-387-4679. You may also contact the Chair, Human Subjects Institutional Review Board at hsirb@wmich.edu, telephone (269-387-8293), or the Vice President for Research (269-387-8298) if questions or problems arise during the course of the study.

I appreciate your time in completing this survey and I thank you in advance for your prompt response.

Cordially,

Mayumi Hata, MT-BC

Appendix E

Contact Information Release Approval from
American Music Therapy Association



American Music Therapy Association

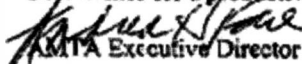
8453 Colesville Rd., Ste. 1000 • Silver Spring, Maryland 20910
Tel. (301) 589-3300 • Fax (301) 589-5175 • www.musictherapy.org

To: Mayumi Hata, Western Michigan University
Fr: Andrea Harbman, Ed.D., AMTA Executive Director
Date: January 11, 2006

Re: Limited approval to use AMTA email listings

Per your request, AMTA grants approval to you for one-time use of the AMTA email listings for a study regarding music therapy. This approval is predicated on the fact that your study is under the direction of an AMTA-approved faculty member and that it is subject to review by the university's IRB. If you require additional information, please let me know.

Best wishes for a productive study.


AMTA Executive Director

Appendix F

Respondents' Comments for Question 25

Comments based on the general/clinical experiences included:

- Our referrals are mostly parental by word-of-mouth. All are private pay. This population is one for which music therapists can provide many services.
- Relating to the previous question, I determine my music therapy caseload according to age of student and severity of impairment (Severe and Moderate Cognitive Impairment).
- Whether or not a student has Williams syndrome is not necessarily a determining factor. Repetition is so important and multi-sensory approaches. Music allows my clients to overcome fears or apprehension in a variety of physical and academic settings. Co-treatment has proved essential in addressing and impacting IEP goals or treatment goals.
- All clients I currently service with WS have made significant documented progress utilizing music therapy. Music is more than a motivator for these children, it makes things 'click'. Advanced clients are able to tell teachers that they need to sing it or bring it to music therapy when confused about a task/skill.
- My client is benefiting from a program created so that he gains experience assisting music therapists. It was arranged through his school vocational training. Goals pertaining to task focus and attention to detail are continually

being achieved

- I feel that one of the best and most useful interventions for individuals with Williams syndrome is music therapy. All parents I have worked with have felt that music therapy is an integral service for their children
- This client group is uniquely susceptible to MT approaches and techniques of intervention. It is vitally important to differentiate between general client-group proclivities and tendencies and the personal needs and histories of individuals
- Classroom teacher of the student I am currently seeing made the initial request that we do an assessment. Student was included in the classroom group (program consult), but the teacher was asking for additional supports to help the student retain academic content. Observations by all involved with this student (parent, OT, ST, classroom teacher, case manager for the campus) were that the student was a strong auditory learner, and highly motivated by music. Materials addressed with the class group were tailored initially for more group work, but I began to include some of the academic content specifically being covered for this student. Retention seemed better within the structure of musical interventions. Assessment showed an increase in attentiveness to difficult academic tasks, higher retention of some concepts, and that continues to be so as

we work on the objectives stated in the IEP.

Comments based on the educational issues included:

- I think that today, students are being more highly educated in specific areas of treatment issues dealing with this disorder than 20 years ago. Of course, this could also depend upon the Mt Program where one was trained and the particular philosophical model of that MT training program. This could be largely a result of curricular changes in MT training, hence the competencies, more than any other reason.

Comments for requesting for more information regarding WS included:

- As a music therapist I believe that university music therapy courses and AMTA conference session should offer information on the importance on music therapy for students with Williams syndrome. Personally, I have only barely heard about Williams syndrome.
- A description of WS would be helpful
- I haven't had experience with this population but know that they are typically very musical...MT must be effective with them. some qualitative case studies of your work would really be interesting and helpful to other music therapists since it is a rare syndrome.

- Presentations or continuing education seminars through AMTA and the CBMT on endocrinology issues, ie. syndromes and diagnostic categories that are relevant to current DSM revisions and MT clinical practice would be appreciated. Very little, if any, has typically been offered in undergrad or graduate MT or special ed. coursework, recent or 'ancient' (like mine from the 1970's).
- Have no idea what Williams syndrome is
- I would like to know more about Williams syndrome because I have heard of it and I think I could work with clients with William's syndrome someday.
- I have heard about Williams syndrome but am not very familiar with it so I don't really know what it is without looking into it again.
- A brief description of Williams syndrome for those who are unaware would be helpful
- I would be interested in a link that tells about Williams syndrome since I am not familiar with it.
- I would have liked to learn about Williams syndrome I'm not familiar with WS

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