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MUSIC AND RETT SYNDROME:
A SURVEY FROM THE PARENTAL PERSPECTIVE

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Carolyn M. Houtaling

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MUSIC AND RETT SYNDROME:

A SURVEY FROM THE PARENTAL PERSPECTIVE

By

Carolyn M. Houtaling

A THESIS

Submitted to Michigan State University
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ABSTRACT

MUSIC AND RETT SYNDROME:

A SURVEY FROM THE PARENTAL PERSPECTIVE

By

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This survey study examined the role of music in the lives of girls and women with Rett Syndrome (RS). The study replicated the work of Merker, Bergstrom-Isaccson, and Witt-Engerstrom (2001), titled Music and Rett Syndrome: The Swedish Rett Center Survey. The researcher, with the help of the International Rett Syndrome Association, sent surveys to 1278 member families who had agreed to participate in research studies. Of those, 438 questionnaires were returned. Respondents were primarily parents of girls and women with RS age 2 through 57 from throughout the United States. The mean age of all respondents was 16. 36 years. The results were as follows: Interest in music was reported by 95% of respondents. Respondents reported on sources and types of music available in the home. Specific music or songs preferences were identified by 82% of respondents; most subjects listed 1 to 3 favorites. Only 54% indicated that some music or songs were disliked. Respondents listed emotional and behavioral reactions that indicated preference or dislike of music or songs. Only 32% of respondents indicated that music therapy had been provided; 88% reported use of music as medicine to treat any of the following symptoms: Upset, stress, pain, anxiety, sadness, boredom, withdrawal, sleep and/or activities of daily living. Quotes are included from the surveys.

DEDICATION

This thesis is dedicated to all girls with Rett Syndrome and their families, but especially to Kim, Amanda, Crystal, Kayla, Veronica, and in memory of Tara.

ACKNOWLEDGEMENTS

This study is based upon the work of Bjorn Merker, Marith Bergstrom Isaccson, and Ingegerd Witt Engerstrom. Their survey was written by Bjorn Merker and published in "Rett Syndrome and the Developing Brain" and in the *Nordic Journal of Music Therapy*. It is used by permission of the authors and the journal. I wish to thank those authors for their pioneering work in the field of Rett Syndrome and for their support with this project.

This thesis would not have been possible without the assistance of the International Rett Syndrome Association (IRSA) and the parents and care givers of girls and women with Rett Syndrome. I wish to thank IRSA for assistance in collecting the survey information and support in this endeavor. It is my hope that the information collected will be valuable to parents, therapists, teachers, and caregivers in enriching the lives of girls with RS. Thanks go to The Great Lakes Regional Association for Music Therapy who provided a special projects grant to help cover expenses.

I would like to thank my family and friends. My husband Alan, my sister Kate and my parents' unfailing love and support throughout this process. Terra Merrill introduced me to the *Nordic Journal of Music Therapy* and to the world community of music therapists, and helped me break through writing blocks. Carol Kolongowski listened and supported my process and read the initial copies for readability and flow. Ted Tims, my thesis committee chair, spent many hours reading my work and advising me. Members of the thesis committee were Cynthia Taggart and Roger Smeltekop, whose expertise in research reporting was invaluable. Finally, thanks to my friends and

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Self Hermaneutic

Relationship to Rett Syndrome

Rett Syndrome (RS) is a genetic, neurological disorder that is seen primarily in females. It results in severe cognitive, communicative and motor impairment. RS has been a part of my history as a music therapist. From my first practicum until today, I have encountered girls and young women with RS in my practice. Over the years, I have witnessed an explosion in research on the subject and followed the revelations in the literature as a possible genetic cause of the disorder was discovered. Because of the relative rarity of the disorder, it is unusual for a music therapist to have the opportunity to work with six people with RS in the course of 15 years of practice outside a Rett Syndrome clinic. This has been my privilege.

I have often wondered how parents experience the child with RS. The agony, bewilderment and frustration involved in the early years of the child's life are beyond my comprehension. The parents and caregivers look to professionals for answers; yet in the early stages, none may be offered. They are left to console and deal with the child as best they can. I believe that the parents and caregivers are the true experts on their daughters. Professionals must find ways to listen to their questions and allow the parents to inform treatment. We must also hone our observation skills to the slightest response that the girls may make.

The girls with RS have captured my heart and my imagination with their beauty, joy, and perseverance. They communicate much with the means that are available to them: their smiles, their eyes, and their expressions. It has always seemed to me that within their facial expressions and behind their eyes, they are saying, "I'm in here, and I understand!" Music and music therapy seem to have a unique potency to suspend their disability for a little while, to improve the quality of their days and to enrich their lives. With this thesis, I hope to learn more about how music impacts their lives on a daily basis.

Path to Research

My undergraduate training was steeped in the positivist world view. I studied behavioral and systems approaches. My early understanding of music therapy approaches focused on observation of the external, outward signs of progress. Internally, I questioned where room for insight and personal determination lay in this approach to therapy.

The American culture is also steeped in the positivistic view. It is observable in many aspects of daily life, including capitalism, material consumption, and outcomes-based education. It can also be observed in the American music therapy community. A cursory glance at the American Music Therapy Association sourcebook reveals many statistical summaries of our population of clinicians and students, revenues, salaries, distribution across the country, and client populations. We seem to be endlessly measuring and quantifying. This was the way I approached my therapy work as well.

As a graduate student, I began to read more about more humanistic and client-centered approaches to therapy. These struck a deep resonance within me. The work of Priestley, Nordoff and Robbins, Ruud, Kenny, and others opened my mind to new ways of thinking about therapy and the self-determination of clients. It also led to a struggle between the positivistic mindset and a more humanistic approach to therapy.

Several people were influential in my development. Ted Tims led me to the some of the world literature about non-positivist approaches to therapy, including Mary Priestley's work, and the Nordoff-Robbins approach to therapy. Colleen Conway's qualitative research course made clear the benefits of a non-positivist research approach and its scientific rigors.

Terra Merrill opened me to the world community of music therapists by sharing the *Nordic Journal of Music Therapy* and introducing me to communication with therapists from around the world. Terra also shared the article "Music and the Rett Disorder: The Swedish Rett Center Survey" (Merker, Isaccson, Witt Engerstrom, 2001), which is replicated in this thesis. This information provided me with the impetus to write my thesis on this particular topic. Tony Wigram and Cochavit Elefant shared their articles and thoughts about music therapy with Rett Syndrome unselfishly and introduced me to the World Federation of Music Therapy web site. Bjorn Merker and Marith Bergstrom Isaccson mentored me through the survey revision and analysis processes. I am grateful for the open way all of these professionals have supported me and shared their knowledge and expertise. Their support demonstrates that music therapy can truly be a world community.

Rett Syndrome: Definition and Clinical Description

Dr. Andreas Rett first described Rett Syndrome in 1966 (Kerr & Witt Engerstrom, 2001). However, it was not until 1983 that the disorder became more widely known (Ellaway & Christodoulou, 2001; Hagberg, Anvret, & Wahlstrom 1993; Lindberg, 1991; Perry, 1991; Van Acker, 1991). Diagnostic criteria for the syndrome were established in 1984 at the second international conference for Rett Syndrome in Vienna. Rett syndrome occurs in a variety of racial and ethnic groups (International Rett Syndrome Association [IRSA] 1999; Kerr & Witt Engerstrom, 2001; Prevsener, 2001). Its prevalence is between 1:10,000 and 1:23,000 (Hagberg, 1993; Kerr & Witt Engerstrom, 2001; Rett Syndrome Association U.K., 2002).

Rett Syndrome (RS) is a complex neurological disorder. It is present at birth and occurs primarily in females, although it can also affect males (Ellaway & Christodoulou, 2001; Pevsener, 2001). Some cases are caused by a genetic mutation on the X chromosome, attributable to the MECP2 gene (International Rett Syndrome Association, 1999; Pevsner, 2001; Rett Syndrome Association U.K., 2002, Siagofoos, 2001). Despite the recent discovery of the role of the MECP2 gene in RS, researchers still do not know what proportion of cases is attributable to this genetic anomaly (Reilly & Cass, 2001). Therefore, clinical diagnosis through observation and clinical assessment using standard criteria is still essential.

The development of a child with RS appears to be normal, up to about six to eighteen months of age. The child with RS typically sits independently and finger feeds at the expected time. Some children begin the use of single words and word

combinations. Many begin independent walking within the normal age range, while others show significant delay or inability to walk independently (IRSA, 1999).

A period of stagnation or regression follows, during which the child loses purposeful use of the hands and begins making repetitive hand movements that become almost constant while awake. These movements include "washing," wringing or mouthing the hands. Irregular breathing, seizures and scoliosis are common. Intelligence is difficult to measure, due to the lack of speech and inability to use the hands to gesture. Many children are misdiagnosed with autism or cerebral palsy.

"Classic" cases of RS are those that fulfill all the diagnostic criteria, while "variant" cases are those that do not. Most variant cases present milder symptoms of RS, especially with regard to gross motor disability and degree of fine motor dysfunction (Ellaway & Christodoulou, 2001). Table 1 shows the primary and secondary characteristics of RS as described in the literature (Hagberg et al., 1993; Kerr & Witt Engertrom, 2001; Perry, 1991; Prevsner, 2001; Van Acker, 1991).

In America and Sweden, RS is described in four clinical stages. These are detailed in the literature (American Psychological Association,1994; Hagberg et al., 1993; Lindberg, 1991; Perry, 1991; Van Acker, 1991; and Kerr & Witt Engertrom, 2001). In the U. K., a three-stage model is becoming more widely accepted. The three stage model combines stages three and four from the previous model (Kerr & Witt Engerstrom, 2001). Historically, the diagnosis is tentative until 2 to 5 years of age (Hagberg et al., 1993; Perry, 1991). However, this may change as researchers and physicians begin to explore relatively recent genetic discoveries. Table 2 includes a summary of the

characteristics of each of the four stages (Hagberg et al., 1993; Kerr & Witt Engertrom, 2001; Perry, 1991; Prevsner, 2001; Van Acker, 1991).

Table 1

Diagnostic Characteristics of Rett Syndrome

Primary Diagnostic Characteristics	**Secondary Diagnostic Characteristics**
▪ Apparently normal prenatal and perinatal period ▪ Apparently normal psychomotor development through the first six months ▪ Normal head circumference at birth ▪ Deceleration of head growth between age 5 months and 4 years ▪ Loss of acquired purposeful hand skills between ages 6 and 30 months ▪ Development of severely impaired expressive and receptive language ▪ Apparent severe psychomotor retardation ▪ Stereotypic hand movements such as hand wringing, hand washing, or rubbing appear after loss of purposeful hand skills ▪ Apraxia and ataxia appearing between ages 1 and 4 years	▪ Seizures ▪ Breathing dysfunction ▪ EEG abnormalities ▪ Peripheral vasomotor disturbances ▪ Spasticity ▪ Scoliosis ▪ Growth retardation ▪ Hypotrophic small feet ▪ Feeding and nutrition problems

Table 2

Rett Syndrome Stages and Characteristics

Stage Number and Title	**Stage One:** ***Early Onset Stagnation***	**Stage Two:** ***Rapid Developmental Regression***	**Stage Three:** ***Pseudostationary or "Wake-Up"***	**Stage 4:** ***Late Motor Deterioration***
Age of onset	5 – 18 months	One to Four years	After passing stage 2	After stage 3 ambulation ceases
Duration	Weeks to months	Weeks to months, up to 1 year	Years to decades	Decades
Characteristics	Delayed development, not significantly abnormal May develop ambulation skills with gait abnormalities Disinterest in play activity Hypotonia	Loss of acquired hand function, replaced with hand stereotypies Loss of acquired communication skills Loss of acquired active playing skills 15% of cases: seizures	Some restitution of communication skills Hand apraxia or dyspraxia Inapparent, slow, neuromotor regression	Loss of ambulation skills; wheelchair dependence Muscle wasting and dystal distorsions

Music Therapy For Individuals With Rett Syndrome

Anecdotal evidence indicates that music plays a significant role in the lives of people with RS. Hill (1997), Lindberg (1991), Montague (1988), and Robbins (2000) state that Dr. Andreas Rett recommended the use of music therapy for girls with RS. Rett Syndrome associations, including the International Rett Syndrome Association (IRSA)

and the Rett Syndrome Association U. K., also advocate music therapy (Hunter, 1999; Montague, 1988). There are Rett Syndrome Associations composed of researchers, therapists and families in over 17 countries (Rett Syndrome Research Fund, 2002). However, the music therapy research on the topic is scant. Most are case studies involving one to three case samples.

A paper presented at the American Music Therapy Association's national conference (Robbins, 2000) provided insight into Nordoff-Robbins music therapy with two case examples: a girl and a woman with RS. In the video examples, the clients' increased communicative responses and musical responses in improvisational settings were highlighted.

Wylie's (1996) case study suggested techniques to improve functional hand use in a child with RS. Her findings were limited and inconclusive. Hadsell and Coleman (1988) described appropriate goals in music therapy for clients with RS: "to promote appropriate hand usage within structured activities, to improve eye contact and social interaction, to develop simple communicative responses, and to develop basic understanding of cause and effect relationships" (p. 53). They described interventions for each goal and provided two case studies with goals, objectives, and strategies for each child.

Wigram (1991) described the assessment and therapy process for one client with RS. In his study, he emphasized the need for a balance between structure and freedom in designing therapy for this population. He cited client progress in four areas: development of musical awareness, including passive and active musical expression, increase in functional hand use and improved physical dexterity, understanding and response to

boundaries set in therapy, and client growth and maturity within the therapeutic relationship (Wigram, 1991, p. 51).

In a pilot study for a dissertation, Elefant (2001) investigated the communicative responses of seven girls with RS in Israel. She examined the ways the girls made choices between songs in the music therapy setting. Picture cards were used to represent each song. The results show intentional choice-making and learning in the girls. The study also investigated emotional response, vocalization, and song preferences.

Preliminary findings indicate that the girls with RS demonstrate song preferences. Familiar songs were most preferred. Musical elements, including fast, flexible tempo (140 beats per minute or greater), vocal play or sound effects, and changes in pitch and timbre, were cited as components of most of the favorite songs (Elefant, 2001). The girls showed preferences through facial expression, emotional response (smiles, laughs), anticipation (heightened attentiveness), tension and alertness to events in the songs. The dissertation (in progress) will examine the musical elements of preferred songs more fully.

Wigram and Cass (1995) described the role that music therapy plays in assessing girls at a Rett Syndrome center in England. At this center, the music therapist functions as a member of the interdisciplinary team. However, the music therapy assessment is the primary tool that is used to examine not only the client's response to music and music therapy but also to assess functional disabilities. A physical or occupational therapist or other team member will usually assist the client as the music therapist facilitates and directs the session (Wigram and Cass, 1995). The significant role of the music therapy assessment at this clinic demonstrates the power of music and a trained therapist to

develop rapport and engage attention, to develop non-verbal communication, to motivate, and to stimulate movement. It also demonstrates the power of the music therapy environment to obtain valuable and detailed information about the client.

Following the music therapy assessment, the center uses a vibroacoustic therapy assessment to observe the physical effects of sound on the client's body. Wigram and Cass (1995) detail the specifics of the assessment, including the bass frequencies, the construction of the vibroacoustic unit, and the musical selections that are used in the assessments. During the assessment, they observe for the following responses: relaxation, reduction of hyperventilation, reduction of stereotyped hand movements, reduction of hand to mouth behavior, increased awareness, focus and concentration, increased awareness of tactile sensation, increased voluntary movement, and visual evidence of pleasure.

Wesecky (1986) used music therapy with individuals with RS and others with severe mental retardation. She noted that the children's positive responses to melody and rhythm may often be their sole social communication. She also described two significant challenges in treating children with RS. First, the stereotypic hand movements interfere with functional hand use. Second, new learning or re-learning is difficult for the girls. She also stated that "in many cases with severe mental retardation, receptiveness of sound and rhythm constitutes the only possibility for gathering experiences. And since learning seems possible only by emotional means, music therapy lends itself particularly well to initiate learning processes" (Wesecky, 1986, p. 256). She suggests that the use of music therapy for children with RS is successful because repetition of the music is perceived as a structure that is recognized and anticipated by the child. The musical aspects of tension

and release are used to elicit response from the child. Responses can be physical, vocal and/or affective.

Each case study provides a window into the responses of one client to music therapy treatment. However, more information is needed about the role music plays in the lives of persons with RS on a wider scale. Boxhill (1989) demonstrates the power of music experiences to enrich the lives of people with severe and profound mental retardation. She states, "Even on the most primitive level, music awakens degrees of awareness and consciousness that can unlock new and enlarged channels of sensory perception and self awareness" (Boxhill, 1989, p. 4). Merker and Wallin (2001) state that "the possibility that Rett patients may show a greater responsiveness to and interest in music than might be predicted from the linguistic abilities as indicators of cognitive function constitutes the musical challenge of the disorder" (p. 328). These statements compel the researcher toward further study of persons with RS and their relationships with music.

Chapter II

Rationale for Further Research

In a Swedish survey, 38% of 70 respondents indicated that their daughters with RS received music therapy and an additional 26% reported that their daughters received a sound-based therapy, such as vibro-acoustic therapy (Merker, Isacsson & Witt Engerstrom, 2001). In an internet survey about functional status, medical impairments and rehabilitation resources, less than 10% of 84 parents reported that their daughters with RS received music therapy (Leonard, Fyfe, Leonard & Msall, 2001). Whether music plays an important role in the lives of this client group remains largely unexplored. Significant obstacles exist in probing this issue.

RS is a relatively uncommon diagnosis. Geographic separation poses one obstacle to obtaining a sufficient quantity of subjects for an observational study about their musical responsiveness and preferences. The physical symptoms of the disorder pose additional challenges. Apraxia and ataxia interfere with fine and gross motor control. Physical response time is frequently delayed or must be facilitated by interfering with stereotyped movement. Thus, non-verbal testing methods, such as preferential looking, may be difficult to employ without in-depth knowledge of each subject (Merker & Wallin, 2001).

Merker and Wallin (2001) suggest several ways to circumvent the obstacles to learning more about musical responsiveness in persons with RS. One such method is "tapping the knowledge of relatives, therapists, assistants and others in immediate personal contact with the patient" (p. 334). The presence and uses of music in the home may provide insight into musical responsiveness in RS. Parents' observations of their

daughters' musical behavior in the home may also provide valuable information to therapists and other families. Therefore, this study seeks to obtain information from parents and caregivers about the role of music in the lives of persons with RS in the United States.

Merker, Bergstrom-Isaccson, and Witt Engerstrom (2001) developed and administered a questionnaire for Rett patient parents at the Swedish Rett Syndrome Center. The questionnaire is reproduced in Appendix A with permission from the *Nordic Journal of Music Therapy* and from the authors (I. Witt Engerstrom, personal communication, March 14, 2002; M. Isacsson, personal communication March 14, 2002; R. Rvolsjord, personal communication April 2, 2002). Seventy families responded to the 17 item survey. A summary of results follows.

The Swedish Rett Center Survey

Out of 144 questionnaires mailed, the sample in the Swedish Rett Center Survey included 15 children ages 4 to 12, 17 adolescents ages 13 to 19, 19 young adults ages 20 to 28 and 19 adults ages 29 to 53 for a total of 70 subjects (Merker et al., 2001). Question 1, regarding whether the subjects had an interest in music, was answered in the affirmative by 96% of the subjects. The second part of the question inquired about the nature of the interest. Responses included descriptions of the effects of music on the emotions, general state, and/or behavioral responses to music. The researchers grouped the descriptions into two classifications with subcategories for each: emotion/state responses included glad/happy (64%), calm/relaxed (23%), activated (6%), interested (6%), fearful (1%). Behavioral reactions included rocking/clapping (42%),

listening/alerting (25%), vocalizing (17%), smiling (8%), and other (8%), such as cessation of stereotypic behavior (Merker et al., 2001).

Most subjects had access to more than one source of musical media exposure (question 2). The results were as follows: recorded music 99%, radio and/or television 93%, music making/singing in the home 54%, headphones use 30%, and other sources such as concerts, music sessions in school, etc. 46%. Question 3 concerning the types and genres of music exposure included the following responses: hit music 72%, children's music 65%, classical music 41%, Swedish folk music 6%, jazz 3%, and other 14%. Most respondents indicated exposure to several genres of music (Merker et al., 2001).

The number of hours spent listening to music (question 4) varied among subjects ranging from 2 to 56 hours per week. Thirty-eight percent of subjects reported receiving music therapy treatment, and an additional 26% reported some form of sound therapy, such as vibroacoustic therapy (questions 5 and 6). Fifty respondents indicated prenatal exposure to music for their daughter with RS. None reported deliberate attempts to expose the unborn child to music (question 7). Questions 8, 12, 13 and 16 were answered sporadically or contained responses that showed that they were misunderstood and were not analyzed further (Merker et al., 2001).

Questions 9 through 11 related to favorite songs of girls with RS. The authors reported that detailed answers were provided by 59 respondents and included a small set of three to five specific songs for each subject. Seven respondents indicated an absence of favorites, including non-specific answers such as "any harmonious music." The authors classified the favorites by genre: children's music 52%, hit music 32%, Swedish

standards 4%, classical music 2%, jazz 1%, other 10%. Forty-nine respondents answered question 10 regarding changes in favorite songs. Of them, 53% (26) indicated that favorites had changed over time (Merker et al., 2001).

Fifty-seven respondents answered question 11, which asked about how the girl with RS demonstrated that a song was a "favorite." Short answers included descriptive words or phrases, with a total of 114 different descriptors given. The answers were similar to those in question 1. However, only seven respondents duplicated the wording from question 1 exactly (Merker et al., 2001).

Questions 14 and 15 related to songs that were disliked. Forty-seven respondents answered the question with only 6 specific songs cited. Twenty respondents described genres, qualitative aspects of music (loud, dissonant), or specific instruments. It was not clear from the answers whether a dislike was indicated or a lack of interest (Merker et al., 2001).

Question 17 was a two-part question about whether families use music as "medicine." It was answered affirmatively in 53 of the 55 respondents who replied to it. The second part of the question asked about symptoms treated by those who answered affirmatively. The researchers classified the responses into three categories: upset, stress, pain 54%; sad, withdrawn, bored 32%; and sleep and other uses 14% (Merker et al., 2001).

This study is the first to support anecdotal and case study evidence from professionals that music appears to constitute a significant experience for persons with RS. However, the findings were limited to 70 respondents from one country. This leads

the researcher to desire a replication of the study with a larger population. This may increase the scope and trustworthiness of the findings.

Research Questions

The specific aims of this study are as follows:

1. To determine whether girls and women with RS in the United States demonstrate music responsiveness as reported by their parents and caregivers.
2. To determine whether these subjects demonstrate musical preferences and dislikes.
3. To determine how these subjects demonstrate preferences and responsiveness as reported by their parents and caregivers.
4. To determine what types of music the subjects are exposed to and seem to prefer.
5. To determine how much time per week is spent in musical activity or listening as reported by caregivers and parents.
6. To determine whether parents and caregivers use music as medicine and for what symptoms.
7. To determine what percentage of the subjects receive music therapy or sound-based treatment.
8. To examine cultural similarities and differences between the responses from families in the United States and those from Sweden.

Chapter III

Method

Subjects

The RS community is fortunate to have an international advocacy organization: the International Rett Syndrome Association (IRSA). The author contacted IRSA for assistance in distributing and collecting the surveys. The IRSA has a mailing list of over 2400 families and caregivers. The database is composed primarily of families of girls with RS. Only three families in the database have information about boys with the genetic markers of RS. The IRSA database also includes a group of 1278 families who reside in the United States and agree to participate in research about RS. These 1278 were selected to receive the surveys. The surveys were sent only to families of females with RS.

Design

The original survey (Appendix A) was revised for three purposes: 1) to clarify items that were misunderstood by the Swedish subjects, 2) to paraphrase items that might not be clear to the American subjects, and 3) to reduce the number of questions and by omitting items that were not analyzed in the Swedish study. Revisions were approved by the original authors and by the *Nordic Journal of Music Therapy* in advance. The complete survey used in this study appears in Appendix B. The instructions letter that accompanied the survey appears in Appendix C. Approval to conduct the study was received from the Michigan State University Committee on Research Involving Human

Subjects. The approval letter appears in Appendix D. The changes to the survey included the following:

1. The first three items requesting birth date, diagnosis and relationship of the respondent to the girl or woman with RS were added to help code and categorize the data.
2. Item 2 on the original survey was combined with item 3 to clarify the task for the respondents, as were items 8 and 9.
3. The following items were rephrased: 2, 4, 7, 10, 12, 13, 15, and 17.
4. The order of the questions on the survey was changed by placing the items about music therapy toward the end of the survey to improve the flow of the questions.
5. The format of the question about the use of music as medicine was changed to a multiple choice format and enlarged to request specific information about particular music used to treat each symptom, if known.

Procedure

The author mailed the surveys, return envelopes and payment for postage to IRSA. The IRSA mailed, collected and returned the surveys to the researcher. The researcher had no knowledge of names of individuals, families, or caregivers. The returned surveys were numbered in the order received. Data were sorted by question and entered into a database. Findings were grouped into categories based on the responses. Classification and categorization of data closely resembles that of the Swedish study (Merker et al., 2001).

Analysis

Questions requiring more than a yes/no answer were sorted according to a classification system of up to seven categories. Depending on the purpose of the classification, two different point systems were used. When the primary issue involved the proportion of the population to which a given category is applicable, a full point per response was entered (e.g., classification of genres of music exposure). When the issue is related to the distribution of possible preferences or responses across categories (e.g., classification of responses to music), a single point per individual was divided into as many fractions as applicable categories indicated by the answers and distributed accordingly. This point system will subsequently be referenced as Merker's point system (personal communication, October 30, 2002).

Findings were compared to those of the Swedish study. Pertinent quotations from surveys are included with the results and discussion. Results were examined through the lens of humanistic theories of music and music therapy including the following: Boxill's (1981, 1985) continuum of awareness and Ruud's (1997a, 1997b, 1998) theories about music and quality of life and music and identity.

Chapter IV

Results and Discussion

Part One: Demographic Data

The researcher sent 1278 surveys to the IRSA to distribute to its members who agreed to participate in research studies. Of those 1278, 440 were returned to the IRSA, and subsequently forwarded to the researcher. Two surveys were discarded: One because the respondent did not answer any questions, and the other because the respondent answered questions about a child that did not have RS. Thus, 438 surveys were useful for data analysis, creating a 34.27 % return rate. The Swedish survey achieved a higher return rate of 50%, but was distributed to a smaller number of participants and had the benefit of a reminder system (Merker et al., 2001).

The no-response rate of 65% is not surprising, because there was no opportunity for reminder notices, and participation in the survey was voluntary. The no-response rate raises questions about how representative this sample is of the RS population in the United States. Unlike the Swedish study, which was conducted through a Rett Center, no information is available to the researcher about those who received the surveys and did not return them. It is possible that the majority of those who responded were among those who "had something to say" about their child's relationship to music. Others, with little interest in the survey subject, may not have responded for that reason. However, the results are presented with this qualification as to possible bias due to the low response rate.

Surveys were tallied by state from which they were postmarked. Every state was represented with at least one survey, except for Alaska and Delaware. A total of 31

surveys did not have legible postmarks. No important results related to state of origin emerged.

Questions one and two: Age and person completing the survey.

Question two asked who completed the surveys. Most respondents were parents. Table 3 indicates the responses from all 438 surveys.

Table 3

Person Who Completed the Survey

Respondent	Number
Parent	425
Relative	8
Care Giver	1
Other	1
No Response	3

Respondents reported about their child or relative with RS. The person with RS will hereafter be referred to as the subject. Question one asked for the birth date, including year, of the subject. Subjects' ages were calculated according to their age on December 31, 2002. Surveys were classified into four age groups. The age range for each group was based on those used by Merker et al. (2001). Children aged two through twelve accounted for 189 (43%) of subjects. Adolescents aged 13 through 19 accounted for 99 (23%) of subjects. Young adults aged 20 through 28 accounted for 90 (20%) of subjects. Adults aged 29 through 57 accounted for 60 (14%) of subjects.

In this study, the number of subjects in each age group varied. The children's age group was the largest and the adults, the smallest. The youngest subject was two years of age. The oldest subject was 57 years of age. In the Swedish study, the sample size was smaller (70) and each age group was roughly equal in size to the others. The age range in the Swedish study was age four to age 53 (Merker et. al, 2001).

The mean age of each age group was calculated. The mean age of all subjects was 16.36 years. Table 4 shows the mean age of each age group.

Table 4

Mean Age of Subjects by Age Group

Age Group	**Number**	**Mean Age**
Children	189	7.42
Adolescents	99	15.99
Young Adults	90	23.37
Adults	60	34.97
Total	**438**	**16.36**

Question 3: Type of Rett Syndrome.

Question three queried about the diagnosed type of RS. Figure 1 represents the responses to this item. The following four responses were available: Classic, Variant, Other, Don't Know. Under "other," 25 respondents indicated "Atypical." Therefore, a fifth bar is represented in Figure 2 for that choice. Classic RS was indicated by 271 (62%) of respondents. A variant form of RS was indicated by 33 (7%) of respondents. Atypical RS was indicated by 25 respondents (6%); "other" was indicated by 9 (2%) of respondents; "Don't Know" was indicated by 91 (21%) of respondents, and 9 (2%) did

not respond to this item. Responses to item three were further analyzed by age group as represented in Figure 2.

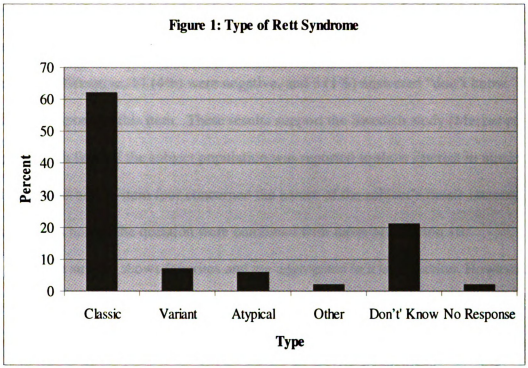

Figure 1: Type of Rett Syndrome reported by percent of respondents

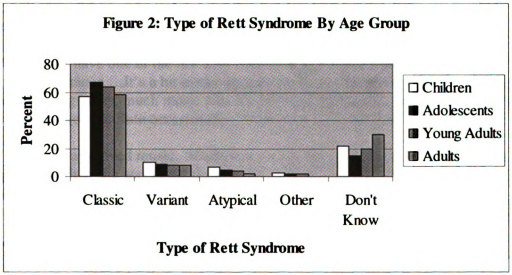

Figure 2: Type of Rett Syndrome by percent of each age group

Part Two: Music Interest And Exposure

Question 4: Music interest.

Respondents answered item four in two parts. The first part asked about the presence of music interest. Of the 434 respondents who answered this item, 414 (95%) responses were affirmative, 17 (4%) were negative, and 3 (1%) answered "don't know." Only 4 did not respond to this item. These results support the Swedish study (Merker et. al, 2001), in which 96% of the subject population was reported to show interest in music.

The second half of item four concerned the nature of the subject's music interest. The results of this half of the question were combined with those of question 10 regarding how the subject shows favorites and are aggregated in a later section. However, the following quotes provide insight into how respondents answered the question about the nature of music interest. Emphasis was added by the respondents and is indicated by capital letters.

> "It is probably THE most important thing in her life, right up there with water play, eating and animated family get togethers. I think it centers her. The familiarity of the music makes something right. I believe without music she would be stressed MOST of the time." (Parent of a 19 year old adolescent)

> "I think we have one of the few kids with Rett Syndrome who has very little interest in music....It's a bit ironic because we're a very musical family. During Mom's pregnancy, much music was played in the house on a stereo. Mom sang a lot and played the flute occasionally." (Parent of a 16 year old adolescent)

> "L. has always loved music. Music was one of the main things that would help quiet her when she was going through the screaming stage. It still helps when she's upset. After she lost her speech she would still look at a song book and hum." (Parent of a 35 year old adult)

> "She loves music and has a good memory for songs. She has heard a classical piece played once by my husband on the piano and the next day recognized it on the radio. Music seems to help her overcome the frustration she feels at not being able to move around and use her hands." (Mother of an 8 year old child)

"She recognizes individual songs. She associates particular songs with particular situations: songs for morning, at meal times, and bedtime." (Parent of a 17 year old adolescent)

"She liked music from baby ages to adult. She'd listen to certain tapes, everything from Raffi to Willie Nelson for hours at a time. She'd bring a tape to us when she'd want music. This was especially up to age 15 – 16 or so. She still likes it but isn't as dependent on it any more. She doesn't listen to it as much any more at all." (Parent of a 24 year old young adult)

"Music is her favorite thing of all! She has always loved music boxes and when you sing to her, she responds with her whole body. It is the best way to quiet or calm her when she's upset, or excite and interest her." (Parent of a 20 year old young adult)

"Music is the only thing that motivates her. She loves it. Music was the first thing that got her out of regression. Music is the only way through which she has made progress." (Parent of a 6 year old child)

Question 5 part one: Available music sources.

Concerning sources of music available in the environment (question 5), 71% of respondents reported access to live music-making or singing in the family. In the Swedish study, only 54% reported exposure to live music in the family. Exposure to recordings was reported by 92% of respondents in the present study, and 99% in the Swedish study. Exposure to TV and radio music was reported by 91% of respondents in America, and in 93% in Sweden. Use of headphones was reported in 37% or respondents in the U.S., and in 30% in Sweden. Other sources of music were reported by 52% of respondents in the present study, and 46% in Sweden. The results are summarized by age group in Figure 3.

Comparing the results of the music exposure question reveals little difference between the two studies. The current study seems to support the Swedish results. Most of the percentages are within 7 points above or below the Swedish results, with the

exception of the live music-making or singing in the home. More American respondents reported live music-making or singing in the family. This may be because the IRSA emphasizes music as a means of communication and therapy for the girls. They provide literature, books, and on-line resources, all of which include sections about the use of music and music therapy.

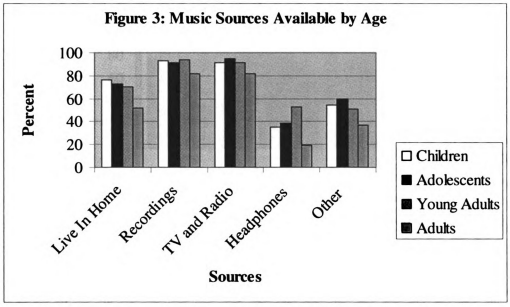

Figure 3: Sources of music available summarized by age group.

Question 5 part two: Music exposure by type.

Question five also asked respondents to list the types of music that were available from each source. The results are summarized in Figure 4 by age. These results also seem to support the results from the Swedish study.

Results from question 5 were grouped according to the following seven categories: a.) Children's: including traditional, newly composed, and songs from Disney movies; b.) Popular: including "oldies," hits from the 1980's through the present, R&B, hip hop, and rap; c) Other: including lullabyes, broadway, new age, easy listening, and

world/ethnic; d) Country: including classic country and new country; e) Classical: including all symphonic and opera art music; f) Christian: including hymns, gospel and contemporary Christian; g) Jazz: including blues, smooth jazz, and big band. Results are summarized by age in Figure 4.

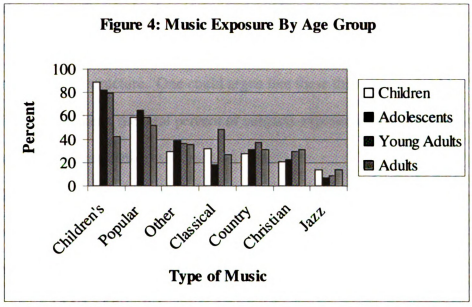

Figure 4: Genres of music exposure by percentage and age group.

The Swedish study utilized only 6 categories for this question. They included Disney music in the "other" category. This was not done in the current study for two reasons. First, because so many respondents indicated exposure to and preference for Disney songs that the "other" category would have seemed to have an inflated ranking, above all the rest of the categories. And second, because Disney music is heavily marketed in this culture as children's music. Therefore, respondents would have been likely to include it in this category.

Comparison to the Swedish study again reveals more similarities than differences. In the Swedish study, 65% of subjects were said to be exposed to children's music. In

this study, 79% were reportedly exposed to children's music. In the Swedish study, 72% were said to be exposed to "hit" music (including all popular music with high media exposure, including Swedish dance band music). In this study, 59% of subjects were exposed to popular music, 31% were exposed to country music, and 21% were exposed to Christian music. To a trained musician, current light rock, new country, and contemporary Christian music would all be classified under a single genre because of their similar musical structure. One could argue that these three categories be combined. If one did combine them, the total percent of subjects exposed to "hits" in the American study would be close to 80%.

Thirty percent of respondents in this study reported classical music exposure and 11% reported exposure to jazz. In the Swedish study, reponses were 41% and 3% respectively. Finally, other types of music were reported by 34% of American respondents and 14% of Swedish respondents.

Despite seemingly wide variances in percentages of responses, the trends are similar between the two studies. Children's music received the highest percentage of exposure, with popular/hit music second. All the other categories were not reported as frequently.

Question 6: Amount of music exposure per day or week.

Answers to question 6 regarding the amount of time per day or week spent listening to music were vague. Most reported a number of hours or percentage of time spent listening without indicating per day or per week. Some respondents also wrote "all of her waking hours." Any attempt to quantify these responses and report them would

require assumptions or speculation. This would make the report of results inaccurate at best.

Question 7: Prenatal music exposure.

The responses to this question were summarized in the database as yes, no, and no response. Table 5 summarizes the results as percentages by age group.

Table 5

Prenatal Music Exposure by Percentage and Age Group

Age Group	Yes	No	No Response
Children	81%	15%	4%
Adolescents	82%	16%	2%
Young Adults	80%	19%	1%
Adults	78%	18%	4%

A few respondents indicated purposeful prenatal music exposure, such as putting headphones up to the belly or singing and playing instruments for the unborn child. It would be interesting to ask about intentional prenatal music exposure. However, since this was not done in this study, and since such a high number of respondents indicated music interest and preferences, the results were not analyzed further.

The following quotations are from mothers who described exposing their unborn daughters to music.

> "I sang Edelweiss to my belly the whole time I was pregnant. After she was born, she recognized the song and smiled when I sang it to her...She also was not startled as an infant while in the stable as a horse neighed since she had been near these sounds her entire "belly ride." (Mother of an 11 year old child)

"I am a guitarist and would play classical pieces for her while pregnant. I would also put headphones on my belly playing classical and baroque pieces for her. I also listened to music from the 70's and after she was born, my daughter would respond happily to DISCO (crazy, huh?)! Daddy is a professional musician, so she heard him a lot as well." (Mother of a six year old child)

I sang a lot when she was in the womb. I had a video of myself singing "Ave Maria" at my own wedding that I played for someone and she started kicking. So, I would do this experiment every week to see if I could get her to move. She would kick every time!" (Mother of an 11 year old child)

"When my husband and I went to a concert, I had to sit down during the performance. It was because my daughter was kicking me so hard along with the beat of the music." (Mother of a 17 year old adolescent)

Part Three: Music Preferences And Dislikes

Question 8: Favorite songs.

The presence of favorite songs was examined in question eight. Respondents were asked if the subjects had favorite songs and to name them in as much detail as possible. The responses to this question were analyzed in three ways, including the frequency of the presence of favorites. Out of 438 respondents, 359 (82%) reported that the subject had favorite songs; 64 (15%) reported no favorite songs and 15 (3%) did not respond. Figure 5 shows the percent of respondents from each age group who reported favorite songs.

Many respondents did not list specific favorite songs. Rather they listed groups, performing artists, recordings or musical genres. This led to the second level of analysis. A total of 237 respondents did not list specific favorite songs or reported no favorites. Figure 6 shows the reported number of specific favorite songs that were listed on the surveys by age group. A total of 203 (46%) respondents listed favorite songs. Of these,

122 respondents listed one to three favorite songs, 74 listed four to ten favorites, six listed 11 to 15 favorites, and one listed a total of 50 favorite songs. Very few favorite songs appeared more than once in the surveys. Of these, most were typical children's songs, such as "If You're Happy and You Know It." Even these appeared fewer than five times each. Therefore, a list of specific favorite songs appears alphabetically in Appendix E.

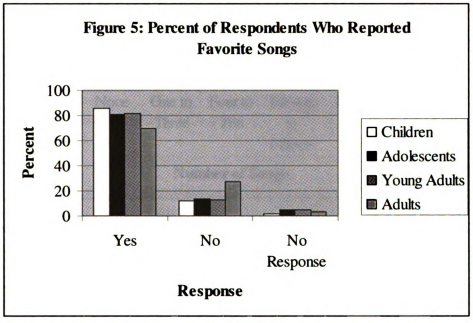

Figure 5: Presence of favorite songs reported by age group.

The final level of analysis placed the favorites by musical genre. The same seven musical genres that were reported in the music exposure section were used in this step of analysis. No respondent reported songs in more than four different musical genres as favorites. Of the 438 subjects, 69 did not report favorites in any genre; 369 reported favorites in one genre only; 128 reported favorites in two genres; 59 reported favorites in 3 genres; and 15 reported favorites in four different genres.

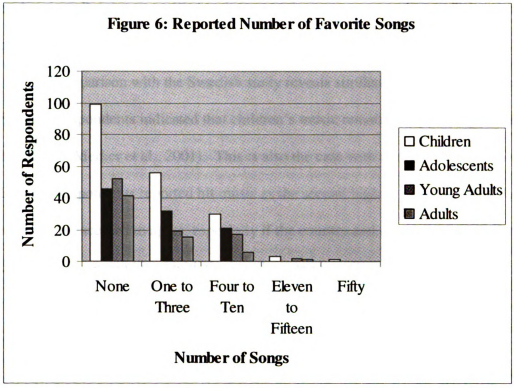

Figure 6: Number of respondents who reported the number of favorite songs by age group.

Merker's (personal communication, October 30, 2002) point system was used to tabulate the percentage of respondents who reported favorites in each musical genre. Each individual represented one full point. If a respondent listed songs from four musical genres as favorites, then each genre received one-quarter of a point. If a respondent listed songs from three musical genres, then each genre listed received one-third of a point. If a respondent listed songs from two music genres, then each genre received one-half of a point. If a respondent listed songs from only one music genre, then that genre received one full point. Genres were not weighted according to the number of favorites listed in

each genre. Points were tallied and converted to percentages. Figure 7 shows the preferences by musical genre grouped by age.

Comparison with the Swedish study reveals similarities in favorites by age group. Swedish respondents indicated that children's music remained the leading favorite into adulthood (Merker et al., 2001). This is also the case with the American sample. Swedish respondents reported hit music as the second highest category. The American respondents seemed to agree, especially if the country and contemporary Christian music categories were combined with the popular category. Classical and jazz music received the lowest response rate in both studies.

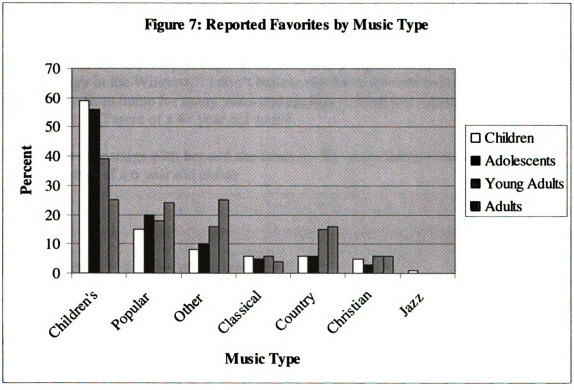

Figure 7: Reported favorite songs by music type, age group and percentage.

Some quotes from surveys about music favorites follow.

> "She has a music table with toys she can hit and they will play a short tune. But she likes music to go on and on, so CD's are best. Sound quality is essential...She has a CD/tape player that she can turn on with a switch herself." (Mother of a 4 year old child)

> "We are guilty of treating her like a typical child. She is exposed to all kinds of music. Sometimes, she listens to her older sister and friends' music, sometimes mom's, sometimes dad's, and peers her own age. She is 14 years old and happy and well adjusted. (Parent of a 14 year old adolescent)

> "The Sneezing Song has a lot of exaggerated sneezes in it, which makes her laugh. She has always laughed at sneezes at home, and I just realized that it is because of this song...The song Is There Anybody Here Named Julie is a favorite. It is fun for her to hear her name and have everyone looking at her and it's very familiar....Everybody Wants to Be A Cat because a cat's the only one who knows where it's at, oh yeah {oh yeah sung in a gravelly voice gets a smile 99% of the time}." (Parent of an 11 year old child)

> "She loves to play with musical toys. She hits these toys to make them play the song; it is very purposeful." (Parent of a 6 year old child)

> "When she was very young, her favorite was a popular song "How Much is that Doggy in the Window." I don't believe she has a favorite now. She was been away from home for many years and appears to have lost interest as she got older." (Parent of a 47 year old adult)

> "We sing songs with her and she loves it. We make funny voices and get loud." (Mother of a 6 year old child)

Question 9: Change of preferences.

Question nine asked whether subjects changed musical preferences and, if so, at what approximate ages this occurred. About two thirds (312 out of 438) of respondents answered the first half of the question. Of those, only about one half answered affirmatively. Most did not answer the second half of the question. Due to this response pattern, only the first half of the question was analyzed. Figure 8 shows preference

change by percent of each age group. The Swedish respondents in the three youngest age groups indicated higher percentages of preference change than American respondents: 67%, 69% and 54% versus 54%, 50% and 41%, respectively. American adult respondents indicated a higher percentage of preference change at 40% than the Swedish adult respondents did with 15%.

Question 10: How favorites are shown.

Question 10 asked respondents to indicate how the subject shows that songs are favorites. Of the 438 surveys received, 368 (84%) participants responded to this item. Most respondents indicated several different reactions to favorites, usually a phrase of up to six different descriptors. Descriptors were divided into two categories: Emotional reactions and behavioral reactions to the favorite songs. Emotional reactions included the following: a) Happy; b) Calm, Relax or Soothe; c) Interested or Attentive; d) Excited or Animated.

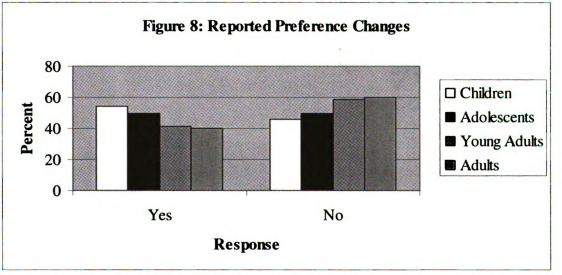

Figure 8: Preference changes by percent of age group.

Behavioral reactions included the following: a) Smile or Eyes Light Up; b) Clapping or Arm Movement; c) Body movement such as swaying, rocking, turning head; d) Moving feet such as walking, running, dancing, or kicking; e) Vocalization such as laughing, squealing, squawking, or talking; f) Other.

Merker's point system was used to divide each respondent's answer into as many fractions as indicated by the response (personal communication, October 30, 2002). For example, if a respondent gave six different descriptors, then each descriptor was assigned one-sixth of a point. After the responses were divided, totals for each descriptor were tallied and converted to percentages. Figures 9 and 10 show the results of this process

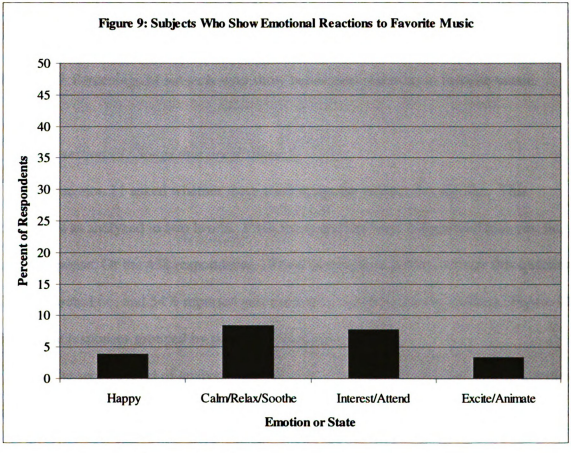

Figure 9: Subjects who show emotional responses to favorite music

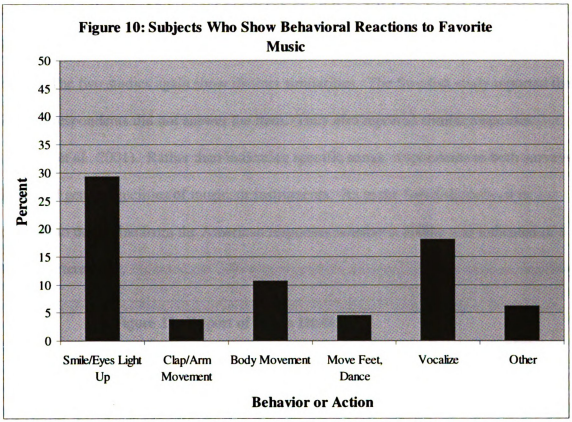

Figure 10: Percentage of subjects who show behavioral reactions to favorite music.

Question 11: Songs that are disliked.

Question 11 asked whether there were songs the subject did not like. This question was analyzed in two levels. First, the responses were categorized into yes, no, or no response. Of the 438 respondents, 17% of respondents did not answer this question; 29% answered no; and 54% reported yes, there were songs that were disliked. Figure 11 shows the responses grouped by percent of each age group.

The second level of analysis examined the more specific responses. The question asked for details including name of song, artist, and recording. Most respondents did not provide these details. Rather, they listed genres of music or qualities of music (loud,

monotonous, slow etc.). A complete, alphabetized list of dislikes included in the surveys is located in Appendix F.

The two studies again show distinct similarities. The Swedish study reported that 33% of respondents did not answer the item. They also reported similar responses (Merker et al., 2001). Rather than indicating specific songs, respondents to both surveys indicated genres, qualities of music, or instruments. As in the Swedish study, it is difficult to determine from the American responses whether a dislike was indicated or a lack of interest.

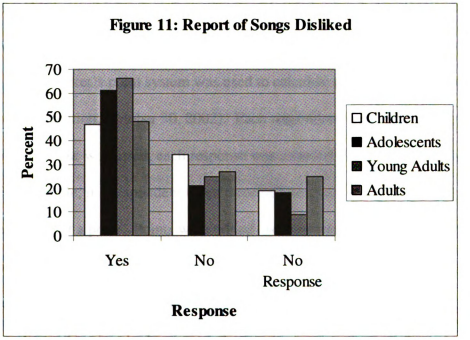

Figure 11: Response to whether there were songs disliked by percent of each age group.

Question 12: How dislikes are shown

Question 12 asked how musical dislikes are shown. Sixty-four percent of respondents answered it. Responses were categorized by emotional responses and

behavioral responses. Emotional responses included the following: a) Upset, Irritated, Frustrated, Fussy, or Agitated; b) Bored, or No Interest; c) Worried, Fear, Startled, Tense, or Discomfort; and d) Unhappy, Sad, Cranky, Pouty, or Grumpy. Behavioral responses included the following: a) Refocus, Leave Area; b) Physical Movement (not leave area); c) Vocalize, Scream, Yell, Cry, or Whine; d) Aggression, Tantrum, Self Injurious Behavior; e) Facial Expression; f) Other. The "other" category included the following responses: breathing irregularities, seizures, rolling eyes, and sweating. The physical movement category included the following responses: hand movements such as clenching fists, hitting music source, fingers in ears, hands to mouth, hands over face, hand wringing, teeth grinding, rocking or body movement, stiffening legs, and fidgeting.

Merker's point system was used to calculate percentages (personal communication, October 30, 2002). Each respondent received a full point. If more than one response was listed, each response was awarded the appropriate fraction of a point. For example, if a respondent listed three different answers, each answer was awarded one-third of a point. Points were tallied and converted to percentages for each category of response. Figure 12 shows the emotional responses by age and percent of those who responded. Figure 13 shows the percent of subjects who show dislikes with behavioral reactions. One hundred percent indicates those who answered the question.

The authors of the Swedish study chose not to analyze the responses to this item (Merker et al., 2001). In the American study, subjects seemed to indicate dislike most with vocalizations. Emotional reactions were second to vocalizations. This contrasts with the larger number of behavioral descriptions given in response to question 10 regarding how favorites are shown.

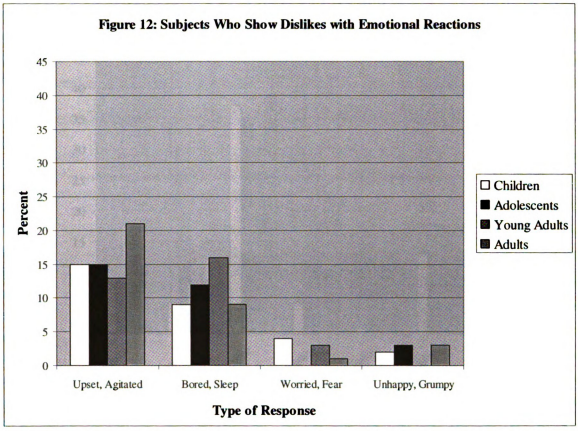

Figure 12: Percent of subjects in each age group who show dislikes with emotional responses.

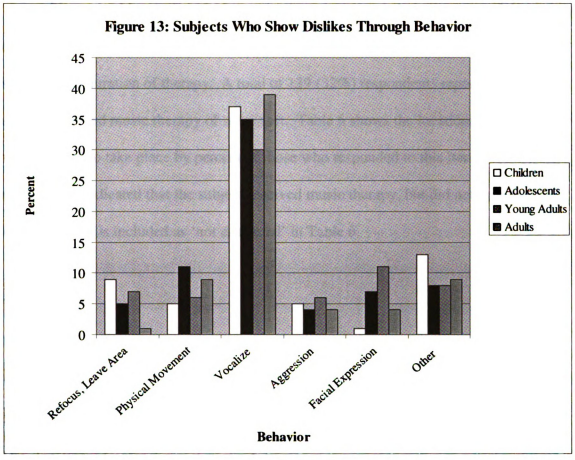

Figure 13: Subjects who show musical dislikes through behavior by percentage of each age group.

Part Four: Music Therapy, Sound Treatment and Uses of Music As Medicine

Question 13: Music therapy.

Question 13 asked whether music therapy had ever been provided to the subject. It further asked where subjects received therapy, what kind of therapy was provided, and when therapy began and ended. This question was analyzed in two levels. First, responses were aggregated into three categories: yes, no, and no response. Only 6 (1%) respondents did not answer this question. Therefore, the yes and no answers were included in the graph. Figure 14 shows the responses by age group.

The second level of analysis involved reconstructing the other parts of the question, including location where music therapy took place, type of therapy, length of sessions and duration of therapy. A total of 139 (32%) respondents reported that the subject received music therapy of some sort. Table 6 shows the locations where therapy was reported to take place by percent of those who responded to this item. Some respondents indicated that the subject received music therapy, but did not specify a location. This is included as 'not answered' in Table 6.

Table 6

Music Therapy Locations

Location	Percent
School	53
Home or Place of Residence	11
Private Clinic or Music Store	7
Day Treatment Center	5
University	2
Not Answered	22

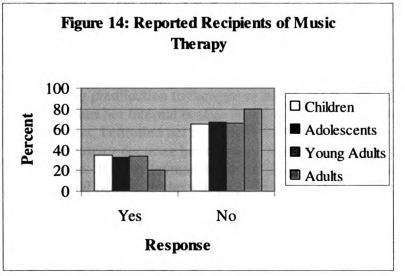

Figure 13: Reported recipients of music therapy by percent and age group.

Types of therapy listed included individual, group, and music therapy consultation with special education teachers. One respondent indicated that Creative Music Therapy based on the Nordoff-Robbins approach was offered. Fifty-three respondents did not answer this part of the question. Length of therapy sessions varied from 30 minutes per week to 3 hours a week. Most respondents indicated 30 – 60 minutes of therapy per week. Duration of therapy treatment varied from a single evaluation to 12 years of ongoing treatment.

Merker et al. (2001) reported that 38% of Swedish subjects received music therapy of some sort. This is a comparable number to the current study's findings. Locations, lengths of sessions and durations were not specified in the Swedish report.

The following quote is about the interesting path one family followed to decide to pursue music therapy for their daughter.

> "At age 5, her school used wrist guards to keep her from wringing and putting her fingers in her mouth. All this technique accomplished was to replace her former behavior with finger tapping. At age 9, I enrolled her in a behavioral modification program to decrease her tapping. To set a 'benchmark' I made a video recording of her at rest, and then listening to her favorite music in front of a clock with a sweep second hand. Later, I played it back in slow motion to count the taps per minute. When her favorite music came on TV her taps increased from 60 per minute to 160 to 180 per minute. Her body language surged along with smiles. Also, her tapping was not random, but showed a definite beat (her tapping was not just repetitive but showed a pattern of opening and closing her fingers). She has a strong predilection to the type of music she enjoys. Either the beat of the music matches her internal beat or the opposite is true. When the prior program proved useless, I enrolled her in a music therapy program. The music could be used to increase or decrease her tapping. Today, she still responds in the same way to her music. It is my layman's opinion that if the beat of the music corresponds to her natural beat, then she will respond positively." (Father of a 25 year old young adult)

Question 14: Other sound-based treatment.

Only 16 (4%) respondents reported the receipt of other sound-based treatment. Of these, ten subjects were children, five were adolescents and one was a young adult. Sound-based treatments listed included the following: therapeutic listening, auditory integration training, and vibroacoustic treatment using a Somatron®. The Swedish study reported that 26% of respondents received other sound-based therapy (Merker et. al, 2001), which is much higher than in the American study. Possible explanations may include the following: in Europe, the use of vibroacoustic treatment is more widely accepted; in Europe, treatment and diagnosis of RS occurs in Rett Centers, which do not exist in the United States.

Question 15: Music as medicine.

Question 15 was answered by 99% of respondents. Eighty-eight percent reported use of music as medicine in the home, while only 11% reported no use of music as medicine. Figure 15 shows the percentage of respondents by subject age group who used music to treat the following symptoms: stress, upset, pain, or anxiety; sadness, boredom or withdrawal; sleep, activities of daily living or other.

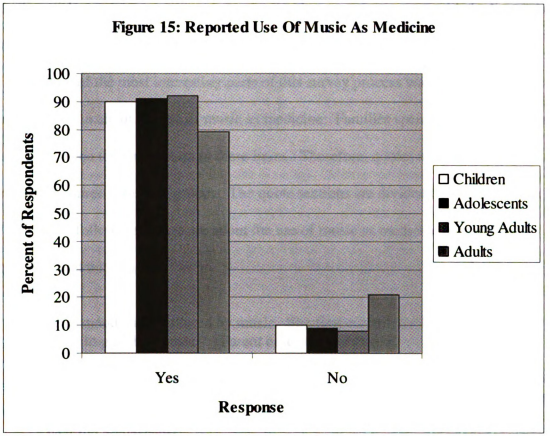

Figure 15: Reported use of music as medicine by percent and age group.

Most respondents did not list specific songs or music used. Instead, they listed a musical genre or repeated favorite songs as listed earlier in the survey. Therefore, a specific list of music for each symptom set will not be provided. Appendix E lists the favorite songs alphabetically. However, respondents listed specific activities of daily living (ADL's) during which music was used. A list of specific ADL's is located in Appendix G.

Swedish respondents reported using less music as medicine (60% or less per symptom group) than American respondents (Merker et al., 2001). However, the item on

the Swedish survey was open-ended, whereas the current survey provided a list of the symptoms. This may account for the greater response rate.

One of the most interesting parts of this survey process was reading the responses to the question about the use of music as medicine. Families spent a great deal of time and thought on their responses to these items. Therefore, quotes are provided below from each of the three symptom groups. The quote sections are divided by symptom group.

The following quotes are about the use of music as medicine for sadness, boredom and withdrawal.

> "Her mood can be altered by music. She first pushed her Big Mack button in order to play her music." (Parent of a 3 year old child)
>
> Music is "very successful at getting her 'returned' to the environment, relaxed for physical therapy, calmed from anxious state or back into things if bored. She loves most music and enjoys both videos and audio only sources." (Parent of a 15 year old adolescent)
>
> "We sometimes bring head sets when she has a lot of waiting to do: doctor's waiting rooms, amusement areas with her family." (Sister of a 33 year old adult)

The following quotes are about the use of music as medicine for stress, upset, anxiety or pain.

> "When she was 3 or 4, we used music as a sedative to stop her screaming periods. She has continued with music from that point on as a way to calm, relax or for enjoyment now." (Parent of a 21 year old young adult)
>
> "In the younger years, during and after the main regression, Disney Sing Alongs saved our lives. Then, she would scream for hours, but Disney Sing Alongs stopped it. Just keep them in, and she was happy. Also, singing to her helped tremendously in the younger years." (Parent of a 14 year old)
>
> "When she was to have surgery in 1983, we taped her favorite songs to play during surgery and in the recovery room. She had a previous episode where she did not wake up very well until I was brought to recovery room to talk her awake and I sang her awake. When we used the taped music, she woke up fine and no problems. It was almost like the music was her companion and took away her

fears, gave her desire to wake up and return to conscious alert. Without the music, it seemed she didn't want to wake up." (Parent of a 48 year old adult)

"My daughter has been in and out of the hospital quite often in the past 4 years. I sing to calm her down, bring her tapes and CD's to the hospital. It seems to really calm her. I don't know what we'd do without music. What a wonderful thing it can do for her." (Parent of a 33 year old adult)

"When she was young and in the screaming stage, recorded versions of Disney songs would stop the crying like a switch: Winnie the Pooh, the Wonderful Thing About Tigger. Though she hasn't screamed in 20+ years, she still perks up and smiles when I sing these songs just for fun." (Parent of a 26 year old young adult)

"After her scoliosis surgery, music was as or more effective than pain killers in managing her pain (and it doesn't cause constipation)." (Parent of a 12 year old child)

During times of stress, upset, anxiety or sadness we "sit and hold her and sing. The personal touch, eye contact along with the music seems to be a help." (Parent of an 8 year old child)

"Specific tapes and/or songs are immediately soothing. There have been times in her life when these HAD to be playing for her to maintain a calm temperament. LIVE piano music is also a favorite, not tapes or CD's." (Mother {plays piano} of an 8 year old child)

"I play the guitar and she relaxes, does not breathe so hard, wringing of hands slows down, facial expression is relaxed and sits quietly." (Mother of a 14 year old adolescent)

The following quotes are about the use of music as medicine for sleep, activities of daily living and other uses.

"Socializing: did not like crowds and we used music for years to calm her in crowds. Now she can go in public without music." (Parent of a 21 year old young adult)

"From early on, our daughter was very attentive and relaxed with music. During a period of her life 3 – 4 years ago, she experiences night terrors due to a new seizure medication. Music was the only calming cure for her." (Parent of a 15 year old adolescent)

She "wears A.F.O.'s" [ankle foot orthosis] "2 times a day and often uses headphones with favorites to entertain and put her in a better frame of mind during this time. Also, it is sort of a distraction as she knows when wearing

AFO's but with music, she tends to forget to see that she has them on." (Parent of a 7 year old child)

She "receives occupational and physical therapy and uses music to get her involved. We also use music response toys to show cause and effect." (Parent of a 6 year old child)

"I will often sing while performing care. She enjoys when I use a variety of vocal ranges and styles to her favorite tunes." (Sister of a 33 year old adult)

"Singing to her calms her and she cooperates. I have a terrible singing voice but she doesn't care. It works." (Parent of a 14 year old adolescent)

"I sing to her a LOT! As I dress her, feed her, in the van, at her swim class-you name it. Happy songs and mostly songs I make up at the time. We also can get her interest (e.g., for photos) by squeaking." (Mother of a 9 year old child)

"To the tune Row, Row, Row Your Boat: Brush, brush, brush your teeth, brush them every day. Make them clean and shiny, brush them everyday. We did that from age 2 to about age 5 and sporadically thereafter. It really helped her defensiveness to the brush. Now, she opens her mouth and holds it open a little bit for us. (Parent of an 11 year old child)

"Music helps me to help her complete a task when she has trouble with motor processing." (Parent of a 13 year old adolescent)

"Bowel movements were always difficult. We always played taped music when she was sitting on the toilet. It was also time limiting. She knew when the tape ended she would get up." (Parent of a 20 year old young adult)

Chapter V

Theoretical Implications

A comparison of the American survey results with those of Merker et al. (2001) reveals little appreciable difference in responses. The American survey supports the Swedish findings, while uncovering little new information of its own. This should be the primary task of research replication: to support, and strengthen the findings of previous studies or to uncover flaws in method or analysis. However, another equally important task for researchers is to contextualize the results of research within current music therapy theory.

As a student and reader of research, I usually leave a study such as this with the question, "So what?" In this section, I will try to contextualize the results through the lenses of Boxill's (1981, 1985) continuum of awareness and Ruud's (1997a, 1997b, 1998) theories about quality of life, and music and identity. Boxill's approach to persons with developmental disabilities requires therapists and professionals to view these clients from a humanistic perspective rather than from the traditional medical model of illness or disease. Ruud's theories about music and quality of life and identity are relevant to the growth and maturation process of persons with and without disabilities. Both theories were selected because they are readily expanded and adapted to family living situations and relate directly to the results of the study.

Continuum of Awareness

Edith Hillman Boxill is a founding theorist in music therapy. Her work gave music therapists working with persons with developmental disabilities a new way to

approach the needs of these persons. Her humanistic approach to therapy contrasted starkly to behavioral and medical models that were prevalent in the early days of the music therapy profession. Her work draws on psychological approaches, such as gestalt therapy, client-centered therapy, and developmental models (Boxill, 1985). Such humanistic models of therapy view the person as a whole, not as a disability or set of symptoms.

Boxill's continuum of awareness posits that music therapy for persons with developmental disabilities is involved with the creative process of cultivating awareness as a part of nurturing the developing being. This continuum of awareness initiates the client into a "condition of consciousness in which s/he could discriminate not only between self and therapist, but also between self and his/her own experience" (Boxill, 1981, p. 17). To achieve this, Boxill devised three main strategies: "1) Reflection: mirroring the here and now client; 2) Identification: the symbolic representation, in musical form, of the here and now client and therapist;" (1981, p. 17); 3) Our contact song: "the first reciprocal musical expression, the first two way musical communication, the first overt musical indication initiated by the client of an awareness of the existence of another" (Boxill, 1985, p. 80). For a more detailed treatment of Boxill's theory, consult her book, *Music Therapy for the Developmentally Disabled* (Boxill, 1985). Boxill's first two strategies are readily applicable to the data received in the surveys. Several families cited the use of Songs of Love Tapes. These are created for each child based on information about her that is provided by the family. The following quotes from surveys illustrate Boxill's reflection and identification strategies used by family members to interact with their relative with Rett Syndrome.

"We also have a couple of 'name songs' that we sing to her. One is just to sing her name over and over in a sing-song way. Also, I often make up songs about how much I love her with her name and my name to the tunes of *Brahms' Lullaby* and *Sakura*. I sing these any time, often when we're cuddling or she's sad, distressed, loud, etc". (Parent of a 9 year old child)

"We sing to her for her daily activities. We've made up everything from a wake up song to a school song to an eating song, sleeping song, etc." (Parent of a 15 year old adolescent)

"I have an impromptu song that I sing during our 'before bed' routine. It's basically the same melody but I use different words or phrases depending on her mood." (Parent of a 6 year old child)

During times of stress, I sing "my own soft songs using her name." (Parent of a 6 year old child)

At bed time, "we sing made up songs using our daughter's name." (Parent of a 5 year old child)

Some parents report having success at applying techniques learned from brief interactions with music therapists, as is indicated by the quotes below.

She received music therapy "back at age 5-6 here in San Jose. She seemed to enjoy it and reach out to 'play' instruments occasionally. We experimented for about 8 months then used the knowledge gained to make music more accessible for her in our home." (Parent of a 12 year old child)

She received music therapy at "West Music in Iowa City. We took her twice and learned a lot from them. It was such a long drive for us we decided to continue the therapy at home. We have and she does well with this." (Parent of a 2 year old child)

The fact that Boxill's theory is applicable to the parent-child relationship in musical interaction points to another possible role for the music therapist: that of musical mentor. In this role, music therapists could work with the family as a unit, providing

suggestions for uses of music in the home to help the family communicate, educate, support, and soothe the child with RS.

One characteristic of children and adults with severe developmental disabilities, such as RS, is that their learning process is slower than typical. Generalization of learning between environments is often slow and difficult. The application of therapeutic techniques and the use of music in different settings outside therapy could help achieve maximum development of an individual's potential if music is an important category of experience for him/her. Teaching family members and care givers such techniques could not only assist them in maintaining positive contact with their children with severe disabilities, but also help them cope with the daily stress of providing support for such a child.

Music and Quality of Life Theory

Ruud's theory of music and identity postulates that "listening to, and talking about music is a way of performing our sense of ourselves – our identities" (1998, p. 32). He defines identity as follows: "identity results from a particular discourse the consciousness has engaged in, the special way of framing or contextualizing one's own life experiences... Metaphoric tools are used to structure and give meaning to the story of identity" (Ruud, 1997, p. 36). Music is one such tool. It can frame and anchor many situations used as the foundation for identity building. Because of its emotional quality, music creates feeling-filled memories that highlight and position peoples' lives (Ruud, 1997a).

Ruud (1998) conducted a series of studies on music and identity. Students created tapes of music that were significant in their lives and were interviewed or wrote papers about the music. These were termed musical autobiographies, and their design was based on the work of Bruscia (Ruud, 1998). Qualitative analysis focused on the events that contextualized the music. The product of analysis yielded a set of four categories that Ruud believed covered all aspects of music and identity. They are as follows: 1) musical and personal space, 2) musical and social space, 3) the space of time and place, and 4) transpersonal space. For more detailed descriptions of Ruud's theory, consult his book: *Music Therapy: Improvisation, Communication and Culture* (Ruud, 1998). Unfortunately, at the time of this writing, Ruud's research study and its results have not been translated into English.

Closely aligned with Ruud's theory of music and identity is the idea that music and music therapy may contribute to the quality of life (1997b, 1998). In his definition of music therapy, Ruud is careful not to place the client in the "sick" role, but rather as an independent agent able to make choices for action. Health is viewed as a "feeling of well-being and a capacity for action" (Ruud, 1997b, p. 91). Culture also plays a role in Ruud's continuum of health and quality of life. According to Ruud, culture is defined as a way of living, and is inextricably linked to the individual's perspective. Music therapy's role in this stance is to increase possibilities for action rather than to cure, heal, or change the client.

Ruud believes that music has the potential to contribute to the quality of life in four ways: 1) increase one's feelings of vitality and awareness of feelings, 2) provide opportunity for increased sense of agency, 3) provide a sense of belonging and

communality, and 4) create a sense of meaning and coherence in life (Ruud, 1998). The first three of these have direct applications to the results of the Music and Rett Syndrome Survey and will be examined in further detail.

Music provides opportunities to increase feelings of vitality and awareness of feelings. Ruud defines vitality as a "combination of spontaneity and reflexivity" (1998, p. 58), including how we feel and what we do with our feelings. A pivotal developmental task is to expand emotional awareness: to experience emotional nuance, and to experience and express various feelings at varying intensity levels. Music may be used to activate, clarify, and/or express feelings. It may also be used to change the mood of a person.

Music therapists who work with clients with severe cognitive impairments, such as RS, are constantly observing them for signs of awareness. Eye contact, changes in affect or mood, and changes in states of alertness are among the subtle responses that are exhibited. The following quotes from the surveys highlight how families use music or notice that it enhances their daughters' emotional awareness.

> Dvorak's *New World Symphony* "makes her sad or even cry. We cannot play Dvorak any more, it makes her scared, and she takes it very emotionally. I would not say she did not like it, she just took it so emotionally that it made her cry." (Parent of a 6 year old child)
>
> "She is very responsive to music. She has definite emotional reactions to it. It can make her ponder, or laugh or smile." (Parent of a 4 year old child)
>
> "We sing to calm her, comfort her, focus her or make her smile." (Mother of a 13 year old adolescent)
>
> We "get smiles and laughter when we sing to her. If she is in a bad or sad mood, we will sing to her to change her demeanor." (Parent of a 15 year old adolescent)
>
> "Music definitely has a big impact on her life. It is what we use the most with her and one of the only interactions she is really getting. If we sing, she is with us,

> smiling and laughing. If we don't, she looks pretty bored, not focused, doing nothing. The moment we sing, her attention is there and a light of life and happiness is on her face." (Mother of a 3 year old child)
>
> "Our daughter will respond to directions sung to her more quickly than those said to her. Her mood can be altered by music." (Parent of a 3 year old child)
>
> "She has a dramatic reaction to certain songs...She cries to sad songs, so response is appropriate. She recognizes the sad nature of them. She also cries when the song "Crying" by Roy Orbison is played every time." (Parents of a 5 year old child)

Music provides opportunities for increased sense of agency. Ruud defines agency as "the ability to take responsibility for one's own life and actions" (1998, p. 61). Related to agency are feelings of achievement, mastery, competency and empowerment. Ruud argues that music can influence development of "perception, cognitive skills, motor performance, social communicative skills, and emotional, bodily and symbolic activity" (1998, p. 62). RS causes severe cognitive and physical disability. Persons with RS have limited communication skills and motor responses. Most do not develop verbal communication skills and have limited ability to use physical gestures, due to the presence of stereotyped hand or arm movement. Independence and choice-making are not easily achieved. However, some families and music therapists report that music can be a catalyst for communication and expression (Elefant, 2001). The following quotes from surveys illustrate this point.

> "She loves music, especially those with a faster beat. Latin dance music is her favorite and she dances every night before bed time with daddy. She selects which song and artist she wants to dance to. We put the CD covers out on the coffee table. She knows by the cover which is which. She chooses by patting with her hand. She also knows what number is her favorite song on the different CD's and can recognize the song number illuminated on the stereo. She lets you know if the number on the stereo is not correct." (Parent of a 6 year old child)

"When she wanted me to sing or to watch me sing, she would push my face to the direction of her face." (Mother of a 12 year old child)

"She can recognize music instantly, especially if it is a song she likes. If she sees a radio that's off, she will hit at it to let someone know she wants it turned on. We've tried head phones, but she doesn't tolerate anything on her head for very long...We take lots of car rides and she loves listening to the radio. If she's in the front seat and a song is playing she doesn't like, she will hit at the radio until I change it. If I change the station because I don't like it, she will hit at it until I put it back on that song again. She's very aware of what she likes." (Parent of an 18 year old adolescent)

"We give her choices of videos sometimes and she will slap at one. That's the one we put in. I have even switched hands on her and she still picks the same one." (Parent of a 17 year old adolescent)

"If we forget to turn it on" [her sing along videos] "she goes right to the TV and complains." (Parent of a 16 year old adolescent)

"She loves music. It's the only other item she asks for using symbols besides food and drink." (Parent of a 15 year old adolescent)

"A lot of times if there isn't any music playing, she will hit the CD player or make the cover pop up." (Parent of a 15 year old adolescent)

"She doesn't like the Back Street Boys video. She leaves the room and stomps her feet in disapproval." (Parent of a 14 year old adolescent)

"We have tried unsuccessfully to get her to listen to 'age appropriate' music like N'Sync or Britney Spears and she just doesn't enjoy it." (Parent of a 13 year old adolescent)

Music provides a sense of belonging and communality. Ruud (1998) defines the sense of belonging as a "feeling of being home in the larger world, in history and geography" (p. 64) as well as relations to other persons, groups and communities. He also demonstrates concern for the fragmentation of society and the marginalization of persons with disabilities through institutionalization, resulting in the loss of stable relationships and community involvement.

Families may have difficulty caring for their adult daughters with RS due to the severity of their physical and cognitive disabilities. Thus, marginalization and social isolation are real concerns for this population. Music may be one of many applicable tools to support community involvement and the maintenance of stable relationships for persons with RS.

The following quotes from surveys illustrate some examples of how families use music or notice that it creates a sense of belonging and communality for their daughters with RS.

> "My son creates music on keyboard and computer. This is they kind of music teenagers dance to or DJ's play at 'raves.' My daughter is welcomed to his room on occasion. She delights in the dance beat and jumps on his bed to the beat. She is very calm during and after this experience which can last up to an hour if he allows." (Parent of a 12 year old child)

> "She enjoys music and dancing with her peers at her day program center." (Parent of a 24 year old young adult)

> "She goes to an adult day care center 5 days each week. Many of the other guests are senior citizens. But she has been going there for 10 years. When they play music, she jumps up and starts dancing. When she does that, the little old ladies there get up and start dancing too. We laugh and say that she is giving dancing lessons" (Father of a 30 year old adult)

> One of her favorite songs is *Is There Anybody Here Named Julie.* "I think because it's fun for her to hear her name and have everyone looking at her and it is very familiar." (Parent of an 11 year old child)

Other families noticed that music can be used to support inclusion of their daughters with RS into activities of the family or their peers. The following quotes support this notion.

> "She uses a switch to participate in band at school: she plays a percussion instrument." (Parent of a 15 year old adolescent)

She "has an older sister who sings and plays to perk her up." (Parent of a 5 year old child)

"Music definitely plays an important part in my daughter's life. But also important, maybe even more, is her need/desire to be included. She does not like to be alone. She much prefers to be helped to be included. Being animated, lively and energetic is the key." (Parent of a 5 year old child)

"Her siblings love to sing and dance to popular music and she totally gets in tune with them and watches and listens closely to their voices and actions." (Parent of an 18 year old adolescent)

"It has provided her with social enjoyment over time; as well as a soothing tool when upset. She has pursued 3 music courses at Syracuse University for audit. She has a membership to our local symphony and likes a variety of musicians and music types. She also participates in a church folk group." (Parent of a 22 year old young adult)

"*The National Anthem* is one she has hears a lot, but she especially loves hearing the kids sing it at school. She also 'lights up' with the recitation of the 'Pledge of Allegiance' by her class, or even when I start saying it." (Parent of an 11 year old child)

"With any mood, music and mama's lap to snuggle in always does the trick. It wouldn't work without the music." (Parent of a 4 year old child)

When getting her ready in the morning and when getting her ready for bed, I make up songs and sing them to her. I am a lousy singer, but she doesn't mind, or at least I don't think she does." (Father of a 30 year old adult)

The quotes in the previous sections are anecdotal evidence lending support to the theories of Boxill and Ruud. They are helpful in framing and explaining the responses of persons with RS to music. However, they were extracted from 36 surveys, only 8% of those received. A more comprehensive study of the applications of these two theories to persons with RS could better illuminate their relevance for care givers and music therapists working with these persons.

Implications for Further Research

Survey research is subject to criticism and questions. This study is no exception. Some may question how parents or family members can be certain whether specific songs or music are preferred by the person with RS. However, I believe that parents know their daughters best. This was a central assumption in the design of the study. However, the criticism remains an open question.

A study in progress by Cochavit Elefant will examine the musical preferences, methods for expressing preferences, and analyze musical elements of preferred music among girls with RS. This study will provide information from the perspective of the trained music therapist and produce insights about the specific musical qualities that parents and caregivers might not know about.

If the present study were to be refined, I would suggest using an interview format with a smaller number of subjects. This would enable the researcher to explore issues that were not addressed adequately, such as the amount of time per week spent in musical activity, changes of preference, music that is disliked, and uses of music as medicine. This method might also uncover new information about the role of music in every day life among families and persons with RS. The survey might also be revised and distributed to music therapists who work with persons with RS.

Future researchers should be encouraged to examine the following questions: What elements of music or musical qualities cause it to be preferred (pitch, timbre, tempo, surprise sound effects, or age and vocal range of singers)? How are music preferences shown in comparison with other known preferences?

Linking the survey responses to Boxill's and Ruud's theories leads to more questions. Can music be used to help persons with RS contain and deal with the full range of emotions, including happiness, frustration, sadness, and/or anxiety, and, if so, how? How do persons with RS develop their identities? How do music and culture influence such development? How can we study identity development in persons with limited verbal communication skills? How can music or music therapy increase connection with their community and culture among persons with RS and other developmental disabilities? How can music therapists help families use music to improve quality of life for themselves and their children with RS? Research studies could be designed and conducted to specifically examine if and how the theories could be supported by empirical evidence.

Implications for Practice

Application of Boxill's "Continuum of Awareness" theory to interaction between persons with RS and family members points to a new role for music therapists to consider. A musical mentor could assist families in dealing with the daily stresses of raising a child with RS or other severe cognitive impairment. There are certain therapeutic interventions that should only occur in the music therapy setting. However, there are many ways that families can harness the power of music on a daily basis. Adapting familiar songs to fit activities of daily living; changes of timbre, dynamics, and tempo to produce anticipatory responses; using music and holding for soothing; and applications of music in anxiety or emotional situations to relieve stress are all examples of how music therapists could mentor families. Results of the Elefant study (in progress)

will illuminate even more musical techniques that might help families interact and support their children with RS. Because music seems to be a significant category of experience for some persons with RS, its emotional, expressive, and stimulating qualities can be harnessed to catalyze increased purposeful hand use, social interaction, and improve the quality of daily living both in and outside the music therapy setting.

Conclusion

Results from both the Swedish Rett Center Survey (Merker et al., 2001) and this research demonstrate that music presents an important category of experience for persons with RS. The research also seems to support previous anecdotal reports from music therapists and Dr. Andreas Rett. Responses to both the Swedish and American surveys demonstrate that participation in music or music therapy may enhance the quality of life, contribute to the formation of identity, sense of personal agency and sense of belonging in the family, community and culture for persons with RS.

"Music must serve a purpose; it must be a part of something larger than itself, a part of humanity" (Pablo Casals as cited in Boxill, 1985, p.iii). Music therapy must also serve a purpose, with growth and development transferable to other settings outside the therapy room. The IRSA has advocated for the inclusion of music in the lives of girls and women with RS. For them and their families, music may be an important avenue of communication, connection and interaction. No words of mine could conclude this work better than those of the families who responded to the survey.

> "Even though she can't sing (and frankly, many people can't), she can still enjoy music just like everyone else. In listening to music she is just like you and me. Music doesn't require the use of your hands nor your ability to communicate.

That in itself is a stress reliever from having to live with having Rett." (Parent of a 9 year old child)

"Music can set the mood, provide an opportunity for anticipation, divert attention, gain attention, and give a pleasant experience to someone who has absolutely no control over their environment." (Parent of a 31 year old adult)

"Music brought my daughter great happiness and I cannot imagine her life without music." (Parent of a 27 year old young adult)

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Appendix A

Swedish Music and Rett Syndrome Survey

Questionnaire for Rett patient parents developed by Marith Bergstrom-Isacsson, Bjorn Merker and Ingegerd Witt Engerstrom for the Swedish Rett Center, 1999 (Translated from the Swedish by Bjorn Merker). Reproduced with permission from the authors and the Nordic Journal of Music Therapy.

1. Is your daughter interested in music? If so, briefly describe the nature of her interest.

2. What kinds of music are available in your daughter's everyday environment?

    a) music-making or singing in the family
    b) listening to records/tapes
    c) radio/television
    d) does your daughter use freestyle or headphones?
    e) other sources of music
    f) no music

3. What type of music predominates in the sources of music from 2, a through e above from which your daughter is exposed? List the answer, such as pop-music, classical music, children's music, after your answers above.

4. Try to estimate the approximate amount of time per day or week which your daughter spends listening to music.

5. Does your daughter receive music therapy? If so, of what kind?

6. Does your daughter receive other treatments involving music or sound, such as vibroacoustic therapy? If so, what type and how often?

7. Do you remember if you were exposed to song or music or sang yourself in the months before your daughter was born? If so, describe briefly.

8. What kind of music was present in your daughter's environment during infancy and up to the time that she developed noticeable symptoms?

    a) music-making or singing in the family
    b) records/tapes
    c) radio/television
    d) did you or other family member sing to or with your daughter?
    e) other sources of music exposure at this time
    f) no music

9. Does your daughter have any favourite songs or tunes (one or more, which for the sake of simplicity we will refer to as "favourites" below)? If so, please name these with as much additional information as you possess about them, such as whether they are traditional songs, records (and if so, which ones) etc. to help us identify and analyze these pieces.

10. If she has favourites, does she change preferences, and if so, how often has this happened?

11. If she has favourites, how does she show this?

12. If she has favourites, do you know when she first could have heard them?

13. If she has favourites, do they include any tune she could not have heard until after the time she developed noticeable Rett symptoms? If so, when?

14. Are there any tunes your daughter does not like? If so, describe them, and try to indicate when she first could have heard them.

15. If there are tunes she does not like, how does she show this?

16. Concerning both possible favourites and tunes your daughter might not like, do you know of any special circumstances which might explain her attitude to these tunes? For example, how often was it played or sung, was it associated with any special situation or person, etc. If so, briefly describe these circumstances.

17. If you use music as "medicine" for your daughter, what symptoms do you treat?

Appendix B

Revised Music And Rett Syndrome Survey

Music and Rett Syndrome Survey

Instructions: please respond in short answers or circle your responses (you may choose one or more than one response if applicable).

1. What is the person with Rett Syndrome's birth date? (this information will be used to classify the responses by age and not to identify anyone specifically) Please respond in month/day/year form ____/____/_____

2. What is your relationship to the person with Rett Syndrome (subsequently referred to as "daughter" in the survey)

   a) Parent (s)

   b) Relative/sibling (please specify i.e. grandparent, sister, brother etc.)

   c) Caregiver

   d) Teacher/educator

   e) Other (please specify)

3. Is your daughter's Rett Syndrome diagnosed as

   a) Classic

   b) Variant

   c) Other (please describe)

   d) Don't Know

4. Is your daughter interested in music? If so, briefly describe the nature of her interest.

5. What sources of music are available in your daughter's everyday environment? In the space following each, list the type of music (classical, popular, children's, country, world/ethnic, jazz etc.) that predominates in each

g) music-making or singing in the family

h) listening to recordings (cd's, tapes, records)

i) radio/television

j) use of headphones

k) other sources of music

l) no music

5. What is the approximate amount of time per day or week that your daughter spends listening to music?

6. Was the mother exposed to music or did sing/play an instrument herself in the months before your daughter was born? If so, briefly describe.

8. Does your daughter have any favorite songs or tunes (subsequently referred to as "favorites" below)? If so, please name these with as much additional information as you possess about them, such as song title, recording title, artist (if applicable), composer, references to the song (movie title etc.) to help us identify and analyze these pieces.

9. If she has favorites, does she change preferences, and if so, at what approximate ages has this happened?

10. If she has favorites, how does she show this?

11. Are there any songs your daughter does not like? If so, describe them in detail, as in question 8.

12. If there are songs she does not like, how does she show this?

13. Does your daughter receive music therapy? If so, where and what kind?

14. Does your daughter receive other treatments involving music or sound, such as vibroacoustic therapy? If so, what type and how often?

15. If you use music as "medicine" for your daughter, what symptoms do you treat? In the space following your responses, please indicate specific music that you might use (singing, song titles, recording name, etc.) with as much detail as possible.

a) stress

b) upset

c) pain

d) anxiety

e) sadness

f) boredom

g) withdrawal

h) sleep

i) activities of daily living (please specify)

j) other (please specify)

Appendix C

Instructions Letter

Carolyn M. Houtaling, MT-BC
439 Windmill Pointe Drive
Flushing MI 48433
Phone: 810.487.0273
Email: houtalin@msu.edu

August 30, 2002

Dear Parents and Caregivers:

You are invited to participate in a questionnaire about the role of music in the lives of persons with Rett Syndrome. The research is based on a study from Sweden by Merker, Isaccson, and Engerstrom in which parents and caregivers reported information on music preferences, responses and interests of women and girls with Rett Syndrome. Their questionnaire has been adapted for use in the United States and is attached with their permission.

With the assistance of the International Rett Syndrome Association, all information collected in the survey will be kept strictly anonymous and your privacy will be protected to the maximum extent allowable by the law. No individual information will be included in the results. Results will be published and made available on an individual basis upon request to the researcher.

The researcher hopes to learn more about how persons with Rett Syndrome in the United States relate to music. This will benefit parents, caregivers, educators, and music therapists in their endeavors to enrich the girls' and women's lives with music. Results may be compared to those obtained in the Swedish study to provide a multicultural perspective on the issues.

If you have any questions about the survey or the research, please feel free to contact the researcher at the address, phone number or email below. You may also contact the Michigan State University Institutional Review Board separately from the researcher if you have any questions about your role or rights as a subject of research. You may contact Ashir Kumar, MD. Chair, Michigan State University Committee on Research Involving Human Subjects, (517) 355-2180.You indicate your voluntary agreement to participate by completing and returning this questionnaire in the addressed, stamped envelope that is attached to the survey. Completion of the questionnaire should require a maximum of 30 - 40 minutes. Responses should be returned by October 30, 2002.
Thank you in advance for your time and participation.

Sincerely,

Carolyn M. Houtaling, MT-BC
Music Therapy Graduate Student
Michigan State University

Appendix D

Michigan State University Committee on Research Involving Human Subjects Approval Letter

MICHIGAN STATE
UNIVERSITY

June 11, 2002

TO: Frederick TIMS
149 Music Bldg.
MSU

RE: **IRB# 02-311** CATEGORY: EXEMPT 1-2
APPROVAL DATE: June 6, 2002

TITLE: MUSIC AND RETT SYNDROME: A SURVEY OF PARENTS AND

The University Committee on Research Involving Human Subjects' (UCRIHS) review of this project is complete and I am pleased to advise that the rights and welfare of the human subjects appear to be adequately protected and methods to obtain informed consent are appropriate. Therefore, **the UCRIHS approved this project.**

RENEWALS: UCRIHS approval is valid for one calendar year, beginning with the approval date shown above. Projects continuing beyond one year must be renewed with the green renewal form. A maximum of four such expedited renewals possible. Investigators wishing to continue a project beyond that time need to submit it again for a complete review.
REVISIONS: UCRIHS must review any changes in procedures involving human subjects, prior to initiation of the change. If this is done at the time of renewal, please use the green renewal form. To revise an approved protocol at any other time during the year, send your written request to the UCRIHS Chair, requesting revised approval and referencing the project's IRB# and title. Include in your request a description of the change and any revised instruments, consent forms or advertisements that are applicable.
PROBLEMS/CHANGES: Should either of the following arise during the course of the work, notify UCRIHS promptly: 1) problems (unexpected side effects, complaints, etc.) involving human subjects or 2) changes in the research environment or new information indicating greater risk to the human subjects than existed when the protocol was previously reviewed and approved.

If we can be of further assistance, please contact us at (517) 355-2180 or via email: UCRIHS@msu.edu. Please note that all UCRIHS forms are located on the web: http://www.msu.edu/user/ucrihs

Sincerely,

Ashir Kumar, M.D.
UCRIHS Chair

AK: br

cc: Carolyn M. Houtaling
439 Windmill Pointe Dr
Flushing, MI

OFFICE OF
RESEARCH ETHICS AND STANDARDS
University Committee on Research Involving Human Subjects
Michigan State University
202 Olds Hall
East Lansing, MI
48824
517/355-2180,
FAX: 517/432-4503
www.msu.edu/user/ucrihs
E-Mail: ucrihs@msu.edu

Appendix E

Alphabetical List of Favorite Songs

Alphabetical List of Preferred Songs

Song Title	**Artist (if listed)**
1 2 3	Gloria Estephan
3 Little Kittens	
A Dream is a Wish Your Heart Makes (Cinderella)	
A Whole New World (Aladdin)	
ABC	Jackson 5
ABC-DEF-GHI	Sesame Street
ABC's	
Ah-Um Went the Little Green Frog	
Ain't Enough	Aerosmith
Ain't No Grave	Russ Taff
Aint Nothin' About You	Brooks & Dunn
Ain't Misbehavin	
Amazed	Lone Star
Amazing Grace	
American Pie	Don MacLean
Angels	Alabama
Animal Crackers in my Soup	
Ants Go Marching	
Any Man Of Mine	Shania Twain
Anybody Wanna Pray	CeCe Winans
Aren't You Glad You're You (from the Bells of St. Mary's)	
Ashokan Farewell (from Ken Burns Civil War)	
At the Foot of Canal Street	John Boutte
Atmospheres Dolphin Dance (St. Clair Entertainment Group Inc.)	
Baby Beluga	Raffi
Bare Necessities (Jungle Book)	
Batty Bat song (Sesame Street)	
Be Careful Little Eyes	
Be Our Guest (Beauty and the Beast)	
Beauty and the Beast	
Becky Sue's Song (Songs of Love)	
Beep Beep Song (Sesame Street)	
Beethoven's Fifth Symphony	
Believe	Cher
Bicycle Built For Two	
Billy Jean	Michael Jackson
BINGO	
Blue	Leann Rimes
Bobby Baker's Band	
Boot Scootin' Boogie	Brooks and Dunn
Born in the USA	Bruce Springsteen
Brahms Lullabye	

Song	Artist
Build Me A Mystery	Sarah McLachlan
By The Sea	
Bye Bye Bye	N'Sync
C is for Cookie (Sesame Street)	
Carmelito	Jerry Riviera
Charlie Brown (1950's)	
Chatahootchie	Alan Jackson
Chicka Boom	
Circle of Life	
Close Your Eyes	Priscilla Herdman
Colors of the Wind (Pocohontas)	
Concerto in D minor: Tchaikovsky	
Copa Cabana	Barry Manilow
Count It Higher (Elmo)	
Crazy	Patsy Cline
Crocodile Rock	Elton John
Cruella Devil (101 Dalmatians)	
Daddy's Hands	Holly Dunn
Dance of the Cucumber	Veggie Tales
Dance, Dance Dance	
Dancing in the Street	
Day By Day	
Day-O	Harry Belafonte
Deotro Monera	Jerry Riviera
Des Colores	Raffi
Dirty Diana	Michael Jackson
Do-Re-Mi (Sound of Music)	
Do Your Ears Hang Low	
Down By the Bay	Raffi
Downtown	Petula Clark
Dream	Everly Brothers
Dream With Me (Lullabye Bear from Avon)	
Drops of Jupiter	Train
Dude Looks Like a Lady	Aerosmith
Edelweiss	
Eine Kleine Nachtmusik	
Elephant Song	
Everybody Wants to be a Cat (Aristocats)	
Everything Grows	Raffi
Fantasia on a Theme by Thomas Tallis	Vaughan Williams
Farm Song	
Feed the Birds (Mary Poppins)	
Fish Song	
Five in the Bed	
Five Little Monkeys	

Song	Artist
Flying in an Airplane	Barney
Forget About It	Allison Krauss
Free Falling	Tom Petty
Get Ready to Wiggle	The Wiggles
Getting to Know You (The King and I)	
Glory Road	Ivan Parker
Go To Sleep My Baby	
Go You Packers Go	The Wizenheimers
God Must Have Spent A Little More Time On You	Alabama
Goodbye Earl	Dixie Chicks
Goodnight Song (Lawrence Welk)	
Got My Mind Set On You	George Harrison
Grandpa's Magical Toys (Wee Sing Video)	
Green Speckled Frog Song	
Green Willow Idyll	Butterworth
Greensleeves	Vaughan Williams
Hakuna Matada (Lion King)	
Happy Birthday	
Happy Tappin' with Elmo	
He Knows How Much We Can Bear	Kate MacKenzie & the Fairfield Four
Head, Shoulders Knees and Toes	
Heavenly Father	CeCe Winans
Heighdy Ho	Cab Calloway
Hella Good	No Doubt
Here Comes the Judge	
Hey Baby	No Doubt
Hey Jude	Beatles
Hey, Hey We're the Monkees	Monkees
Hi Ho (Snow White)	
High Hopes	
High School song	
Hokey Pokey	
Hold On, I'm Comin	Michael Bolton
Hole in my Pocket	
Hopelessly Devoted to You	Olivia Newton John
Hot In Here	Nelly
Hound Dog	Elvis
How Much is That Doggie in the Window	
Hummer's Dance	Lorenna McKinnett
Hush Little Baby	
Hush Little Baby	Sylvia Long
I Am a Child of God	
I Am a Hippity, Hoppity Bunny Kid (Muppets: Billy Bunny's Animal Songs)	

Song	Artist
I Can Sing a Rainbow	
I Can't Help Falling In Love With You	Elvis
I Get Around	Beach Boys
I Get the Blues When It Rains	Larry Elegant Orchestra
I Hope You Dance	Lee Ann Womack
I Just Called To Say I Love You	Stevie Wonder
I Just Want to Fly	Sugar Ray
I Love You	Barney
I Love You a Bushel and a Peck	
I Saw the Light	Jesse Dixon
I Sent You Roses	Reba McEntire
I Walk the Line	Johnny Cash
I Want It That Way	Backstreet Boys
I Want To Talk About Me	Keith Whitley
I Want You Back	Jackson 5
I Will Always Love You	Whitney Houston
I Won't Grow Up	Mary Martin
I'd Like to Visit the Moon (Sesame Street)	
I'll Fly Away	
I'm a Believer	Monkees
I'm a Little Teapot	
I'm Alive	Celine Dion
I'm Bringing Home a Baby Bumblebee	
I'm Moving On	Rascal Flats
I'm So Excited	Pointer Sisters
I've Gotta Crow (Peter Pan)	
If I Had a Boat	
If I Had a Hammer	
If I Had A Million Dollars	Barenaked Ladies
If I Never Knew You (Pocohontas)	
If You're Happy and You Know It	
I'll Fly Away (O Brother Where Art Thou Soundtrack)	
I'm A Believer (Shrek Soundtrack)	Smashmouth
I'm a Big Girl (tune of I'm a Christian)	
Imagine That (Tigger)	Winnie the Pooh
Impossible/It's Possible (Cinderella)	
In a Cabin in the Woods	
Is There Anybody Here Named Julie	
It's Not Easy Being Green	
It's Raining, It's Pouring	
It's Your Party (Richard Simmons video)	
Itsy Bitsy Spider	
I've Been Working on the Railroad	
Jeg Elske Deg (family tradition w/name & I love you")	
Jesus Loves Me	

Song	Artist
Jesus Loves Me	The Barrett Sisters
Jesus Loves the Little Children	
Jingle Bells	
Just Another Day	John Mellancamp
Keep On Rockin me Baby	Steve Miller Band
King of the Road	
KKKKatie	
Kum By Yah	
La Traviate by Verdi	
Larry Boy	Veggie Tales
Lemon Drop Song	Barney
Les Poissons (little Mermaid)	
Let's Play Together	Barney
Let's Take A Ride (Sesame Street)	
Let's Go Down To the River and Pray (O Brother Where Art Thou Soundtrack)	
Little Bitty	Alan Jackson
Little Bunny Foo Foo	
Little Red Caboose	
Little Red Wagon	Raffi
Living La Vida Loca	Ricky Martin
Locomotion	
Lonely Goatherd (Sound of Music)	
Long Way Gone	Dixie Chicks
Look at the Baby	James Jacob Brody
Love is a Very Special Thing	
Love Letters in the Sand	Pat Boone
Love Me Do	Beatles
Love Me Tender	Elvis
Love of My Life	Brian McKnight
Lovely One	Michael Jackson
Lowdown Hoedown	
Lucille	Little Richard
Mambo #5	
Man, I Feel Like A Woman	Shania Twain
Maresy Doats	
Mary Had a Little Lamb	
Mashed Potatoes	Wiggles
Mathilda Gorilla	
Messiah (Handel)	
Michael Row Your Boat	
Mickey	Toni Basil
Mighty Like a Rose	
Military Style (Elephants marching song from Jungle Book)	
Mother Goose song	Barney

Song	Artist
Move	Ludacris
Mr. Knickerbocker	Barney
Mr. Sun	
Muffin Man	
My Bonnie Lies Over The Ocean	
My Favorite Things (Sound of Music)	
My Girl	Temptations
My Kind Of Girl	Brian McKnight
My Maria	Brooks and Dunn
National Anthem	
New York, New York	Frank Sinatra
Nothing's Going To Harm You (from Sweeney Todd)	
Nutcracker	
Oh Shine on Are in the Evening	
Oh Susannah	
Oh The Cows in the Meadow they go Moo, Moo, Moo	
Oh What A Beautiful Morning	
Oh What Do You Do In The Summer Time	
Oh You Beautiful Doll	
Oh, By the Way	Joe Scruggs
Oklahoma!	
Old MacDonald	
On a Winter's Night	
On Bended Knee	Boys II Men
On The Road Again	Willie Nelson
On Top of Spaghetti	
Once Upon a Dream (Sleeping Beauty)	
One Foot in Eternity	Rick Tarquino
One, Two, Buckle My Shoe	
Only a Boy Named David	
Only One Look	Lillie Knauls
Oops, I Did It Again	Britney Spears
Orange Blossom Special	
Over In the Meadow	
Over the Hills	
Over the Rainbow	Reggae for Kids
Pachelbel's Canon	
Pampers TV commercial	
Part of Your World (Little Mermaid)	
Paw Paw Patch	
Peanut Butter Song	Barney
Peggy Sue	Buddy Holly
Peggy Sue (Richard Simmons video)	
Peppermint Twist	
Peter and the Wolf	

Song	Artist
Pictures At An Exhibition (Chicken Part) by Moussourgsky	
Pink	Aerosmith
Pink Cadillac	Natalie Cole
Pizza Party	
Planet Song	Nick Jr.
Poison Ivy	Jim Gill
Pop Goes the Weasel	
Pretty Woman	Roy Orbison
Puddle of Mud	
Puff the Magic Dragon	Peter, Paul and Mary
Puppet on a String	Elvis
Put Down the Ducky	Sesame Street
Que Sera, Sera	
Queen of the Night's Song (Mozart)-sung by family in funny way	
Rainbow Connection	Muppet Movie
Rainbow Song	Barney
Ran So Far Away	Flock of Seagulls
Refrigerator Magnet	Joe Scruggs
Ring Around the Rosie	
Robin, Robin	
Rock A Bye Baby	
Rock Island Line	Johnny Cash
Rock My Soul	
Rock Solid Faith	Ken Blount
Rock the Boat	Aaliyah
Rocket Robin (A Day With the animals Video)	
Rockin' Robin	Bobby Day
Rocky Mountain (Wee Sing Video)	
Rocky Top	
Row Your Boat	
Rudolph the Red Nosed Reindeer	
Safety Dance	Men Without Hats
Sally the Camel	
Seventy Six Trombones	
Shake Your Sillies Out	
She Loves You	Beatles
She's My Girl	Billy Gilman
She'll Be Comin' Around the Mountain	
Shout	Tears for Fears
Sillyville (Wee Sing Video)	
Sing the Alphabet	
SiTu MeFaltas	Jerry Riviera
Six Little Ducks	
Skidamarink	

Song	Artist
Skip to my Lou	
Some Enchanted Evening (South Pacific)	
Song of Sixpence	
Space Cowboy	N'Sync
Splish Splash	
Spoon Full of Sugar	
Sugar Pie Honey Bunch	
Sunny Side of the Street	
Sunny Side of the Street	Maria Muldaur
Supercalifragilistic	
Superman	Five For Fighting
Swinging on a Star	Maria Muldaur
Tainted Love	Soft Cell
Take Me Out To the Ballgame	
Tammy	Debby Reynolds
Teddy Bear Song	Wiggles
Tell Me Whose Girl You Are (Ethnic)	
Tell Me Why	Judd's
The Elf Song	Barney
The Head Bone Connected to the Knee Bone	
The Lark Ascending	Vaughan Williams
The Lily of the Valley (Southern Gospel)	
The Other Day I Saw a Bear	
The Riddle Song	
The River	Garth Brooks
The Silly Song (Snow White)	
The Sneezing Song	Jim Gill
The Sweetheart Tree	
The Swimming Song	
The Wanderer	
The Washing Machine	Jim Gill
Theme from "Cheers"	
Theme from Lamb Chop	
Theme from the Flintstones	
Theme from the Muppet Show	
Theme from Titanic	Celine Dion
Theme to Barney	
Theme to Bear in the Big Blue House	
Theme to Blues Clues	
Theme to Clifford	
Theme to Dora the Explorer	
Theme to Dragon Tales	
Theme to Duck Tales	
Theme to Elmo's World	
Theme to Jeopardy	

Song	Artist
Theme to Land Before Time	
Theme to Law and Order	
Theme to Mary Kate and Ashley Olsen TV series: So Little Time	
Theme to P. B. & J Otter	Disney
Theme to Price is Right	
Theme to Rugrats	
Theme to Sesame Street	
Theme to Stanley	Disney
Theme to Teletubbies	
Theme to the Brady Bunch	
Theme to Thomas the Tank Engine	
Theme to Trumpet of the Swan	
Theme to Veggie Tales	
Theme to Wheel of Fortune	
There Was a Bold Fisherman	
There's a Ghost in this House	Allison Krauss
There's Your Trouble	Dixie Chicks
This is How You Remind Me	Nickelback
This Little Light of Mine	Raffi
This Little Piggy	
This Old Man	
Thunder Road	Bruce Springsteen
Thunder Rolls	Garth Brooks
Till There Was You	
Tomorrow (from Annie)	
Too Rah Loo Rah Loo Rah	Rosemary Clooney
Turn Around	Harry Belafonte
Twinkle, Twinkle Little Star	
Ugly Duckling	Danny Kaye
Unchained Melody	
Under the Sea (The Little Mermaid)	
Unicorn Song	
Waltzes with Bears	Patricia Herdman
Waltzing Matilda	
We Are Family	Pointer Sisters
We Did It (from Dora The Explorer)	
We Will Rock You	Queen
We Wish You a Merry Christmas	
Wendy	
What Do You Smell	
What I Like About You	Romantics
Wheels On the Bus, The	
When a Man Loves a Woman	Percy Sledge

Song	Artist
When You're Blessed	Whitney Houston & Patti LaBelle
When You're Smiling	
Whip It	Devo
Who Let The Dogs Out	Baha Men
Why Don't You Write Me (A Day With the Animals Video)	
Winnie The Pooh	
Wipe Out	Surfaris
Wise Man Built His House Upon a Rock	
Wooly Bully	Sam the Sham
Yackity Yak, Don't Talk Back	
Yankee Doodle	
Yodel song from Sound of Music	
You and Me Against the World	Helen Reddy
You Are Beautiful (Christian song sung in church)	
You Are My Friend	
You Are My Sunshine	
You Are Special	Barney
You Can Count on Me (Jim Henson's Fraggle Rock Video)	
You Can Fly (Peter Pan)	
You Deserve a Break Today (MacDonald's Theme Song)	
You Got a Friend in Me (Toy Story)	
You Might as Well be Walking on the Sun	
You, You, You	Ames Brothers
You'll Be In My Heart (Tarzan)	
Zip A Dee Doo Dah (Song of the South)	

Appendix F

Reported Music Disliked by Respondents

Music Types

Children's (recorded)

Christian, Church, Gospel

Classical

Country

Jazz

Marching Band Music

Non-Children's

Non-Elvis

Opera

Popular: Alternative, Grunge, Hard Rock, Heavy Metal, Hip Hop, Punk, Rap

Specific Songs

Barney's Goodbye Song

Forever

Happy Birthday

Kum Ba Yah

Silent Night

Somewhere Out There

Theme Song from Golden Girls

Theme Song from Jaws

Theme Song from SpongeBob Squarepants

Where is Love

Who Let the Dogs Out

Music from Hunchback of Notre Dame

Groups or Artists

Baby Mozart Video

Backstreet Boys

Barney

Girl Groups of the 1950's-1960's: Dusty Springfield, Aretha Franklin, Darlene Love

Toby Keith (two songs, not specified)

Barry Manilow

Alanis Morrisette

Ann Murray

Oak Ridge Boys

Van Halen

Appendix G

Activities of Daily Living Where Music is Used as Medicine

Activities of Daily Living Where Music is Used as Medicine

Academics: body parts, colors, coloring, pre-school information

Background for all activities

Bathing

Brushing teeth

Bus (preparation for school)

Combing hair

Doctor or dentist appointments

Dressing

Driving or riding in the car

During physical or occupational therapy

During wearing of orthotics

Eye contact or attention

Floor play

Fun, entertainment or relaxation

Massage

Meal time

Meeting new people

Movement

Nail clipping

New facts

Range of motion, stretching