San Jose State University
SJSU ScholarWorks

Master's Theses | Master's Theses and Graduate Research

2009

Music in the lives of two children with autism : a case study

Elizabeth Ron Fang
San Jose State University

Follow this and additional works at: http://scholarworks.sjsu.edu/etd_theses

Recommended Citation
Fang, Elizabeth Ron, "Music in the lives of two children with autism : a case study" (2009). *Master's Theses.* Paper 3348.

This Thesis is brought to you for free and open access by the Master's Theses and Graduate Research at SJSU ScholarWorks. It has been accepted for inclusion in Master's Theses by an authorized administrator of SJSU ScholarWorks. For more information, please contact scholarworks@sjsu.edu.

MUSIC IN THE LIVES OF TWO CHILDREN WITH AUTISM: A CASE STUDY

A Thesis

Presented to

The Faculty of the School of Music and Dance

San José State University

In Partial Fulfillment

of the Requirements for the Degree

Master of Arts

by

Elizabeth Ron Fang

December 2009

© 2009

Elizabeth Ron Fang

ALL RIGHTS RESERVED

The Designated Thesis Committee Approves the Thesis Titled

MUSIC IN THE LIVES OF TWO CHILDREN WITH AUTISM:
A CASE STUDY

by

Elizabeth Ron Fang

APPROVED FOR THE SCHOOL OF MUSIC AND DANCE

SAN JOSÉ STATE UNIVERSITY

December 2009

Dr. Diana Hollinger	School of Music and Dance
Dr. Gordon Haramaki,	School of Music and Dance
Prof. Kara Ireland D'Ambrosio	School of Music and Dance

ABSTRACT

MUSIC IN THE LIVES OF TWO CHILDREN WITH AUTISM:
A CASE STUDY

by Elizabeth Ron Fang

This thesis is a qualitative case study about two children with autism spectrum disorder and the role of music in their lives. It explores how music serves as a non-threatening medium for learning and developing skills necessary to function successfully in life. The stories of the children and their parents are shared through their personal account and the author's observations.

The literature in the field reveals that a structured/functional use of music helps communication, social interaction, appropriate behavior, motor skills, and academics in children with autism. Each child is able to actively participate in music-making within varied and appropriate settings as music accommodates different levels and abilities. With successful experiences, these children gain confidence and self-esteem, learn a skill, establish a socially appropriate hobby, and acquire outside acknowledgement and praise. Informal but functional uses of music at home, school, or elsewhere can benefit and aid children with autism. The stories of the participants show music's potential in helping individuals with autism live a more fulfilling and promising life.

ACKNOWLEDGEMENTS

This thesis is a product of the combined efforts of many individuals to whom I am ever grateful. First, tremendous thanks to my participants, who are the motivation for this work. They opened their hearts and lives unselfishly for my research— offering information freely, patiently answering my inquiries, welcoming me into their homes, and dedicating themselves from beginning until the end. Their time and trust are beyond measures.

Second, I sincerely thank my advisor, Dr. Diana Hollinger. In this journey, she joyfully served as my guide, leading and directing me each step of the way. Thank you for the exceptional effort, time, and energy poured without restraint, and all the sacrifices made on my behalf. I will always remember our laughs and talks with Allie prancing around us. Thank you for your unwavering confidence and faith in me. You have been the greatest!

I am also grateful to the rest of the members on my committee, professors of San José State University: Dr. Gordon Haramaki and Professor Kara Ireland D' Ambrosio. Both were towers of strength I could run to for counsel and advice. Thank you for always being there with a smile, open ears, concern, and loads of wisdom. Thank you for accepting the responsibility and burden of this task willingly despite your busy schedules. Both of you are phenomenal!

Last but not least, I wish to thank my family and friends who trod this road with me —all the way. Thank you for your prayers. Your love, patience, encouragement, and

care were my constant companions in this race, pushing me onwards towards the goal. Thank you for bearing with me during this time without complaint!

As the adventure comes to a close, my heart is full of thanks. I could not have finished this project without any of you. Thank you so much!

The Lord bless you all.

TABLE OF CONTENTS

Chapter Page

1: INTRODUCTION……1

Background of the Study……2

Purpose of the Study…… 5

Need for the Study…… 6

Method of the Study……7

Limitations of the Study……8

Nature and Size of the Sample……8

Uniqueness of the Setting……8

Time Period of the Study…… 10

Definition of Terms……10

"Child with Autism"……10

Autism Spectrum Disorder (ASD)……11

Further Terms……12

Conclusion……12

2: REVIEW OF THE LITERATURE……13

Nature of Autism……13

General Characteristics……13

History of Autism and Important Figures……18

Music's Influence on Health and Behavior……23

Music and Autism…….….25

Responding to Music…….….26

Why Music? ……..…27

Music Therapy……....29

Uses of Music…….30

Special Education in the United States…… ……..35

History of Educating Students with Disabilities…….36

History of Music in Special Education……...38

Laws and Legislative Events Affecting Special Education……39

Intervention Strategies……....43

Conclusion……..50

3: METHOD AND DESIGN……..…….....….. 52

Primary Participants……54

Secondary Participants…….…….…….56

Research Sites…….……..…….….56

Data Collection…….……..…….56

Interviews and Observations…….…..…….…...58

Artifacts……...……59

Confidentiality…….……60

Data Analysis ……..…60

Trustworthiness……...61

Summary…….……62

4: MIKE……..…64

Our First Meeting……..64

His Story……68

Family Background……...68

Early Years……70

Diagnosis and Early Interventions…….72

Mike Goes to School……. 75

Mike's Musical Journey…… 78

Mike at School Today……80

Band Class……. 80

Speech Therapy……..84

Lunch Time……86

Electronic Music Class…….. 89

Mike's Life Outside of School…….. 92

Piano Tutoring……93

A Piano Lesson……...97

Music, Motivation, Memory……...99

Music as Common Ground……....100

Making Music Together…….....101

Ready, Set, Action…….....104

Open House at Mike's……...105

Wendy's Journey…….....109

Mike's Voice…….111

Teaching Mike…….....113

Impressions and Perceptions of Others…….....117

Personal Issues……..118

Wendy's Message to Mike……120

Mike's Future……....120

Epilogue……....121

5: RYAN……....123

Our First Meeting……... 123

His Story……...…130

Family Background……..... 130

Early Years……..….131

Diagnosis and Early Interventions……...….132

Ryan's Musical Journey……..… 138

Ryan Goes to School……..…..140

Ryan at School Today……..…....141

Music Class……..……143

Opera Rehearsal……..…….147

Halloween Music Class……..…….....148

Ryan's Life Outside of School……..……..152

Camping……..……...….152

"Making Circles"…….…….. ….157

Play Date…….165

Beauty and the Beast…….….169

Rachel's Journey……....175

Lessons Learned…….…175

Advice for Other Parents with Special Needs Children…….....175

Ryan's Future…….176

Epilogue……..176

6: THERE AND BACK AGAIN……...…….……...177

Speech and Communication……...177

Memory…….....179

Learning……...……181

Social Interaction……...……..184

Stimulus and Musical Ability…….……185

Confidence and Self-esteem…….……. 187

A Final Reflection……..…….188

BIBLIOGRAPHY…….…….. 190

APPENDIX……200

A: Glossary…….……..200

B: Consent Form for Participants (Adult and Child)……..….….206

C: Sample Interview Questions…….…….…...212

Chapter 1: Introduction

The number of individuals diagnosed with autism is increasing at such an alarming rate worldwide that today it affects one in every 91 people in the U.S.[1] As autism is a "spectrum" disorder and each individual on the spectrum is so different, no one method or approach works for all autistic people. Music, however, is an engaging stimulus for children with autism. Much of the literature on autism states that children who do not respond to speech will often respond to music. In fact, they respond more frequently and appropriately to music than any other auditory stimulus.[2] In addition to responding positively to music, children with autism are often musically talented.[3] Hoelzley takes this one step further and suggests that musical ability is a fundamental component of autism.[4] Impairments in areas such as speech and communication, social

---

1. "Autism Speaks Responds to New *Pediatrics* Autism Study Putting Prevalence at 1 in 91 American Children, Including 1 in 58 Boys," http://www.autismspeaks.org/press/autism_nchs_prevalence_study_1_in_91.php (accessed October 5, 2009).

2. Elizabeth Starr and Krista Zenker, "Understanding Autism in the Context of Music Therapy: Bridging Theory and Practice," *Canadian Journal of Music Therapy* 6, no. 1 (1998): 1.

3. Alice-Ann Darrow and Tammy Armstrong, "Research on Music and Autism: Implications for Music Educators," *Update: the Applications of Research in Music Education* 18, no. 1 (1999): 16. See Kanner (1971), O' Connell (1974), and Kolko et al. (1980) for responding positively to music. See Hairston (1990), Ricks & Wing (1997), Oppenheim (1974), Thaut (1988), and Applebaum et al. (1979) for high level of musical ability.

4. Robert Accordino, Ronald Comer, and Wendy Heller, "Searching for Music's Potential: A Critical Examination of Research on Music Therapy with Individuals with Autism," *Research in Autism Spectrum Disorders* 1, no. 1 (2007): 102. See Hoelzley (1993).

interaction, sensory perception, and association with repetitive behaviors, challenge these individuals in all areas of life resulting in the creation of two worlds, theirs and ours, causing isolation and alienation. Therefore, music is important because it can serve as a bridge between these vastly different worlds.

This thesis is a qualitative case study about two children with autism spectrum disorder and the role of music in their lives. The study is based on observations of the children and their parents at home, school, and other activities, as well as, interviews conducted with their parents and teachers. Verbal interaction with the autistic participants was limited due to their lack of comprehension, speech, communication, and social interaction. The first chapter of this thesis presents the background of the study, describes its significance, and displays an overview of the methodology used. Limitations of this study and definitions of special terms conclude this chapter.

Background of the Study

Autism is a pervasive developmental disability that is rapidly growing in our world today. As autism is a rather recent discovery, first clinically documented by Leo Kanner in 1943,[5] the search for a deeper understanding and knowledge of this condition is ongoing. Presently an exact cause or cure for autism remains unknown. However, early diagnosis and active interventions in life can lead to positive outcomes.[6] Medical

5. Elisabeth Hill and Uta Frith, "Understanding Autism: Insights from Mind and Brain," *Philosophical Transactions: Biological Sciences* 358, no. 1430 (2003): 282.

6. Nicole Allgood, "Parent's Perceptions of Family-based Group Music Therapy for Children with Autism Spectrum Disorders," *Music Therapy Perspectives* 23, no. 2 (2005): 92.

research is currently investigating possible causes such as immunizations, environmental factors, genetic mutations, and viral illness.[7]

Music has long been used as a source of healing. In ancient times it was not only used for physical sickness but also mental illness.[8] Whereas medicine was able to influence the physical body, music was believed to boost the spirit and morale, restoring balance.[9]

After World War I, music therapy emerged as a discipline through the performance of music in veteran hospitals. As doctors and nurses witnessed the notable physical and emotional responses to music in patients, the increasing demand for music as therapy gradually led to the establishment of the first music therapy program at Michigan State University in 1944.[10] Interestingly, the birth of music therapy as a discipline coincides closely with the discovery of autism. Initially confined in adult psychiatric settings, only much later was music therapy broadened to helping children with disabilities.[11]

The direction of education over the past half century has shifted towards including

---

7. Hill and Frith, "Understanding Autism," 282.

8. Esther Gilliland, "The Healing Power of Music," *Music Educators Journal* 31, no. 1 (1944): 18.

9. Doron Antrim, "Music Therapy," *The Musical Quarterly* 30, no. 4 (1944): 409.

10. Leslie Bunt, "Music Therapy," In *Grove Music Online*. *Oxford Music Online*, http://www.oxfordmusiconline.com.libaccess.sjlibrary.org/subscriber/article/grove/music/19453 (accessed September 5, 2009).

11. Jacqueline Peters, *Music Therapy: An Introduction* (Springfield: Charles C. Thomas Publisher, 1987), 41.

individuals with disabilities. The creation of certain laws now brings those with disabilities into the normal public school day through the practice of mainstreaming and inclusion. Various laws such as the "Individuals with Disabilities Education Act" give students with disabilities, autism included, rights to an equal education in the "least restrictive environment".[12] This is a radical change when one looks at the history of special education to a time when those with disabilities were segregated and shut away in institutions.[13]

The study of autism continues, as little is known about a cure or specific cause. Due to the broad spectrum of this disorder, each child with autism is different. This makes it even harder to generalize, as what works for one child will work for all.

Through increasing brain research scientists have discovered specific brain differences between children with autism and typically developing children.[14] Studies provide evidence of existing structural abnormalities in the brains of people with autism. Bailey (1998) has noted differences in the cerebellum, various cortical regions, and regions of the limbic system (critical for emotional and social behavior). Consistent findings of the autistic brain in past years reveal that it is "on average larger and heavier than the normal brain." Of great interest is that the increased size was not evident at birth

---

12. Mary Adamek and Alice-Ann Darrow, *Music in Special Education* (Silver Spring: the American Music Therapy Association, 2005), 23.

13. Paul Ackerman, Robert Jaeger, and Anne Smith, "History of Special Education," http://www.answers.com/topic/history-of-special-education (accessed September 14, 2009).

14. Jack Scott, Claudia Clark, and Michael Brady, *Students with Autism* (San Diego: Singular Publishing Group, Inc., 2000), 52.

but from 2-4 years, suggesting autism is not present at birth. Frith (2003) proposes a failure of normal synapse pruning during the developmental process as an underlying cause. Because pruning eliminates faulty connections and optimizes coordinated neural functioning, a lack of pruning in autism may lead to increased brain size and poor functioning of certain neural circuits. Nevertheless these studies present a challenge due to scarcity of the material and difficulty in relating the observed brain abnormalities to mental functions because of lacking "good behavioral data on the individual cases."[15]

Many models and interventions for autism exist. Music is one that seems to be an effective tool.[16] Studies consistently show the special interest, unusual sensitivity, and ability of those with autism to participate successfully in musical activities. As a result, researchers have begun using music to target areas of impairment such as speech and communication, social interaction, and stereotypic behaviors.

Purpose of the Study

The purpose of this double case study was to observe, describe, and analyze the importance, effectiveness, and uses of music in the lives of two children with autism. Their parents are advocates of the power of music to help their children and thus actively

---

15. Hill and Frith, "Understanding Autism," 283. See Bauman & Kemper (1994), Kemper and Bauman (1998), Bailey (1998), Lainhart (1997), and Courchesne (2001) for studies providing evidence of existing structural abnormalities in the brains of people with autism.

16. Richard Hadley, Wynton Hadley, Virginia Dickens, and Earlyn G. Jordon, "Music Therapy: A Treatment Modality for Special-Needs Populations," *International Journal for the Advancement of Counselling* 23, no. 3 (2001): 215.

find ways to bring music into their children's lives. In both cases, music is used functionally, for a specific purpose. I attempted to answer the following questions:

1. How do the parents use music with the child?
2. In what ways does music help the child?
3. Why does music help?
4. What is the role of music in the child's life?
5. What is the importance of music to the parents and child?
6. What is it like to live with autism (experience living with autism)?

I sought to gain the perspectives of the adult participants (parents and teachers) in all the questions above. For the child participants with autism, I focused on questions #5 and #6, as verbal interaction was limited due to their difficulties with comprehension and communication. This study explores how music serves as a non- threatening medium in which the child with autism learns and develops skills necessary to function successfully in life.

Need for the Study

The effectiveness of music as therapy for individuals with autism rests largely on anecdotal accounts with little empirical evidence. Although researchers such as Marwick and Gold have suggested scientific testing under controlled conditions for proving music's effectiveness,[17] the ethical considerations and complexities of designing experimental studies state otherwise, creating a gap in scientific knowledge and testing.

17. Accordino, Comer, and Heller, "Searching for Music's Potential," 113.

Because experimental research is impractical, a picture must be built through a collection of repeated qualitative or narrative studies. This thesis serves as one study in developing a larger, clearer picture of this topic. As there is a need for knowledge in this area, any information on how music can be used or is used to help those with autism is extremely valuable.

The voices of children and their families are less often heard within the narrative reports on music and autism. Originating in segregated contexts, studies written by music therapists for other professionals frequently exclude the stories of the participants. Likewise, articles written by educators speak solely from the perspective of the teacher. I seek to present the stories of these children and their parents through their personal account and my observations. Through this thesis, I tried to allow these voices to be heard. Much like an ethnographer, I share their lives so that others may learn. The importance of using music to help children with autism is reflected in these stories, providing evidence of music's potential in helping individuals with autism live a more fulfilling and promising life. Informal but functional uses of music at home, school, or elsewhere can benefit and aid the child with autism.

Method of the Study

I conducted qualitative research in the form of a case study on two children with autism. One participant is the child of a university music professor, aged five. The other is eighteen years of age and highly accomplished in music. His parents help lead a non-profit special needs organization. Both participants attend public schools and at the time

of research were in kindergarten and grade eleven. By choosing different ends of the spectrum, I was able to view and obtain different stories of children in different stages of development.

I collected data through observations, personal interviews, electronic interviews, pictures, recordings, documents, and artifacts.

Limitations of the Study

Nature and Size of the Sample

Autism is a spectrum disorder because of the broad spectrum of individuals labeled autistic. Variants in intellectual level, development of communicative speech, and the severity of the autistic symptoms result in every child with autism displaying his/her own unique characteristics. Therefore, the sample of my study, two cases from this wide spectrum, can by no means fully represent this diverse population. Each of my main participants uses music differently in accordance with their individual needs, abilities, and place on the spectrum.

Uniqueness of the Setting

I visited the participants at their schools at least twice a month. For one subject, I was given permission by the principal to only observe him during music class. To compensate for the school observations, his parents invited me to their home where I saw him doing other activities such as watching television, eating, playing with his toys, playing with other children, etc. I also babysat this participant on occasion, learning a

great deal through these experiences. I was invited to several family outings including camping, watching a school play, and shopping. Originally, I wished to see him in his therapy sessions, but these all occurred during school, so I was unable to observe him in the fully holistic view I hoped.

Interviews often followed observations. During these times, I wrote field notes after the interviews because our talks often took the form of casual conversations during breaks, after classes, at home, in the car, while eating, etc. Email communication became an extremely useful follow up tool.

For the other participant, I was given the opportunity to work at his high school as a student teacher in a fellowship project by my advisor. This provided me the opportunity to engage in school activities. It was a wonderful way to collect data because I could observe him during music class while helping the music teacher. I was even given the chance to be his aide for short periods of time. When I did not need to help the music teacher, I was allowed to shadow my participant in his other classes such as math, speech therapy, art, and electronic music.

After school, I tutored this participant in piano. His piano music was now too difficult for his mother to read so that practicing with him became a burden. Since I am a pianist, she asked me to help him practice. This provided me one-on-one time to communicate and interact with him in the medium of music. I also attended several meetings of an organization for children with special needs, of which his father is president. These meetings were a great time to talk with other parents and get acquainted with other children with disabilities. As I have not had much interaction with children

with disabilities before my thesis, I found this an excellent place to experience knowledge and familiarity around those with special needs. Additionally, I observed during extra-curricular activities including band rehearsals and private music lessons.

Time Period of the Study

This study was conducted over a nine month period beginning January 2009 and ending September 2009.

Definitions of Terms

"Child with Autism"

Throughout this thesis, I chose to use a "person-first" language which puts the person before the disability. So rather than referring to an "autistic child," using the "person-first" language, this child would be called a "child with autism." As Adamek and Darrow state "The purpose of this approach is not to minimize or deny a disability, but to affirm that the student is more than the disability and that the disability does not supersede all of the other human attributes that the child possess."[18] The language used by professionals to describe a disability has changed drastically over the years, reflecting changes in how society views people with disabilities. Before, people with mental retardation were labeled "idiots," "morons," or "feeble minded." A person with a physical disability might be called "cripple" or "physically handicapped." This language carries a stigma, is demeaning, and segregates our society. The concept of "person-first"

18. Adamek and Darrow, *Music in Special Education*, 8.

was one of the reasons the Education of All Handicapped Children Act of 1975 was later renamed Individuals with Disabilities Education Act in 1990.[19]

Autism Spectrum Disorder (ASD)

The American Psychiatric Association lists five subtypes of ASD under the umbrella term of Pervasive Developmental Disorders: 1) Autistic disorder, 2) Asperger's disorder, 3) Rett's disorder, 4) Childhood disintegrative disorder, and 5) Pervasive developmental disorder not otherwise specified.[20] This thesis focuses on children with autism, the first of the five subtypes. "Autism (autistic disorder) is a complex developmental disability that typically appears during the first three years of life and is the result of a neurological disorder that affects the normal functioning of the brain."[21] Characteristics include developmental delays, absence or impairment of speech and language, poor social skills, oversensitivity (sound, light, etc.), resistance to change, lack of direct eye contact, odd or unusual repetitive play, and self-stimulation.[22]

It is important to remember that each child on the spectrum is unique. Inconsistencies appear even amongst individuals with the same diagnostic label. Presently, Autism Spectrum Disorders are behavior defined disorders as there are no

---

19. Scott, Clark, and Brady, *Students with Autism*, 63.

20. Ryan Hourigan and Amy Hourigan, "Teaching Music to Children with Autism: Understanding and Perspectives," *Music Educators Journal* 96, no. 1 (2009): 40-45.

21. Autism Society of America. http://www.definitionofautism.com/ (accessed October 5, 2009).

22. Adamek and Darrow, *Music in Special Education*, 183.

biological markers or medical tests to diagnose ASD.[23] Scientists continue in search of a cause or cure.

Further Terms

Further definitions of common terminology can be found in the glossary, Appendix A.

Conclusion

The nature of music and the natural aptitude for music in children with autism create the possibility for great synergy between the two. Music appears to reach children with autism in ways that other stimulus and interventions cannot. Additionally, these children find music pleasurable and are able to succeed in this area. Music therapy or even a structured use of music activities can help them develop and practice skills needed to function successfully in our society. Despite varying degrees of music use, music serves an important role in the lives of these children.

23. L. Heflin and Donna Alaimo, *Students with Autism Spectrum Disorders: Effective Instructional Practices* (Upper Saddle River: Pearson Education, Inc., 2007), 17.

Chapter 2: Review of the Literature

This chapter reviews the literature on the relationship between music and children with autism. Music is an engaging stimulus for children with autism. Research shows that they respond positively to music and often demonstrate a high level of musical ability.[1] Impairments in areas such as speech and communication, social interaction, and sensory perception challenge individuals with autism in all areas of life resulting in the creation of two worlds, theirs and ours. Music can serve as a bridge between these two vastly different worlds.

This review is divided into four main sections: 1) nature of autism; 2) music's influence on health and behavior; 3) music and autism; and 4) special education in the United States.

Nature of Autism

General Characteristics

Autism is a pervasive developmental disability that affects one in every 91 people in the U.S. today.[2] This rate is rapidly increasing as 1 out of 2,500 children were

1. Alice-Ann Darrow and Tammy Armstrong, "Research on Music and Autism: Implications for Music Educators," *Update: the Applications of Research in Music Education* 18, no. 1 (1999): 16.

2. "Autism Speaks Responds to New *Pediatrics* Autism Study Putting Prevalence at 1 in 91 American Children, Including 1 in 58 Boys," http://www.autismspeaks.org/press/autism_nchs_prevalence_study_1_in_91.php (accessed October 5, 2009).

diagnosed with autism in 1984, 1 or 2 in every 1000 in 1997, and 1 in 150 in 2007.[3] A neurological disorder that impacts brain function and behavior, this disability is not specific to any racial, social, or ethnic group.

Individuals with autism display severe impairments in the development of communication and reciprocal social interaction, have restricted interests, and demonstrate repetitive or stereotyped behavior.[4] To be diagnosed with autism, these impairments and behaviors must be evident by the age of three. Autism occurs four times more often in boys than girls. Current research has found a gene variant (CACNA1G) that may explain the increased risk of boys to autism, but further testing is needed.[5]

Presently, there is no known cure for autism; however, active interventions— especially early in life— can bring about positive changes and improve quality of life.[6] Autism is known as a spectrum disorder because of the broad spectrum of differences between individuals labeled autistic. Variants in intellectual level, development of communicative speech, and the severity of autistic symptoms result in every child with autism displaying his/her own unique characteristics. The characteristics of autism often

---

3. Nicole Allgood, "Parent's Perceptions of Family-based Group Music Therapy for Children with Autism Spectrum Disorders," *Music Therapy Perspectives* 23, no. 2 (2005): 92.

4. Elisabeth Hill and Uta Frith, "Understanding Autism: Insights from Mind and Brain," *Philosophical Transactions: Biological Sciences* 358, no. 1430 (2003): 281.

5. Elaine Schmidt, "UCLA Discovey May Explain Why Autism Strikes Boys Four Time More Than Girls," http://www.medicalnewstoday.com/articles/150787.php (accessed September 4, 2009).

6. Allgood, "Parent's Perceptions of Family-based Group Music Therapy," 92.

overlap with other disabilities; however, there are distinct features that distinguish it from other disabilities.[7] A discussion of each area of impairment follows.

Verbal and Nonverbal Communication. As Scott, Clark, and Brady note, "Communication is the process of sharing information and ideas from one person to another. It involves encoding, transmitting, and decoding of messages."[8] Autism affects the communicative areas of speech, language, and socially acquired nonverbal codes such as body language, eye contact, touch, etc. Children with autism do not develop communication to the degree of typical children. Their verbal communication abilities can range from no speech at all, a delay in development, or fluent but inflexible speech.

Echolalia (the repetition of phrases or words) is commonly seen in people with autism. This form of speech often serves as a social function like turn-taking in conversations or communicating a request. If used in the correct context, echolalia can be useful and meaningful. For example, if a child says, "I am thirsty. Can I have juice?" when wanting something to drink, this child engages in meaningful communication by using echolalia in a correct context. On the other hand, the same phrase has little meaning when spoken as a greeting.

Because of their difficulties in starting and maintaining conversations, those with autism tend to engage in monologues on topics of limited general interest, such as train

---

7. Mary Adamek and Alice-Ann Darrow, *Music in Special Education* (Silver Spring: The American Music Therapy Association, 2005), 182.

8. Jack Scott, Claudia Clark, and Michael Brady, *Students with Autism* (San Diego: Singular Publishing Group, Inc., 2000), 11.

9. Ibid., 14-15.

schedules or baseball scores. They are also very concrete and rigid in their use of language. Metaphors, idioms, or irony have little meaning to them due to the lack of literal meaning, abstract level of expression.[9] Because individuals with autism lack nonverbal communication skills, they have difficulty interpreting nonverbal cues, acquired social customs learned by typical individuals through acculturation.

Social Interaction. While most typical children seek out the interactions of adults or peers in play, children with autism are happy to be by themselves. They often seem unaware of others in their environment. Individuals with autism do not naturally use eye contact in interaction (it is something they must learn) and do not usually enjoy being held.[10]

Impairments in social interaction vary according to age and severity of autism. Although some children and adults desire to make friends, the problem appears to be a lack of understanding in how to make friends or sustain the relationship once it is established. As Starr comments, "they seem unable to fathom the social reciprocity, nuances and conventions of social interaction needed in a friendship."[11]

Aspects of Behavior. The behavior of children with autism falls into three categories: stereotypic behavior, self-injurious behavior, and hyper- or hyposensitivity. Stereotyped behaviors are repetitive body movements, such as rocking, or a repetitive use of objects, such as lining up cars. Biting one's arms or banging one's head against walls are

---

10. Ibid., 16.

11. Starr and Zenker, "Understanding Autism in the Context of Music Therapy," 4.

examples of self-injurious behaviors exhibited by individuals with autism. A child who is hypersensitive to sound can scream when a vacuum cleaner is turned on while another hyposensitive to sound can appear deaf to a train passing by.

Stereotypic behaviors are often used by individuals with autism for self-stimulation. However, restricted patterns of behavior can also serve different purposes at different times.[12] For example, a child might use hand flapping for self-stimulation or communication.

In hopes of fulfilling their needs or wants, people with autism engage in self-injurious behavior to obtain stimulation/ information from the environment. Without the ability to clearly communicate verbally, a child with autism may slap his face to ask for food, draw attention to himself, avoid pain, or undesired activities.[13] It can be a guessing game to figure out what the individual wants based on his or her behaviors.

Autism creates a unique sensory system for those with autism. Their senses may be hypersensitive, overtly sensitive to touch, smell, sound, etc., or hyposensitive, dull in response to stimulation. An individual hypersensitive to touch can interpret a light touch as painful, but another hyposensitive to touch can run into a wall repeatedly without feeling pain. Both hyper- and hyposensitivity may be present in the same individual[14] so that a child might be hypersensitive to smell, but hyposensitive to sound.

---

12. Scott, Clark, and Brady, *Students with Autism*, 24. See Carr & Durand (1985) and Iwata et al. (1982).

13. Ibid., 24-25.

14. Ibid., 27.

Organization and Perception. Individuals with autism have difficulty making sense of the world around them. Uta Frith, a major researcher on autism, suggests the existence of a fault in the central thought processes in the brains of people with autism that interferes with their ability to process information into a coherent whole.[15] Because of this difficulty in perception, children and adults with autism demonstrate an obsessive inflexible reliance on routines to aid their survival in an unpredictable, frightening world. Changes in the environment, such as a different arrangement of chairs in the classroom, are also intolerable for individuals with autism. Such changes can cause them great distress.

The cause of autism is unknown. Medical research is currently investigating possible causes such as immunizations, toxic chemicals, genetic mutations, and viruses.[16] However, while causes are unknown, and there is yet to be a cure, there are many therapeutic options for autism. Early diagnosis and interventions can have positive results and enhance the potential of children with autism.

History of Autism and Important Figures

No one truly knows when the first child with autism was recognized as different from other children with disabilities. For many centuries, people with autism were part of a group labeled "idiots" and "insane." However, as society began to recognize the

---

15. Sandra Brown, "Autism and Music Therapy- Is Change Possible, and Why Music?," *Journal of British Music Therapy* 8, no. 1 (1994): 15.

16. Allgood, "Parent's Perceptions of Family-based Group Music Therapy," 92.

rights of all people and care for the well-being of those with disabilities, we find our first clinical documentation of a boy who may have been autistic.[17] In 1799 a young boy was found living by himself in the rugged country of southeastern France. The boy, later named Victor, was eventually brought to Paris where a physician, Jean Itard, was interested in "civilizing" the child.

Records of Victor's medical examinations and the process of Itard's study have fortunately survived. Itard believed that Victor was impaired due to environmental deprivation and hypothesized that the boy could learn the patterns of normal behavior and development thorough proper mental and moral education. At the time, Victor did not speak and had no social skills. However, his survival in the wild and ability to elude captors indicated a high degree of intelligence, which caused Itard to believe that retardation was not the problem. In the five years of his study, improvements were seen in Victor but not to the degree that he became "civilized." Itard is known today as the father of special education, thus making Victor the first student in special education.[18] Interestingly, the origins of special education began with the education of autism.

Leo Kanner, director of the Child Psychiatry Clinic at John Hopkins University, was a leading authority in child psychiatry. In 1943 he published the first clinically documented report on autism entitled *Autistic Disturbances of Affective Contact*.[19] He presented case descriptions of eleven children aged two to eleven whose conditions were

---

17. Scott, Clark, and Brady, *Students with Autism*, 42.

18. Ibid., 46.

19. Hill and Frith, "Understanding Autism," 282.

"so remarkably different and unique from anything reported so far" that he considered them a separate diagnostic entity. Although the children were very different from each other in their abilities, family structure, and age, he commented that they exhibited numerous common characteristics that did not fit into any previously established diagnosis. The dominant characteristic Kanner noted was the "inability to relate to themselves, people and situations." Exhibited by the children was an "extreme autistic aloneness that, whenever possible, disregards, ignores, shuts out anything that comes to the child from the outside."[20] The characteristics that he observed and recorded have stood the test of time and are still used by professionals to diagnose autism today.

Kanner was not the first to use the term "autism" in relation to disabilities. Bleuler, a Swiss psychiatrist, had already coined the term in 1919 in conjunction with schizophrenia in adults. Bleuler's autism referred to a transitional phase where one loses perception and transcends "into an isolating, divergent perception of reality experienced by people with schizophrenia."[21] This confusion of the term has led many people to think that autism in children was a form of "early onset schizophrenia." Kanner was the first to recognize the specific behaviors of his case studies as different than schizophrenia and mental retardation.

There are, however, cases of autistic and schizophrenic traits coexisting in individuals. Reports reveal several children with autism developing schizophrenia later in life, as well as individuals with schizotypal personality disorder displaying a wealth of

---

20. Scott, Clark, and Brady, *Students with Autism*, 2.

21. Ibid., 49.

autistic traits— "being socially anxious, having no close friends, using a limited number of facial expressions, not showing affection, being unaware of social cues, having circumscribed or unusual interests, and being resistant to change." [22]

Esterberg, a researcher on schizophrenia, suggests two possible reasons for these occurrences: 1) autism and schizophrenia share some of the same affected genes or 2) some susceptible genes in these spectrums are often inherited together. She explains, "Individuals who lack genes on a particular stretch of chromosome 22—called the 22q11 chromosomal deletion —are known to be at heightened risk for both the autistic-spectrum and schizophrenia-spectrum disorders."[23] Therefore, certain genes influence both autism and schizophrenia.

Highly interesting is the coincidence between the autism work (a year apart) of Leo Kanner and Hans Asperger. There is no proof of collaboration between the two or even an awareness of the other's work. Trained in medicine and child development, Asperger's work in Austria described children similar to Kanner's. Significant differences were that Asperger's children had highly developed language skills and generally higher intelligence. Aspergers is recognized today as a higher functioning form of autism. Unfortunately, because Asperger published his work in German, his work was unknown to the English speaking world until 1989 when Uta Frith provided a translation

---

22. Joan Arehart-Treichel, "Overlap Found Between Autism, Schizophrenia-Spectrum Disorders," http://pn.psychiatryonline.org/cgi/content/full/43/19/20-a (accessed October 5, 2009).

23. Ibid.

of his 1944 article.[24] Through Kanner's and Asperger's study we gained a deeper glimpse into the broad range of the Autism spectrum.

Many writers during Kanner's time promoted the belief that the failure of parents to provide adequate emotional support and nurturing was the cause of this condition, resulting in endless guilt, shame, and grief among parents of autistic children. In 1967 Bettelheim coined the term "refrigerator mother" to describe a mother's lack of emotional connection with her autistic child. He considered autism to be the result of "cold, unfeeling parents" but particularly targeted the mother as the primary factor in the development of autism in young children.[25]

Rimland was one of the first researchers to explore a physiological or neurological cause for autism. Absolutely convinced that his wife and he were good parents, he believed a biological origin was responsible for this disorder and not bad parenting or a "refrigerator mother."[26] As researchers search for underlying physiological reasons, current research has uncovered specific brain differences between children with autism and typically developing children. Studies provide evidence of existing structural abnormalities in the brains of people with autism. Consistent findings of the autistic brain in past years reveal that it is "on average larger and heavier than the normal brain." It is interesting that the increased size was not evident at birth but from 2-4 years, suggesting autism is not present at birth. A failure of normal synapse pruning

---

24. Scott, Clark, and Brady, *Students with Autism*, 49-50.

25. Allgood, "Parent's Perceptions of Family-based Group Music Therapy," 92.

26. Scott, Clark, and Brady, *Students with Autism*, 52.

during the developmental process is proposed by Frith (2003) as an underlying cause. Because pruning eliminates faulty connections and optimizes coordinated neural functioning, a lack of pruning in autism may lead to an increase in brain size and poor functioning of certain neural circuits. Bailey (1998) has also noted differences in the cerebellum, various cortical regions, and regions of the limbic system (critical for emotional and social behavior). Nevertheless these studies present a challenge in relating the observed brain abnormalities to mental functions because of lacking "good behavioral data on the individual cases" and scarcity of the material.[27] Thus, the exact causes of autism are still unknown, but it is no longer thought to be the result of poor parenting. Instead, it is now believed to be a neurological disorder.

Music's Influence on Health and Behavior

Music has long been used as a source of healing.[28] The ancient Egyptians and Persians had faith in music's remedial virtues. To the Greeks, Apollo was the god of both music and healing. Plato described music as medicine for the soul, while Aristotle valued music as an emotional catharsis.[29] Medicine was able to influence the physical

---

27. Hill and Frith, "Understanding Autism," 283. See Bauman & Kemper (1994), Kemper and Bauman (1998), Bailey (1998), Lainhart (1997), and Courchesne (2001) for studies providing evidence of existing structural abnormalities in the brains of people with autism.

28. Richard Hadley, Wynton Hadley, Virginia Dickens, and Earlyn G. Jordon, "Music Therapy: A Treatment Modality for Special-Needs Populations," *International Journal for the Advancement of Counselling* 23, no. 3 (2001): 215.

29. Leslie Bunt, "Music Therapy," In *Grove Music Online*. *Oxford Music Online*,

body, but music was believed to boost the spirit and morale, restoring balance. Hippocrates, the father of medicine, took his mental patients to the temple to listen to music in 400 B.C.[30] A classical Biblical example of healing through music is the story of how David rid King Saul of an evil spirit through harp playing. Thus, music was not only used for physical sickness but also mental illness.

Written documentation found from 600 B.C. reported the curing of plagues, mental disorders, snake bite, deafness, and fevers with the help of music. Writers of medieval times recorded the testimonies of healing with music and many essays of the eighteenth and nineteenth centuries provide instructions on the methods, instruments, and different kinds of music to use.[31]

Dr. Ira Altshuler, head of the psychiatric department of the Eloise Hospital in Detroit who has achieved remarkable results with music in the treatment of neurosis, said in a speech before the Music Teachers National Association, "Words do not only affect thought processes, ideologies and emotion, but provoke action. . . . Music has an even stronger power than the spoken word. In addition to affecting thinking and emotion it also affects the spirit."[32]

---

http://www.oxfordmusiconline.com.libaccess.sjlibrary.org/subscriber/article/grove/music/19453 (accessed September 5, 2009).

30. Esther Gilliland, "The Healing Power of Music," *Music Educators Journal* 31, no. 1 (1944): 18.

31. Ibid.

32. Doron Antrim, "Music Therapy," *The Musical Quarterly* 30, no. 4 (1944): 409.

After World War I we see the emergence of music therapy as a discipline when music was played in veteran hospitals. Music was prescribed for war neurosis, aphasia, insanity, and paralyzed muscles.[33] As doctors and nurses witnessed the positive effects of music in patients, the increasing demand for music as therapy gradually led to the establishment of the first music therapy program at Michigan State University in 1944.[34]

Music and Autism

Taking into consideration the lack of supporting empirical research, the acceptance of music as an effective therapy for individuals with autism is impressive. Most of the literature in this area consists of narrative case studies and clinical observations in segregated contexts, such as music therapy settings. In short, the effectiveness of music therapy is primarily based on anecdotal evidence with little empirical data demonstrating its efficacy.[35] Marwick (1996) states the need for scientific testing with unbiased and controlled paradigms in determining the effective influence of music in achieving specific outcomes in clients.[36] However, empirical research is a challenge taking into consideration the involvement, responsibility and liability, of

---

33. Ibid.

34. Bunt, "Music Therapy," In *Grove Music Online*. *Oxford Music Online*, http://www.oxfordmusiconline.com.libaccess.sjlibrary.org/subscriber/article/grove/music/19453 (accessed September 5, 2009).

35. Robert Accordino, Ronald Comer, and Wendy Heller, "Searching for Music's Potential: A Critical Examination of Research on Music Therapy with Individuals with Autism," *Research in Autism Spectrum Disorders* 1, no. 1 (2007): 103. See Evers (1992).

36. Ibid., 104, 113.

human subjects. Variations on the autism spectrum may also be a factor. As each individual on the spectrum is different, a picture must be built through repeated narrative or qualitative studies. This study serves in adding to that picture. The following section addresses four themes: 1) responding to music; 2) why music?; 3) music therapy; and 4) uses of music.

Responding to Music

Children with autism have consistently shown a sensitivity and attentiveness to music. Their special responsiveness and unusual interest in musical stimuli are noted in many clinical observations and studies of children with autism.[37] Much of the autism literature states that children who do not respond to speech will often respond to music. In fact, they respond more frequently and appropriately to music than any other auditory stimulus.[38]

In addition to their enjoyment of music, these children often demonstrate a high level of musical ability. Hairston (1990) reported that many children with autism could sing a melody at a very early age. Others suggest these children can recall simple patterns of sounds with great accuracy and often display a good sense of rhythm. Further studies show that their pitch imitation is good or better than children without autism. Thaut (1988) has commented on the exceptional performance of children with autism in

37. Darrow and Armstrong, "Research on Music and Autism," 16.

38. Starr and Zenker, "Understanding Autism in the Context of Music Therapy," 1.

music compared with other subject areas.[39] These children also perform unusually well in comparison with many typical students. It was originally thought that this superiority was the result of savant learned skills, but research shows that those with autism who were musically inexperienced also exhibited extraordinary good pitch perception. Hoelzley (1993) takes this one step further and suggests that musical ability is a fundamental component of autism.[40] Research indicates children with autism usually respond to musical stimuli and often have musical abilities beyond those of typically developing children. As these children possess a special interest in music and the ability to participate successfully in musical activities, many researchers are now investigating the use of music to modify their atypical behaviors.

Why Music?

Music is a unique form of communication. Its nonverbal communicative aspect is of great value in working with those with autism because one can communicate and establish a relationship where words alone fail.[41] The order and structure in music

---

39. Starr and Zenker, "Understanding Autism in the Context of Music Therapy,"16. See Hairston (1990), Ricks & Wings (1997), Oppenheim (1974), Applehaum et al. (1979), and Thaut (1988) for high level of musical ability.

40. Accordino, Comer, and Heller, "Searching for Music's Potential," 102. See Accordino (2007) and Warner (2004) for extraordinary pitch perception in musically inexperienced individuals with autism. See Hoelzley (1993) and Rimland (1964) for musical ability as a component of autism.

41. Jacqueline Peters, *Music Therapy: An Introduction* (Springfield: Charles C. Thomas Publisher, 1987), 50.

(sounds and rhythm) appeal as they can help individuals with autism organize their perceptions of the chaotic world, providing a safe, structured experience free of confusion.[42] Further, music is a powerful multisensory stimulation hard to ignore. In music sounds are heard (auditory stimulation) and vibrations felt (tactile stimulation). Moving to music includes kinesthetic stimulation and live performances provide visual stimulation.[43]

Perhaps the most valued element of music in working with children with autism is the ability of music to provide a means of self-expression and enhance feelings of self-worth. Unable to express themselves verbally, music can function as a vehicle for expressing moods, attitudes and feelings in a positive manner.[44] The nature of music also allows music activities to be adapted for success at different levels of achievement, thus meeting autism at any level of severity. To function in society, one must be able to relate successfully and appropriately to those around them. Due to its social aspect, activities in music often occur in a group setting. A positive, enjoyable activity, music may persuade and motivate individuals with autism to join the group and interact with others.[45]

---

42. Darrow and Armstrong, "Research on Music and Autism," 18.

43. Michelle Lazar, "Music and Students with Multiple Disabilities," http://www.tunedintolearning.com/why (accessed April 14, 2009).

44. Leslie Bunt, "Music Therapy," In *The Oxford Companion to Music*, edited by Alison Latham, *Oxford Music Online*. http://www.oxfordmusiconline.com.libaccess.sjlibrary.org/subscriber/article/opr/t114/e4637 (accessed September 5, 2009).

45. Peters, *Music Therapy: An Introduction*, 51-52.

Music Therapy

For an activity to be called music therapy, it must contain five elements: 1) be prescribed to help a specific behavior or condition, 2) involve the use of music or music activities, 3) be directed or supervised by specifically trained personnel, 4) be received by a client, and 5) have a definite therapeutic goal.[46]

The music therapist has the same therapeutic goals for a client as other members of the medical or education team. The difference is the treatment modality: rather than using words, the music therapist uses music and musical activities to establish contact with the client. Once contact is made, the music therapist then works to build the therapeutic relationship and improve the client's level of functioning through involvement in carefully structured musical experiences. The music and musical activities are carefully selected based on the therapist's knowledge of the effects of music on human behavior, the client's strengths and weakness, and therapeutic goals such as the development of motor, academic, communication, social, or emotional skills.[47]

Emerging as a profession in the 1950s, music therapy was initially confined to adult psychiatric settings. Soon, however, the value of music in the treatment of special needs children became apparent and many music therapists began to work with this population.[48]

---

46. Ibid., 9.

47. Ibid., 7-8.

48. Ibid., 41. See Lathom (1980).

Uses of Music

Duerkson (1978) identifies five general ways in which music activities can be used to help clients gain non-musical skills. First, music is a carrier of information. Special songs can be created to include information that the client is trying to learn by presenting factual information in song lyrics or a sequence of events that the participant needs to memorize. This method works especially well with children with autism, because they seem to follow, comprehend, and react to instructions set to music. Setting a sequence of events (like brushing your teeth) to music helps these children recall information and behave in a socially acceptable a manner (such as a waiting your turn).

Academic concepts can also be taught and reinforced in musical activities such as games, chants, dances, or songs.[49] Pairing songs with visuals and movement can enhance their understanding of specific words and the meaning of songs. Because structure and organization is a basic need for people with autism, a structured use of music provides predictable experiences that promote positive behaviors.[50] By using a standard lesson format and familiar music and activities in a classroom setting, music can be presented in a clear and predictable way that allows students with autism to grasp onto the comfort of a consistent routine; thus decreasing inappropriate behavior provoked by anxiety and confusion. Teachers in classrooms often sing transition songs to help students with

---

49. Michelle Lazar, "Music & Academics," http://www.tunedintolearning.com/why (accessed April 14, 2009)

50. Darrow and Armstrong, "Research on Music and Autism," 18. See Goldstein (1964), Burleson et al. (1984), Nelson et al. (1984), and Alvin (1978).

autism transition from one activity to the next in a smooth manner.

Second, music can serve as a reinforcer or motivator.[51] Because children with autism find music pleasurable, positive skills and behaviors can be reinforced and rewarded through listening or participating in musical activities. In addition, most children with autism do not respond to social reinforcements such a praise or affection.[52] Researchers have demonstrated the successful use of music to eliminate stereotypic behaviors and to encourage participation in activities that help improve language, social, and/or motor functions.[53]

Third, music can serve as a background for learning. Playing music as part of the background of a learning environment masks unwanted sounds, breaks monotony, and establishes a specific mood. Carefully selected music can facilitate learning, improve task performance, concentration, and attention span.[54]

Fourth, music can function as a physical structure for a learning activity. When 'choreographing'' special motor action to music, the rhythmic structure of music can improve physical rhythmic activities such as respiration, walking, and relaxation.[55] For a child with autism, rhythm can be used to accompany speech, encourage verbalization and

---

51. Darrow and Armstrong, "Research on Music and Autism," 16. See Toigo (1992), Jorgenson (1974), and Watson (1979).

52. Darrow and Armstrong, "Research on Music and Autism," 16.

53. Adamek and Darrow, *Music in Special Education*, 196.

54. Dunja Degmecic, Ivan Pozgain, and Pavo Filakovic, "Music as Therapy," *International Review of the Aesthetics and Sociology of Music* 36, no. 2 (2005): 297.

55. Michelle Lazar, "Music & Motor Skills," http://www.tunedintolearning.com/why (accessed April 14, 2009).

appropriate pacing.

Fifth, by examining the clients interactions with the music therapist, other individuals in the group, and musical material, music serves as a reflection of the client's progress towards the therapeutic goals and his/her level of functioning.

Uta Frith, an active researcher and writer on autism, noted that more has been written on the language impairments of children with autism than any of the other defects. At least 75% of those who can speak demonstrate echolalia.[56] As communication is debatably the most difficult challenge for those with autism, music is often used to target this area. Grandin shares how some of these children are able to sing responses when they have difficulty speaking words. Similarly, Buday notes the ability to follow directions increased when instructions were set to music rather than spoken.[57]

Singing special songs and chants created by the music therapists for a specific purpose can practice the articulation of specific speech sounds and improve word discrimination skills. Clients can practice correct rhythmic and inflectional patterns for words, phrases, and sentences through carefully constructed songs where the melodic and rhythmic treatment of the text correspond to the natural rhythms and inflections of speech.[58] Call and response activities can develop imitation skills first through singing and instruments, then in speech. Vocal and physical communicative responses can also

---

56. Darrow and Armstrong, "Research on Music and Autism," 16. See Frith (1989).

57. Darrow and Armstrong, "Research on Music and Autism," 17. See Grandin (1988) and Buday (1995).

58. Peters, *Music Therapy: An Introduction*, 83.

be evoked through instrumental playing and singing.

In comparison with other school academics, music teachers can assess musical progress without verbal communication as music provides a nonverbal means of performance.[59] On a social level, participation in group music activities can be used to achieve greater self and group awareness, improve interaction and communication with others, increase cooperation skills, and experience and express emotions and thoughts in a socially appropriate manner.[60] A means of nonverbal communication, music is a medium for children with autism to express themselves without the embarrassment, trauma, and difficulty of attempting to speak. Thus, music can serve as a bridge between their nonverbal world and our threatening world of words.

As each individual is different, no one method or approach will work for every child. A music therapist must be knowledgeable and creative in planning intervention strategies that address the individual needs, abilities, and interests of each autistic child.[61] The first couple of sessions are often spent with the music therapist exploring what musical elements or instruments evoke a response in the child. Children with autism are withdrawn and often in their own world. Thus, every movement is interpreted as communication and responded to musically by the music therapist.[62]

Certain specialized "schools" of treatment have evolved in the profession of

---

59. Darrow and Armstrong, "Research on Music and Autism," 18.

60. Peters, *Music Therapy: An Introduction*, 98.

61. Ibid., 54.

62. Mary Priestley, *Music Therapy in Action* (London: Constable and Company Limited, 1975), 44.

music therapy. Some are based on musical approaches, while others are derived from psychotherapeutic or educational theories and models. I will not cover all the methods as not all approaches are relevant to music therapy and autism nor would it be practical within the limits of this thesis. I will, however, focus on one method that was specifically developed with handicapped children in mind and appears in the majority of the studies I examined.

Creative Music Therapy, developed by Nordoff and Robbins, aims to develop contact with the child within the context of a musical experience through improvisation and exploration.[63] Influenced by the ideas of Rudolf Steiner and the humanistic concepts of Abraham Maslow, Nordoff and Robbins believed that "within every human being, there is an innate responsiveness to music, and within every personality one can 'reach' a 'musical child' or 'music person.'"[64]

At the beginning, the music therapist works to create a supportive musical and emotional environment that accepts and enhances a client's responses. Once a connection is made, the next goal is building a relationship through musical interaction. Through musical improvisation on various percussion instruments (pitched and non-pitched), a carefully encouraged communicative relationship gradually births the acquisition of skills both verbal and nonverbal. The skills are then applied to other activities during the music session and eventually generalized to activities outside the

---

63. "What is Music Therapy?" http://www.nordoff-robbins.org.uk/musicTherapy/index.html (accessed October 15, 2009).

64. Tony Wigram, Inge Pedersen, and Lars Bonde, *A Comprehensive Guide to Music Therapy* (London: Jessica Kingsley Publishers, 2002), 15.

music therapy session.

For example, the objective of learning to share an instrument such as the piano (social interaction) with the music therapist, if successful, is then generalized to learning to share a drum, xylophone, etc. This goal is then implemented outside of music such as a classroom setting where the child can now share a book, toy, etc. Through improvised music, researchers are able to establish contact with children who have not previously exhibited any form of spontaneous communication.[65]

Participation in music therapy is not the only option for using music to help children with autism develop skills and practice verbal and nonverbal responses. A structured use of music activities (listening, singing, playing, moving, etc.) in the classroom or at home is also an important pathway to helping these children. Some children with autism are highly dependent on music to function in life while others use it informally as a means of relaxation and comfort.

Special Education in the United States

Students with autism present educators with a unique challenge. Many teachers agree that autism presents some of the "most challenging behaviors exhibited in any disability."[66] Educators have also noted that the strategies used for teaching students with

---

65. Darrow and Armstrong, "Research on Music and Autism," 17.

66. Karen Sewell, "Educating Children with Autism," http://www.autism-society.org (accessed May 5, 2009).

other disabilities will generally not work for students with autism.[67] However, due to laws such as the Individuals with Disabilities Education Act, students with autism are often mainstreamed into the music classroom. This presents the music educator with immediate challenges such as successfully teaching the student both musical and non-musical skills, interacting with the student, and creating an environment that meets his/her needs. Many music educators do not feel adequately equipped to teach a student with special needs.[68] In this section, I will examine special education through the following categories: 1) history of educating students with disabilities; 2) history of music in special education; 3) laws and legislative events affecting special education; and 4) intervention strategies.

History of Educating Students with Disabilities

The education for students with disabilities has progressed significantly from its origins. In the 1800s, students with disabilities were not considered eligible for public education, but were provided educational services in separate and segregated schools and classrooms.[69] One of the first educational programs for children with disabilities was the *American Asylum for the Education and Instruction of the Deaf and Dumb*, established in

67. Ibid.

68. Ibid.

69. Paul Ackerman, Robert Jaeger, and Anne Smith, "History of Special Education," http://www.answers.com/topic/history-of-special-education (accessed September 14, 2009).

1817 by Thomas Gallaudet.[70] Although the educational opportunities of students with disabilities increased by the 1900s, the majority of these students still received limited or no public school education and little contact with students in general education.[71] In the 1950s, parent groups began to advocate for an improvement in the services to children with disabilities. This led to increased federal and state support for special educational services, and throughout the 1960s students with less severe disabilities were given more options for public school education.

The societal changes of the 1970s towards deinstitutionalization and normalization for people with disabilities were a major turning point. Many institutions closed down and residents were moved to smaller, more normalized settings in the community.[72] The belief of normalization was that "all students have individual differences and that all members of the community should respect those differences."[73] This belief created the practice of mainstreaming in schools where students in special education classes could join typical students in a regular education class (such as music) for part of the school day.

The early 1980s sought to provide more integrated educational experiences for

---

70. "Special Needs Education History," http://www.livingwithcerebralpalsy.com/specialneeds-history.php (accessed September 5, 2009).

71. Adamek and Darrow, *Music in Special Education*, 16.

72. Ackerman, Jaeger, and Smith, "History of Special Education," http://www.answers.com/topic/history-of-special-education (accessed September 14, 2009).

73. Adamek and Darrow, *Music in Special Education*, 16.

students with disabilities through the development of inclusion models. With the practice of inclusion, these students could now be educated in the general education class (together with typical students) for the full school day with support from special education services. Thus, one can trace a significant shift in educational practices from educating students with disabilities in segregated settings to educating these students in a general education setting with support from special education services.

History of Music in Special Education

Several special education programs as early as the 1800s included music in their instruction.[74] Music was first utilized in special education with children who were blind, hard of hearing, deaf, or mentally retarded, as a way to facilitate learning and reinforce the student's achievements. Music also served in diagnostic and clinical assessment, identifying strengthens and weaknesses in children.[75] Adamek and Darrow report that early literature on music in special education often cites music as an important part of the curriculum for students with disabilities.[76] Some schools included singing, rhythm activities, instrument playing, and other musical activities to enhance the student's learning. Like the use of music in schools today and the discipline of music therapy,

---

74. Ibid., 17.

75. T. Wigram and C. Gold, "Music Therapy in the Assessment and Treatment of Autistic Spectrum Disorder: Clinical Application and Research Evidence," *Child: Care, Health and Development* 32, no. 5 (2006): 535.

76. Adamek and Darrow, *Music in Special Education*, 18.

music activities were used to meet the current educational needs of the students and to prepare the students for interactions in their community.

Laws and Legislative Events Affecting Special Education

During the early history of public school education in the United States, children with disabilities were denied appropriate services for their educational needs either through total exclusion or functional exclusion. With total exclusion, the school refused to admit the child and thus denied the child's access to education. With functional exclusion, the child was accepted into the school, but not provided with an educational program appropriate for the child's specific needs, resulting in little benefit from the educational program.

Children with disabilities were often misclassified due to biased and discriminatory evaluation procedures.[77] Once placed in special education, there was little hope for re-evaluation and integration with students without disabilities.

The educational reform movement of the late 1960s and early 1970s brought many changes to special education. Based on the ideas of civil rights and equal protection under the law, individuals with disabilities were viewed as "less able" but no longer considered "less worthy."[78] One important factor in the special education reform was the involvement of family members as advocates for appropriate educational

---

77. Ackerman, Jaeger, and Smith, "History of Special Education," http://www.answers.com/topic/history-of-special-education (accessed September 14, 2009).

78. Adamek and Darrow, *Music in Special Education*, 19.

services.

Before the 1970s, there was no special education law in the United States.[79] In fact, because education was not mentioned in the Constitution, there was no general school law. Public education was seen as the responsibility of the state and local governments, and the rights of students and teachers were little recognized by the court. At the time, there was also no court decision prohibiting discrimination based on disability, race, or gender. Since then, an increased involvement in educational issues by the federal court, greater focus on the civil rights movement, and the deinstitutionalization of people with disabilities have established the rights of students with disabilities in schools.[80]

The following are several laws, court cases, and legislation events that have impacted special education:

Brown v. Board of Education. Brown v. Board of Education (1954) was a landmark civil rights case dealing with the issue of educating African children in separate settings from white students ("separate but equal"). The Supreme Court determined that this model did not provide equal educational experience for the minority students, denied students the opportunity to interact with other students of varied backgrounds, and promoted stigma that the minority students were inferior to white students. This decision ended the

79. Ibid., 20.

80. Ibid.

exclusionary education practices based on race and built the foundation that the later eliminated the exclusionary educational practices for students with disabilities.[81]

Education of the Handicapped Act. Enacted by Congress, the Education of the Handicapped Act (1970) expanded federal grant programs and funded state and local pilot projects for special education. Funds were also granted to higher educational institutions to develop special education teacher training programs.[82]

Pennsylvania Association of Retarded Citizens (PARC) v. Commonwealth. In 1971, the federal district court in Pennsylvania overturned a state law that allowed schools to exclude students who had been diagnosed with mental retardation. This court decision established the right of a free and appropriate education for children who were mentally retarded.[83]

Mills v. Board of Education. The Mills v. Board of Education (1972) was an expansion of the PARC. This decision established the educational rights of children with other disabilities. The court stated that students with disabilities must be educated even when finances in the district were low; thus ensuring these students did not suffer more than typical students during financial difficulties in the district. The judge also decided that exclusion from education due to the basis of disabilities was unconstitutional, similar to the Brown v. Board of Education decision that segregation of race was unconstitutional.

---

81. Ibid., 21.

82. Ibid.

83. Ibid.

These decisions established the framework of the P.L. 94-142, later known as the Individuals with Disabilities Education Act.[84]

Education for All Handicapped Children Act, P.L. 94-142. The Education for All Handicapped Children Act (1975) was later renamed Individuals with Disabilities Education Act, IDEA, in 1990. According to this law, no child could be denied a free and appropriate public education, and that education must take place in the most integrated, least segregated setting possible.[85]

Six basic underlying principles of special education were established through this legislation:

1) Zero reject, free and appropriate education must be provide to all children with disabilities;
2) Nondiscriminatory evaluations must be used to determine eligibly and need for services;
3) Educational services must be provided in the least restrictive environment;
4) Services must be individualized to meet the needs of the student (creation of the Individualized Education Program, IEP);
5) Parents have the right to be included and involved in the development of their child's educational program;
6) Procedural protections must ensure that the requirements of the law are met (due process).[86]

Between 1980-2004, further amendments were made to the P.L. 94-142/IDEA. Some changes included extending the rights and protection of the law to preschool children and the provision of early intervention programs for ages birth-2 (1986), the

84. Ibid., 22.

85. Ibid., 23.

86. Ibid., 23-24.

addition of autism and traumatic brain injury to the list of eligible disabling conditions (1990), measurable IEP objectives and the inclusion of a general education teacher on the IEP team (1997), and the requirement for "highly qualified" special education teachers and the required use of "researched-based techniques and materials" (2004).[87] The six principles of the IDEA govern the education of children with disabilities and ensures access to educational services.[88]

Intervention Strategies

The nature of autism presents numerous challenges for educators. However, much of the time, a teacher's fear and stress in teaching students with autism stems from a lack of knowledge about the disability and the specific student. Once sufficient knowledge is obtained, the teacher can confidently modify his/her instruction based on the needs of the individual student and feel better equipped to interact and help the student with autism. The teacher's task of information gathering can be simplified by approaching the right resources. I have put together a list of 24 basic tips and strategies to start.

1) Learn about the disability.[89] An educator can talk with the special needs teacher at the school, ask the student's parents, read books, watch videos, etc. What

87. Ibid., 25-26.

88. "History of Special Education," http://www.learningrx.com/history-of-special-education.htm (accessed September 14, 2009).

89. Adamek and Darrow, *Music in Special Education*, 56-57.

challenges does the disability bring into the classroom? What are some methods for overcoming those difficulties?

2) Know the individual [90] by asking people on the child's educational team such as the therapists, aide, other teachers, etc. The more you know about the child (strengths, weakness, motivators, interests, etc.), the more you can structure and adapt a way of teaching that suits the child's needs. The parents are invaluable resources on the child. There should be active communication and collaboration between the teacher and the parents. Review the student's Individualized Education Program (IEP) which provides information on the child and the annual goals that the student is working on. Your educational strategies should target the goals listed on the IEP which provides common objectives for all the teachers of that student and similarly encourage the student to work on his/her goals in all educational settings. The music class can also serve to develop non-musical skills. Be aware of the student's sensory needs, communicative skills, aspects of behavior, social skills, etc.[91]

3) A structured, clutter-free classroom environment with minimal distractions helps these students stay organized and focused.[92] This can be a challenge in the music classroom which has more flexibility than the general classroom. The various

---

90. Kim Davis, "Tips to Consider when Including a Student with ASD in Art, Music, or Physical Education," *The Reporter* 12, no. 3 (2007): 7.

91. Kim Davis, "Reframing Our Thinking and Getting to Know the Child," *The Reporter* 8, no. 3 (2003): 22-27.

92. Kara Hume, "Clean Up Your Act! Creating an Organized Classroom Environment for Students on the Spectrum," http://www.iidc.indiana.edu/irca/education/CleanUp.html (accessed May 6, 2009).

instruments, changing classroom set up, and different sounds and colors can create distractions, over stimulation, and sensory overload.

4) Seek a functional communication system between you and the child with autism.[93] Often a communication system is already in place that is used by the parents and other teachers. Because a consistent, predictable communication system is important for students with autism, adopting a form of communication familiar to the student and adapting it to music is highly efficient and reasonable.

5) Students with autism are primarily visual learners. Using visuals to communicate and teach is a necessary and vital strategy that will make life easier for both you and your student. Visuals, such as pictures and written words, can be used to support routine and schedules, the meaning of academic concepts, giving instructions, and establishing rules. [94]

6) Modify and adapt the curriculum, environment, activities, and materials to meet the needs of the student with disabilities.[95] Vary the level of participation expected to what the student can handle and achieve successfully. Adapt the way instruction is delivered by using visuals, having a structure and routine, being consistent, preparing the student for any changes, and breaking down tasks into small steps. Modify how students with autism can respond to the instruction by creating alternate ways of meeting the

---

93. Autism Society of America, "Educating Students with Autism," http://www.autism-society.org (accessed May 6, 2009).

94. Cathy Pratt and Scott Bellini, "Educating Students with Autism: Are There Differences in Placement?," *The Reporter* 1, no. 5 (1996): 9.

95. Kim Davis, "Aspects of Support for Learning," *The Reporter* 11, no. 1 (2006): 10-11.

outcomes or goals. For example, if a child with autism has trouble writing an assignment due to poor grammar skills and unreadable penmanship, have him/her draw the information instead. Use the same materials for all students but make the goals for the student with autism less complex. If the class is learning a dance with Orff ensemble accompaniment, have the student play a simple part of the music, such as an ostinato pattern, or just focus on learning the dance with assistance from a peer buddy.

7) Make sure students with autism understand the expectations. Use concrete, simple language, speak at a moderate pace, and do not give too many directions at a time. If there is a multi-step task, give the directions in small sections. When these students know what is expected, they will exhibit less behavioral problems which are caused by anxiety and confusion.

8) Promote independence by planning "fading prompts" which gradually wean them away from your assistance. When they do need assistance, do activities with them, rather than for them.[96]

9) Find a way to motivate the student with autism. What things interest and motivate the child? Ask the parents and other teachers what methods they use as motivation and bring their techniques into the music class.[97]

10) Give frequent positive reinforcements. This helps the child with autism build self-esteem and confidence in his/her ability. Reinforcements can also help the student

---

96. Autism Society of America, "Educating Students with Autism," http://www.autism-society.org (accessed May 6, 2009).

97. R. Stuart, "Motivating Students who have Autism Spectrum Disorders," *The Reporter* 1, no. 3 (1996): 1.

learn what you expect of him/her and improve skills such as social interaction, appropriate behavior, etc. Discover what are good rewards for the specific child.

11) If you have an aide, be glad! An aide is a useful resource in helping the student with autism complete tasks, display appropriate behavior, practice social interaction, etc. As an adult, he/she can also function as a teacher's assistant in managing the other students in the classroom. A second pair of eyes, hands, mouth, and ears provides additional help and assistance to the classroom teacher.[98]

12) Allow extra time for students with autism to respond. Due to their impairments in speech, language, perception, and sensory integration, processing information and the meaning of instructions takes time. Similarly, give them time to cope and refocus when overwhelmed. Do not request information from them when they are upset.[99]

13) Develop predictable and structured routines.[100] Use a consistent lesson format that allows the student with autism to grasp onto the safety of a structured experience. Put the class routine visually somewhere in the room where the student can refer to.

14) Students with autism have difficulty transitioning between activities. Give them prior warning so they can prepare themselves and finish up the task at hand.[101]

---

98. Adamek and Darrow, *Music in Special Education*, 60-61.

99. Autism Society of America, "Educating Students with Autism," http://www.autism-society.org (accessed May 6, 2009).

100. Davis, "Aspects of Support for Learning," 10.

101. Kara Hume, "Transition Time: Helping Individuals on the Autism Spectrum Move Successfully from One Activity to Another," http:www.iidc.indiana.edu/irca/education/TransitonTime.html (accessed May 6, 2009).

Teachers in general classrooms often sing transitional songs between activities to make transitions smoother. By choosing a transitional song for a specific activity and using it systematically, the student knows what to expect and is put at greater ease.

15) Peer mentoring or a buddy system is a helpful and useful technique in which the teacher pairs a student with disabilities with a typical student. There are benefits for both parties involved as they learn from each other. The typical student is exposed to individuals different than himself/herself, gains awareness and respect for those with disabilities, and builds confidence and joy in helping others. For the student with autism, a peer is an excellent role model.[102] Peer buddies can help the student with autism learn a subject or accomplish a particular task. In doing so, the teacher is given greater room and flexibility to focus his/her attention on more students rather than spending all his/her time helping one individual.

16) As verbal communication is a challenge for students with autism, consider all behavior displayed by the student with autism as a form of communication.[103] What is the student trying to express? Identify what causes inappropriate behaviors (are there any distracting things?, is it sensory overload?, confusion?). Once you recognize triggers that ignite meltdowns or tantrums, you can work to avoid placing the student in a situation where he/she will be provoked. Be sure to also ask the parents, aide, and others teachers for information on what upsets the child.

---

102. Davis, "Tips to Consider when Including a Student," 9.

103. Autism Society of America, "Educating Students with Autism," http://www.autism-society.org (accessed May 6, 2009).

17) Remember to give 'breaks' to meet their sensory needs. Allow the child with autism to go outside or engage in physical activities to dispel stimulation build up and sensory overload. Breaks will improve their attention and concentration, help them be more organized, less anxious, and decreases the possibility of tantrums and inappropriate behaviors.

18) Stay positive. Your attitude as a teacher is reflected in your teaching and interaction with the student. A positive attitude generates more success than a negative attitude. [104]

19) Empower students with autism to be active participants in the classroom by giving tasks that allow them to be successful.[105] The more these students experience success, the more you can gradually expand their circle of interests and abilities to try new things. Successful experiences build confidence and self-esteem.

20) Give students with autism the same respect you show to typical students.[106] In addition to these students feeling equally treated, you are also a model for your typical students. Be the leader who creates an environment that allows the student with autism to grow and feel accepted.

21) Accept students with autism for who they are and look beyond their disabilities. Above all, they are individuals. The concept of 'putting the person first before the disability' was the reason the Education for All Handicapped Children Act was

---

104. Stuart, "Motivating Students who have Autism Spectrum Disorders," 2.

105. Autism Society of America, "Educating Students with Autism," http://www.autism-society.org (accessed May 6, 2009).

106. Ibid.

renamed Individuals with Disabilities Education Act. According to Adamek and Darrow, "the purpose of this approach is not to minimize or deny a disability, but to affirm that the student is more than the disability and that the disability does not supersede all of the other human attributes that the child possess."[107]

22) Help them develop their talents, interests, and strengths which can lead to later success in life.[108] Do not box their abilities and potential by their disability.

23) Be creative in your instructional strategies. Because autism is a spectrum disorder, each student with autism is different. No one program or approach will meet the needs of every individual with the disability.[109]

24) Never give up and love them unconditionally. Push on when others stop. Educating students with autism is a rewarding challenge. This population of students compels educators to reevaluate themselves (attitude, character, instructional methods, etc.) and reexamine their teaching philosophy. These children need someone to have faith in them, and their parents need someone to stand by them in support.

Conclusion

The nature of music and the natural aptitude for music in children with autism creates the possibly for great synergy between the two. The characteristics of music are able to reach children with autism in ways that other stimulus and interventions cannot,

---

107. Adamek and Darrow, *Music in Special Education*, 8.

108. Autism Society of America, "Educating Students with Autism," http://www.autism-society.org (accessed May 6, 2009).

109. Ibid., 49.

plus these children find music pleasurable and are able to succeed in this area. Music therapy or even just a structured use of music in the classroom or their lives can help them develop and practice skills (communication, social, behavioral, and academic) that are needed to function successfully in our society. Music can also provide children with autism a safe, structured routine in life allowing them to be a peace with themselves and others through a better understanding of the world and themselves. An important vehicle for expression, music gives children with autism, especially those who are nonverbal a chance to communicate and express themselves in a way that is socially acceptable and appropriate. It brings these children happiness and comfort when other things cannot. Music may be the one thing that helps them live life with a greater sense of purpose.

Chapter 3: Method and Design

This thesis is a qualitative case study. As I sought to tell stories about the lives of two children with autism and their families, I felt a holistic approach of inquiry would provide the best results. Furthermore, the questions I wished to answer were based on human behavior and thought, which are flexible and ever-changing. Case study research focuses on a "single phenomenon or entity" to "uncover the interaction of significant factors characteristic of the phenomenon."[1] The role of music in the lives of two children with autism is the center of my examination.

Clandinin and Connelly state that "narrative is the closest we can come to experience."[2] Therefore, this study is told in narrative form so that the readers may experience the stories of the participants at a deeper level, in the fullest way. My hope is that the stories come alive in the minds of the readers. Narrative allows a deeper, more human connection with the participants and their stories.

Much like other qualitative researchers, I was overwhelmed by the "sheer bulk" of information[3] to be looked at in my aim to present a holistic picture of this study. I was often at loss when I faced the mass of information available. Making choices about what to look at, prioritizing what I should learn, and deciding what to research next was an

---

1. S. Merriam, *Case Study Research in Education: A Qualitative Approach* (San Francisco: Jossey-Bass Publishers, 1992), 29.

2. D. Clandinin and F. Connelly, *Narrative Inquiry: Experience and Story in Qualitative Research*. (San Francisco: Jossey-Bass Publishers, 2000), 188.

3. Corrine Glesne and Alan Peshkin, *Becoming Qualitative Researchers: An Introduction*. (White Plains: Longman Publishing Group, 1999), 131.

ever-present struggle in my process. There was always something more to examine. Eventually, the process of organizing and analyzing the piles of information gathered felt like my mind was on "information overload."[4] What stories and information were important to include and how I was to interpret them became of great concern.

The self (beliefs and subjectivity) of a researcher serves as a principal research tool in qualitative inquiry.[5] Forming the personal lens in which the study is absorbed and interpreted, my background in church ministry, music education and performance, and years of caring for children influenced my search of meaning and significance in this project. Within the roles of participant/observer, inquirer, researcher, and writer, I present an account that describes and interprets the ways in which music helps/allows my two participants to lead successful and happy lives.

Although interpreting meaning from these cases is different from generalizing findings in other research forms, the participants' experiences and stories may inform parents and teachers of ways in which music can benefit those with autism. According to Stake, case studies can provide "valued and trustworthy knowledge" by illustrating "how a phenomenon occurs in the circumstances of a particular exemplar."[6] It is my desire that this study will yield insight, encourage music use, and serve as a springboard for music-making explorations. Music can function as a bridge between their world and ours, a medium for interaction and communication.

---

4. Clandinin and Connelly, *Narrative Inquiry*, 76-77.

5. Glesne and Peshkin, *Becoming Qualitative Researchers*, 102 .

6. R. Stake, "Case Studies," In *Handbook of Qualitative Research*, ed. N.K. Denizen and Y.S. Lincoln (Thousand Oaks: Sage Publications, 1994), 242.

Primary Participants

The primary participants in this study are two male children with autism spectrum disorder who use music functionally in their lives. Statistics state that autism occurs one in every 58 boys, four times more often than girls,[7] so I felt that using two boys could give the most representative information possible in such a study. By choosing participants at different ends of the age spectrum, I was able to gain different perspectives and stories of children in different stages of development. Similarly, participants of contrasting ethnic backgrounds, distinct levels of musical achievement, and varying degrees of speech allowed the possibility for new insights influenced by a wider range of responses and thoughts.

As autism creates communication and social barriers, I sought supportive, open, amiable parents, willing to share their experiences and stories with me. Selecting parents who could articulate clearly and express themselves was also important because much of the information was gathered through interviews with parents rather than the children.

My first participant is a Chinese-American, 18 year old teenager named "Mike." He goes to "Jackson High School" located in a beautiful, spacious city in California. According to the school's 2008 statistics, the student population is 43% White, 41% Asian, and 13% Hispanic. The median yearly household income is $70,000. Mike stays in special day class for English and math but is mainstreamed into his electives which are

7. "Autism Speaks Responds to New *Pediatrics* Autism Study Putting Prevalence at 1 in 91 American Children, Including 1 in 58 Boys," http://www.autismspeaks.org/press/autism_nchs_prevalence_study_1_in_91.php (accessed October 5, 2009).

mostly music. His mother, “Wendy,” serves as his aide at school, helping him meet his academic goals in each class. Outside of school, she functions as his chauffeur, taking Mike to his numerous instrumental lessons, rehearsals, and performances. Mike’s father, “Dan,” works as a computer engineer. Even though this takes up much of his time, he shows his commitment to his son by serving as president of an organization for children with special needs. On weekends he practices playing keyboard with Mike. Together, they have performed many duets: father on bass and son on keyboard.

The second participant is “Ryan.” He is bright, 5 years old, Caucasian, and an only child. He attends “Roseville Elementary School” in a small, historic town of California. This school is not very diverse in its student population, consisting primarily white of upper class backgrounds. The annual family income is around $171,000. Under full inclusion, Ryan cheerfully joins his classmates for each class with his aide, “Hannah,” at his side. Hannah’s job is to help Ryan learn and accomplish academic objectives. Ryan’s mother, Rachel, works as one of the two music teachers at Roseville Elementary and also teaches college level music education courses. Her teaching career as a music educator spans fourteen years, and she is currently studying for a D.M.A. “Charlie,” Ryan’s father, received his Bachelor’s degree in English. He has worked in the hospitality industry and sales for 10 years. On the side, he is also a college baseball umpire. This year, he is entering a Master’s degree in education. Charlie’s schedule is more flexible than Rachel’s, so he devotes his free time to staying home and taking care of Ryan.

Secondary Participants

In addition to my primary participants, I also interviewed and observed secondary participants, including school teachers, private teachers, and therapists. I used their information to increase my knowledge about situations, gather different viewpoints, initiate insight, and form further interview questions. By using material from these other sources, I hoped to contextualize and enhance my descriptions of participants' experiences in this narrative.

Research Sites

I visited various sites for this study. Observations at the participants' schools and homes occurred on a weekly or bi-monthly basis. I also attended lessons, rehearsals, special needs organization meetings, and other events at schools, churches, recreational parks, teacher's homes, and a Chinese music center.

Data Collection

Data collection occurred from the beginning of January 2009 until September 2009. I collected data through observations, personal interviews, electronic interviews, field notes, pictures, recordings, documents, and artifacts.

I visited the participants at their schools at least twice a month. For Ryan, I was only given permission by the principal to observe him during music class, so supplemented these observations with visits to his home where I observed and interacted with him. I also babysat Ryan on occasion and was invited to several family outings

including camping, watching a school play, and shopping. Originally, I wished to see Ryan in his therapy sessions, but these all occurred during school hours at school, and this was outside the scope of my permission.

Interviews often followed observations. I wrote field notes after the interviews as our talks often took the form of casual conversations after classes, at home, or in the car. Rachel was very kind and helpful in offering information by providing the latest reports, expanding without me asking, and giving me any information she thought was helpful. She naturally tried to use more music when I was around and got Ryan to talk more. Charlie was friendly every time I met him. Although I saw him less than Rachel, he was open when I asked him questions. He was not shy to talk about this son's condition.

My advisor gave me the opportunity to work at Mike's high school as a student teacher in a fellowship project. This provided me the opportunity to engage in school activities. I collected data by observing Mike during class while helping the teacher and also served as his aide for short periods of time. When the music teacher did not need my help, I shadowed Mike in his other classes such as math, speech therapy, art, and electronic music.

After school, I tutored Mike in piano. His piano music was now too difficult for Wendy to read so that practicing with him became a burden. Since I am a pianist, Wendy asked me to help Mike practice. This allowed me one-on-one time to communicate and interact with Mike in the medium of music. I also attended several meetings of an organization for children with special needs, of which his father is president. These meetings were a great time to talk with other parents, get acquainted with children with

disabilities, and watch how the teachers interact, teach, and help the children, etc. This was an excellent place for allowing me to experience knowledge and familiarity around those with special needs as I had not had much interaction with children with disabilities before my thesis.

Wendy sent two articles she wrote about Mike's life because she could not reply quickly and thoroughly in electronic interviews due to English being her second language. Written in Chinese, my parents aided me in translating the articles. These articles provided information and immense insight about Mike's early childhood, serving as a spring board for future questions. I wrote field notes after the interviews because of the casual form of our conversations. Interviews often followed observations. Wendy was very open and cheerful in speaking about Mike's condition. She enjoyed sharing about his latest accomplishments, what life skills she was working on with him, the competitions he would be entering, etc. Always friendly, she talked from her heart, intensely passionate about her beliefs in helping Mike.

Interviews and Observations

I asked Mike questions during lunch at school and piano tutoring. Ryan and I talked at his house and occasionally at school. Interviews with their parents occurred in person and electronically through e-mail. At times, a casual talk would lead into a much deeper conversation. During these times, I chose not to break the flow by taking out my recorder. I did not wish the informant to grow rigid and close up because of seeing the recorder. Thus I perfected the skill of taking rapid notes, jotting down the key points and

storing as much detail in my memory as I could. When I reviewed the notes later on, I would then type them out, filling in and fleshing out what I remembered. To double check for accuracy, I shared my notes with the parents to review.

I began my interviews with a list of sample questions; however, I did not bring them out during the interview. As I was aiming for a casual approach rather than an inquisition, a list of questions would not help achieve a natural, free atmosphere. According to the way the interview flowed, I asked questions from the list to keep us on track but also gave room for the informant to communicate what they wished to share. My strategy was to meet with some questions I wished to ask and have an open mind to learn and receive. This produced greater and more varied information.

For observations, I attended classes, rehearsals, lessons, special events, organization meetings, and family outings. During these times, I took pictures, notes, and sometimes audio recorded.

Artifacts

Glesne defines artifacts as documents that "correlate our observations and interviews and thus make" the "findings more trustworthy." [8] According to Clandinin and Connelly "viewing these documents in the context of narrative inquiry constitutes something that might be called an archaeology of memory and meaning."[9] I collected several kinds of artifacts including CD recordings, programs, fliers, videos, and pictures.

---

8. Glesne and Peshkin, *Becoming Qualitative Researchers*, 52.

9. Clandinin and Connelly, *Narrative Inquiry*, 114.

Much of the artifacts were shared by the parents without me asking. Artifacts such as CD recordings and videos allowed me to further process the information I gathered while programs, fliers, and pictures helped me relive the experience and interpret my data.

Confidentiality

To maintain confidentiality, the children and parents of this study are identified by pseudonyms. Similarly, schools, organizations, bands, and teachers mentioned in the study are not named.

Permission for this study was granted by the parents of my participants because both child participants were under the age of 18. As both adults and children are informants in this study, the adults were also asked to sign the consent forms of their minors. A copy of the consent form is provided in Appendix B. I was granted permission to one school by serving as a student teacher through the fellowship project. The other school gave me access on the sole condition of coming as a music teacher observing a music class. Observations at lessons, rehearsal, therapy sessions, and classes were allowed with prior notice to the teacher and permission by the parent.

Data Analysis

Data analysis was an ongoing, complex process as it involved "organizing what you have seen, heard, and read so that you can make sense of what you have learned."[10] New information arose with each interview and observation. Questions grew with the

10. Glense and Peshkin, *Becoming Qualitative Researchers*, 127.

queries I sent and received back. As each door opened more doors, it seemed as if I could not collect enough information. There was always something more to explore. I would take notes during interviews and observations, then type them onto my computer, expanding on what I saw, heard, and felt. Thankful for the way it helped me sort through my thoughts and recall my experience, I tried to grab onto the memories.

While rereading my notes, certain themes began to gradually emerge. Each theme revolved around music touching some part of the child's life. It was fascinating to notice similarities and differences in the way music connects with each child. Some things could not be explained and simply must be accepted. Evidence of the workings of music was before me on paper and in person. Nevertheless, for awhile, I tried to dig deep into the scientific workings of how music was able to capture the child in ways other things and people could not.

I examined the data and grouped it into themes and categories upon which I will further elaborate. Through narrative, I tell their extraordinary stories of determination, struggle, love, patience, and unconquerable spirit. It is my hope that music and their stories also touch your heart in mysterious ways.

Trustworthiness

Glesne notes that "Time at your research site, time spent interviewing, and time building sound relationships with respondents all contribute to trustworthy data."[11] In questioning my bias and the accuracy of my information, I sent drafts to the parents of

11. Ibid., 146.

my participants for revision and comments. E-mail was a common form of communication in asking follow up questions and checking for correct information. For this study, I spent nine months in the research process including interviews in person and through the internet, collecting and reviewing material, and discussing possible interpretations and perceptions with others. I attempt to present a well rounded, truthful picture of this study within the allocated time period; however, more remains for me to see and learn. As Clandinin and Connelly comment, "living, telling, retelling and reliving mark the qualities of a life. A book on narrative inquiry, one reflective on this ongoing quality of life, simply stops at some point or moment when the authors and their most intimate readers, say, enough is enough, at least for now."[12]

In order to establish trustworthiness in other ways, I spoke to individuals familiar with autism and music including a music teacher with autism, my advisor, other students at my school, parents of special needs children, a special education teacher, and others. Additionally, everything I learned through interviews and observations, I compared with existing research to make sure I was building an accurate and holistic picture of this study.

Summary

This thesis is a qualitative case study about two children with autism spectrum disorder and the role of music in their lives. I use a narrative form of telling as humans are familiar with stories and learn from them. Furthermore, by placing myself within the

12. Clandinin and Connelly, *Narrative Inquiry*, 187.

narrative I can best communicate their stories and my experience, how I have changed and what I have learned.

Chapter 4: Mike

Our First Meeting

The church sits amongst towering trees bare against winter's setting sun. Across the road lies a field of grass with trees lining its back perimeter. Not far off is an empty lot with a lone fruit stall, now closed for the night. I look ahead at my destination. The one story church, grandly painted white, is the bi-monthly meeting place of "Special Needs Community Group," a children with special needs organization. Here for the first time, I will meet Mike, his mother, father, and the rest of this large "family."

Arriving at the church, I do not know what to expect. I have had very little contact with people with disabilities prior to my study. In fact, this meeting will be my first time seeing so many children with special needs all in one room. Taking a deep breath, I walk in. Most of the members gather in the church hall talking and laughing. Others mingle in the hallways or surround a booth filled with brochures and pictures. The children play together or play by themselves with their own toys. The scenario appears normal or at least under control. No tantrums, fighting, or screaming yet, I think.

Glancing around, I feel slightly out of place. Where is Mike's mother? I wonder. I remain rooted in my position unsure of where to go. Several minutes pass. At the far end of the room, a middle aged woman wearing a Christmas sweater and black pants excuses herself from a group of people and walks towards me. She has a youthful face framed by short curly hair, and she wears a big smile.

"Hi, are you Elizabeth?" she asks.

"Yes. You must be Mike's mother," I reply, sighing with relief at finding her.

She laughs. "I'm so happy you could come. It will be good for you to observe here tonight. I'll have my husband show you where the classrooms are later." She briefly speaks of their schedule that night, what activities will take place, which rooms they will be in, where and what the parents will do while the children are in class, and other background information about their organization.

"You should also stay for dinner," she invites warmly. "Tonight we are having potluck to celebrate Christmas. It will be so much fun."

"I would love to," I reply eagerly, nodding my head. "Thank you."

At this time, a teenager, appearing out of nowhere, kisses Wendy on the cheek. He peers at me with a look of suspicion and cautiousness. Or is it fear I detect in his stance? Wearing a black zip-up vest, khaki pants, and running shoes, he stands silently.

"Elizabeth, this is Mike." Wendy makes the introductions.

I smile kindly and reply cheerfully, "Hi Mike."

"Mike, say 'hi' to Elizabeth." Wendy encourages, her hands placed reassuring on his arms.

My first impression is that he is close with his parents and enjoys interacting with them. I wait patiently with a smile.

"Hi, (pause)…Elizabeth!" My name sounds foreign on his lips but his greeting is sincere. He runs off soon after to play. My second impression is that he is extremely obedient to his mother.

That night I shadow Mike, attending classes in music, art, and dance. He tries

hard to participate in all the classes giving his full effort and energy. Music is by far the easiest for him to keep up with the teacher. He is comfortable and happy while he sings and plays with streamers. The foot step sequences in dance class are too complex and fast for him to perform successfully. However, he does not give up but continues dancing the whole lesson, just several steps behind the teacher. In art class the children draw faces on balloons with colored markers. Occasionally the balloons pop frightening some children and causing them to scream. Other children cry because the sound of the balloon popping hurt their ears.

"Please don't pop the balloons," a girl with down syndrome pleads. She comforts the crying girl next to her, putting her arm around her in embrace.

"Some people here have sensitive ears," the teacher firmly reminds. "Let us be more careful with the balloons."

I am afraid this will be the case with Mike. As autism creates a unique sensory system, the sound may be much louder and more painful than what I am experiencing. Mike does not scream or cry, but he tries to escape, walk out of the classroom, showing his obvious displeasure at the noise.

While the children are in classes doing various activities, the parents stay in the main church listening to a speaker. A different speaker shares information on helping children with special needs at each meeting. After the parents' seminar and children's classes, everyone enjoys dinner and socializes together.

Tonight is a special Christmas celebration. Tables full of food lie in one long row like a banquet feast. People likewise stand in a line and begin filling their plates with

food. The feasting begins after several announcements about upcoming events. I collect only a little of everything, but still end up with a full plate. Parents and children sit at the many tables eating and talking. The atmosphere is joyous, light, and carefree. Festive. From one of the tables, Wendy waves her hand calling me over. I eat dinner with Mike, his mother, and a family friend that night. Dan, Mike's father, stands at the side of the room, watching, making sure everything is in order. He gets his food last, only after he is certain everyone else is fed, settled, and happy. Unlike some children on the spectrum, Mike is not a picky eater. He devours everything on his plate and accepts second servings.

Looking around, I am surprised by the number of special needs children within the Chinese population. Although the members of this organization are not restricted by race, the meeting is comprised largely of Chinese Americans. The Chinese culture is not very open on the topic of disabilities. I know because I am Chinese American. Before this study, I never heard a discussion on this topic or saw many Chinese children with special needs. These children are often looked down upon and their parents put to shame. My experience today opens my eyes to this misguided, unfair way of thought. These children and their parents do not have a choice about the challenges they face, but they make a choice to make the best of things. They stand strong and learn to live.

During clean up, Mike begins to play a lovely grand piano in the corner of the hall, running through several pieces by memory. Confident and absorbed in the music, he starts an extremely fast, virtuosic piece. As the intensity of the piece grows, so does the volume.

"Mike, that's too noisy," his mom calls from across the room. "Play something peaceful. Play Moonlight."

Seconds later the haunting melody of the first movement of Beethoven's Moonlight Sonata floats through the air. I stand listening in wonder at his musical abilities. From the side doors, my father walks into the room over to where I am standing with Wendy. He is here to take me home.

"Dad, this is Wendy, Mike's mother. Over there is Mike." I point in the direction of the piano. "Doesn't he play the piano well?"

"Oh, is he a piano major?" My father asks Wendy curiously. He does not detect any evidence of autism in Mike while he plays.

"No, he has autism," Wendy explains in a light-hearted manner, "He will not be able to do that [major in music]." A hint of sadness is evident in her voice.

"Oh…he is very good," my father responds sympathetically.

That night, the image of Mike at the piano and the melody of Beethoven's Moonlight Sonata follow me home.

His Story

Family Background

Wendy, Mike's mother received her university degree in Taiwan majoring in Chinese literature. She had chosen a degree in Philosophy during her first year, but by the second year switched into Chinese literature. However, Wendy believes that her contact with Philosophy has influenced the way she approaches life. Philosophy "helped

me a lot. [It] makes me the way I am, how I think, examine details." After she graduated, she got a job as a Chinese teacher fulfilling her dream, "I always wanted to be a teacher."

Mike's father, Dan, also graduated from university in Taiwan. In 1980, he was accepted for a Ph.d program at Hartford University and moved to Boston. The following year, Wendy also moved to Boston with their one year old daughter, Mike's oldest sister. Mike's second oldest sister was born in Boston during their 5 year stay while Dan completed his studies. His first job was for IBM "all the way across to California." Mike was born several years later. His mom did not need to worry for his sisters. They did well in their academics, achieving good reports at school.

"They always got excellent ratings. They know what they are doing. Normal kids are very easy…," says Wendy. In comparison with Mike, "Every step is slowly, slowly. He learns something, but maybe does not have any idea what he is doing. Every step is deep and heavy."

Each member of Mike's family had their own way of accepting his condition as evidenced in their relationship and interaction with him. Mike's oldest sister, Lydia, was 10 years old when he was born and had a hard time accepting him because of peer pressure. She did not know how to tell her friends about autism and was afraid to be rejected or laughed at. Her breakthrough came in high school when she finally told her friends about Mike through an email and they accepted him. "She was so surprised," recalls Wendy remembering Lydia's relief. Lydia became Mike's first piano teacher. "I even paid her!" exclaims Wendy, "but she was so tough and strict with him."

In contrast, Mike's second sister, Jane, is "sweet with him. They get along and she teaches him." Jane now works as a counselor. Wendy smiles as if seeing a great future, "She is able to help him [Mike]." Both Lydia and Jane are now busy with their careers. Neither one lives at home.

Early Years

Mike was born in the summer of 1990, the third of three children. His delivery was something his family would never forget. Born two months early, he came into this world covered with blood. His mother barely survived due to the amount of blood she lost. Mike weighed 4 pounds and 3 ounces, about half the weight of a normal baby. His first experience in this world was one of pain and discomfort. Unlike a normal baby he needed to wear an oxygen mask, had blood drawn for tests, stayed in an incubation box, and kept on losing blood. He stayed at the hospital for four weeks.

Miraculously, by one month of age, he grew to be a healthy, cute 7 pound baby. By nine months he could sit up, at ten months he learned to crawl, and grew teeth by eleven months. Around one year of age, Mike started producing sounds, babbling, and trying to talk. He was extremely handsome and cute; his family's treasure, loved and cherished by everyone. He learned to walk at sixteen months. Although, this was a little slow in development compared with other babies, his parents did not think it was a problem, as everything else in his development appeared normal. Then he stopped talking completely. His attention shifted to the spinning and turning of objects, light, and shining and sparkling things. He began playing with objects in abnormal ways such as

spinning plastic plates, flipping the light switch on and off watching the lights flicker, and turning over his tricycle so that he could spin the wheels with his fingers. He loved car rides because during these times he could engage himself with the traffic lights, watching the red, green, and yellow lights shine and change.

Mike played in different, creative ways compared with other babies. One babysitter commented on seeing Mike throw a rock onto the carpet, then tile, wood, and finally take the stone outside to throw it on the ground. He had wanted to hear the different sounds made by the rock hitting various surfaces. Through his play with toys, his parents noticed his interest in sounds, his focus on auditory stimulation. Mike would rarely press the buttons for the ABC letters to pop up from the toy box, but rather he would lie on his back holding the toy above him. Sometimes he would shake the box being content hearing the flaps hit against the box. Other times he would place the box back down and tap it, watching and hearing the flaps fall randomly and erratically. His focus grew to the extent of ignoring the insistent calls of his mother.

Only music would cause him to turn from these things and look at people. "He would not answer the call, was aloof, and only paid attention when there was music. When he was very little he went around finding stimulation—ticking, flashing lights, etc.— but when I sang a scale, it got his attention," his mother recalled. Mike would sit up immediately, cock his head, and be fully interested. Even at these times, he responded to the music, rather than the people singing or playing the music.

Originally his mother thought that his intense concentration and focus was the characteristic of a smart child, so she did not pursue any interventions. "He had a long

concentration span. That's not normal for a baby, for him to pay so much attention to one thing. But we didn't know that."

Besides responding to music, Mike's early interest in music became evident at the piano. The piano was his play toy. A typical day at the piano unfolded with him sitting and playing with one finger, one hand, and both hands or standing on the bench with both hands on the keys for support and playing with one foot, banging the keys, pressing notes. He liked to copy his sister, Lydia, on the piano. When Lydia played loud chords on the piano, he achieved a similar effect by bouncing up and down, sitting on the keys for his own power clusters.

His early musical abilities in music included playing any song he could sing using one finger. Many times, his mom believed he was composing on the piano. Mike could also hum back, imitate, what she sang to him. His mom use to hum different sounds (um, am, etc.) when kissing him. Wendy recalls with a smile and amazement, "He would like… melt." The stimulations from the vibrations went straight to his mind. "Mike loved it."

Diagnosis and Early Interventions

However, by two years old, Mike still did not talk or show any signs of wanting to. In concern his parents took him to see a pediatrician. The doctor saw that Mike was very cute and smart, so told them not to worry. Wendy recalls, "Our pediatrician said, 'Einstein never talked until 5.'"

Not satisfied, their family and friends encouraged them to seek the advice of other

doctors. On a trip one summer, their relatives in Taiwan felt that there was something strange about Mike because he did not talk or respond when they called his name. Wendy's brother-in-law was reading about special needs at the time and saw a "match," similarities between what he was reading and Mike. Wendy immediately took Mike to the hospital for a diagnosis. The doctor diagnosed Mike with autism using a behavioral chart.

His parents fell in a deep valley of shock, frustration, and disappointment. "We were *really* sad. Dan cried for a day…for a few weeks." Their future dreams were shattered. "Our dreams about him broke into pieces. We didn't know what to expect. If he will grow or get married, etc. All the future you plan for him shatters like glass. It was *really* hard." Mike's mother would often cry. But even through the grief, it is important to stand up and continue. Wendy remembers, "Then you start to be busy—engaging with the school district, testing…so busy."

One day, when Mike was still a toddler, Dan and Wendy met the founder of an organization for children with special needs. This man became a mentor and friend. He opened their eyes to special education resources, helped them climb out of the abyss, and gave them hope for Mike's future. He urged them to become advocates for special needs awareness, which gave them direction. Before long, Mike's parents were working at this organization.

Mike lived in his own world. He could look at a clock, play with a toy, or listen to a music box for long periods of time. So intent was his concentration that he would not even move. He locked himself in his world of sound and light. He spent his time

finding stimulations that attracted him. He had detached, separated himself from this world.

When Wendy noticed his atypical behavior, she looked for outside help. Mike was placed in several intervention programs including speech therapy, sensory integration therapy, occupational therapy, music therapy, and play groups. However, because he was unwilling to participate, to cooperate with the therapists, there was little improvement. He was stubborn, not wanting to do what was asked of him. Although he knew basic numbers, colors, shapes, he could not demonstrate this ability during his therapy sessions because he was uncommunicative. Rather, at the most unlikely times, his abilities would manifest themselves. He would not respond on cue, but only in his own time. His mother thought perhaps it was because his language development had not reached a stage that allowed him to respond properly. Thus Wendy began to focus on developing his speech.

Eating time became a practice time for eye contact and speaking. It was only during eating (basic needs) that Mike truly noticed his mother. The rest of the time he was in his own world. To practice 'eye contact' Wendy would take a spoon, fill it with food, and move it in front of Mike's face, having his eyes follow the spoon. Eventually the spoon was brought up to the level of her eyes, establishing eye contact with his mother. To open his mouth for food, she said, "Ah." Mike copied her. Closing the mouth was "Mm." Three weeks later, he could say "Ahm." Shortly after, Mike said "Ma," his first word. His mother cried. Mike was 4 years old at the time.

This major step forward did not change Mike's progress to one of "happily ever

after." Learning was still slow and unstable. Some days were better than others. Rather than continuous development, his growth was more "stops and starts." Mike needed constant reminders.

Other intervention programs followed. At six years old Mike began three hours of 'Behavior Modification' every day and 'Discrete Trial Training' five days a week. Three months later, his parents noticed great improvements in speaking, concentration (from scattered attention to more focused), and recognition. Because his improvements were so evidently seen, his school agreed to pay for the costly intervention fees.

Although music brought Mike happiness, it sometimes made him cry. Around preschool age, when Wendy sang songs like "My Bonny Lies Over the Ocean" and "America the Beautiful," Mike would sob intensely. "It touched his heart," she explained. It was as if he understood the meanings of the songs, illustrating his deep connection with music.

Mike Goes to School

When Mike started first grade, he was 7 years old. Wendy became his one-on-one aide, working as a school employee. She requested the school to move him from special education into mainstreaming. The school agreed. Three months later, Wendy pushed to have Mike enter full inclusion. Mike's new teacher was wonderful and accepting. Likewise the students cooperated with his needs. He learned to work individually and in group settings, could follow the teacher's directions, practiced good interaction, and developed independence. His mom believes that a "normal" learning

environment had a big influence on his learning and development. "Inclusion was very important. When he was little, people use to think special needs people belonged in special education and normal people in regular education. People did not really mix. The idea [for inclusion] is not to make you the same IQ as they are, but to make you be able to blend into that environment. Everyone works at their own ability."

However Wendy's main reason for getting Mike into full inclusion was her dislike of the special education classes. "The *critical* reason was that I really could not find good special education classes," she told me, "We went through so many different ones. Not many of them functioned well… especially for autism. They didn't know how to deal with it."

She further comments on the slow progress, lack of structure and routine, inconsistent schedule, and attitude of the teachers. The schedule and activities in class frequently changed if the teachers thought the students could not accomplish a certain task. Often, the teachers did not really have high expectations for the students. She acts out a scene for me pretending to be the teachers, "'He doesn't want to play. It's okay. Oh, he doesn't want to do this. That's okay.' They pamper them too much! I wanted to push Mike more. The schedule was also so inconsistent." To allow Mike to grow and develop his potential, Wendy sought to remove him from this setting.

Wendy soon found a kind teacher at school who was willing to let Mike come in and try full inclusion. In regular class the routine was clear: first write in your journal, then circle time, followed by art, and so forth. Mike behaved himself by being quiet and good. Although he did not always pay attention in class, he did not disturb the other

students trying to learn. "Lots of people [students with disabilities] cannot do this. They will make noises, scream, and be disruptive."

Whenever, his behavior became inappropriate, Wendy quickly took him outside. "Sometimes he would laugh but I immediately took him outside because we have *no right* to disturb the other kids." She made sure he did his work. Wendy recalls her early experiences in inclusion as a "power struggle" where she "had to win." In order for Mike to stay in inclusion, he needed to prove that he could learn and behave. Gradually Mike could focus for one hour, two hours, the whole morning, then the whole day.

Wendy has been Mike's aide since he was in first grade. She reflects back on the decision to become his aide because he was non-verbal. "If he doesn't talk, then no one will understand," she says. Wendy further shares her views on the state of special education in California, "in California, special education is not very stable. Teachers and aides move around a lot. If the aides are always changing, it is hard to make progress."

Her concerns revolved around the likelihood of Mike working with many different aides. Mike's limited speech and personality required a degree of stability in the person that worked with him. She comments on the time required for the aide and Mike to become familiar with each other. "By the end of the school year, nothing is done. When the aide changes, he or she doesn't know what he [Mike] did before. I know his front, back, and how to connect him with environment."

Wendy is the only mother in the school district who is an aide. As the school district does not usually approve this idea, she was discreet. "I could not announce from the beginning, 'I want to be my kids' aide. It was gradual.'" According to procedures,

the parents first had to request that their child needed one-on-one attention. If the school agrees, there is an opening posted for the aide position. Wendy went to the school district office to qualify herself as an aide. Afterwards, she was able to apply for any vacancy. Mike had an aide job opening. There were four other candidates interviewing for the position as Mike's aide. His mother was offered the job because she knew the most about autism.

Wendy's approach to helping Mike at school is to "serve as a teacher, not a mother." This is because many children act out when their mothers come. "Maybe that is why many mothers are not willing to work here," she states, "You need strength and commitment."

Mike's Musical Journey

At 8 years of ages, Mike's musical talents started to develop and blossom. His mother believed that music opened the windows of his heart. Mike's first major breakthrough occurred at his first piano performance. When he turned his head after finishing his piece, he saw the smiling faces, shining eyes, and heard the thunderous applause. "He smiled so big!" Wendy recalls, "He loved it. It was as if he floated into the air."

After that, learning was not so painful. He liked to receive the praise of others. Since then, whenever he plays piano, his eyes are directed toward the audience, no longer staring at his hands. He seeks to hear applause, praise, and encouragement from the audience. He wants to interact and communicate with them.

His mother continues to stimulate his mind by learning different things: piano, abacus, Chinese language, gymnastics, cello, and drawing. By middle school, her focus shifted to developing his musical talents. Presently, Mike can play drum set, timpani, Yangqin (Chinese hammered dulcimer), piano, and cello. He is starting lessons on the saxophone and double bass. There are other instruments where Mike practices with his mother but does not take private lessons. These include the recorder and Sheng (Chinese instrument). Her approach is not to have him excel on every instrument, but to identify areas needing improvement and work on them. Wendy states, "Before, Mike used to play timpani with his whole arm instead of with his wrists. He had to work on that. So, I started him on dulcimer because his wrists needed to be more flexible."

As Mike has trouble speaking, Wendy is building up the muscles around his mouth and his breathing through wind instruments. "He takes saxophone, not because I want him to play, but to exercise his cheek [muscles] for speech. Practicing breathing is really helpful for his health."

Wendy uses different instruments to let Mike build his motor skills through playing these instruments. She states, "All kids with special education go to occupational therapy, but it is boring. I can make the exercises happen when playing music. Mike exercises his hands by playing the piano, works on using his wrists in drums, hand coordination in Sheng, etc. Music is more fun and you can also learn something."

Many parents comment that she is giving Mike too many instruments. However, Wendy approaches these instruments as "therapeutic activities" where Mike can learn skills. Another reason why his mother brings various instruments into his life is because

Mike possesses a potential and talent for music. "It is like he is born with all the elements [of music] inside. I have to pull them out…" Wendy says. He plays his numerous instruments at an advanced level. The ability to play more instruments will open more doors, job opportunities in the future. His mother is equipping him for the future. She believes music will be his future.

Mike at School Today

Mike currently attends "Jackson High School" in a beautiful, spacious city in northern California. He was in full inclusion until high school. Now, Mike stays in special day class for English and math, but is mainstreamed into his electives which are mostly music focused: band, orchestra, art, and electronic music.

Band Class

Mike sits behind a set of four timpani at one corner of the room. Behind him is a white board. The instrument storage room is on his right while to his left various marimbas and xylophone percussion form a divider between him and the rest of the percussion section. He is content in his own space playing with his mini audio recorder. This and many other gadgets are his treasures, kept in his pocket and taken out when he has time to play with them.

Flipping through a pile of paper, his mother sits in front of the timpani next the music stand. Wendy is familiar with music because both of Mike's sisters play musical instruments. However, not being a musician herself, it is often difficult to aide Mike in music. I admire her courage as she learns music together with Mike.

The other students are busy talking, warming up, and making much noise. John, the school music teacher, sharply clicks his baton against the music stand. As the noise dies down, Mike stands, puts away his recorder, and picks up his timpani mallets. Wendy flips open his binder filled with music and awaits further instructions. A little later, the music begins.

A smile lights up Mike's face as he joins in. He truly looks like he is enjoying himself, having great fun. The more rhythmically complex his part, the happier he is. When he is not playing, he watches the other students in the band, no longer in his world but present in ours. He counts aloud the measures during large periods of rests so that he can come in at the right time. Through all this, Wendy points to the music, tracking the progress with her finger or a pen. She sings along as she points to every beat. Mike cannot read music, only the letter names his mother writes on his score. Whenever Mike receives new music, Wendy immediately writes in the letter name for every note. Thus, Mike's scores are filled with letters, circles, color, and hand written notes. She does the same to all his instrumental music. However, these letter names are more for Wendy to check that Mike is playing the correct notes because he learns primarily by ear through recordings. After several weeks of playing the pieces, he has mostly memorized the music and does not need to look at his scores.

Throughout the rehearsal, Wendy jots notes in the score reminders for expression marks, when to watch the conductor, wrong notes, tricky rhythms, etc. Wendy's devotion and determination to help Mike succeed in music is to be commended. In order to help Mike develop his musical abilities, Wendy also needs to learn music. At her age it is not

easy, but she learns together with him. She has to learn first so that she can explain and teach Mike in a way he understands.

The voice of the conductor cuts through my thoughts bringing me back to the present. The students are starting a different piece. Wendy conducts as Mike begins with his crescendo roll, her hand trembling in a fist before opening up and outward into a cut off. Mike understands what his mother is communicating, the different hand gestures she makes at different times. The music grows louder with an ostinato pattern in the timpani. Suddenly, Mike gets the rhythm wrong.

Stopping the band, John sings the correct rhythm for Mike. Mike tries again, but is still late. Together, they practice a couple of times, John singing and Mike playing. Usually Mike catches on quickly; however, this rhythm seems to throw him. John begins losing patience—speaking louder, sighing, and frowning. Wendy earnestly tries to absorb what the teacher is saying in order to help Mike, but struggles. Mike's expression is one of seriousness and concentration as he works on fixing his mistake. He is no longer smiling. Just before John is about to give up and move on, Mike plays the passage correctly. A smile of relief floods John and Wendy's faces. Quickly, John praises him. The band rehearses another section of the piece before the bell rings, signaling the end of class.

John does not doubt Mike's ability to play music. Every couple of weeks he makes the students play for him individually to make sure they are practicing and know their parts. He does not listen to Mike because he knows that Mike has learned the music.

Wendy believes John does not give Mike enough opportunity. One time, a neighboring school was seeking a high school accompanist for their choir. John made an announcement in class to encourage the students to audition for the role. As Mike knows how to play the piano, Wendy thought it was a great opportunity. She went up to John after the rehearsal to inquire further but returned shortly with a sad look on her face. John had replied that the job required interaction with the singers along with the ability to communicate with the conductor and other things. He did not think Mike could do it. "He sees Mike's disabilities more than his potential," Wendy explains.

Misunderstandings are a part of the life of an individual with disabilities. While John was rather harsh in rejecting Mike this opportunity, Wendy did not fully understand the requirements needed for such a job. An accompanist is one who needs to be flexible, able to adapt and interact with the other musicians, can sight read fluently, and be able to play not just the accompaniment part—can play vocal parts separately, together, or in any way the conductor requests. Furthermore, sensitivity to nonverbal cues and the flow of the music are highly important. It would be a challenge for Mike and Wendy to work with the choir.

This year, their band and orchestra played at a music festival. Different ensembles perform and are judged by four adjudicators. The adjudicators recorded their comments onto tape. Their orchestra received a superior rating and the wind ensemble received an excellent rating. One of the judges mentioned "Great timpani!" Afterwards, Wendy immediately asked the judge if she could keep the recording. She likes collecting

different artifacts and memories that give Mike encouragement about his musical abilities.

Speech Therapy

As Mike walks into the room with his mother close behind, his speech therapist greets them with a smile. "Hi Mike. Hello Wendy."

"Mrs. Laura," replies Mike politely.

Mrs. Laura is a petite woman in her forties or fifties with shoulder length sandy hair, glasses, and blue eyes. She has a kind and caring face. "Who is your friend?" she asks.

He pauses. "Elizabeth." Mike looks from his therapist to me.

I am surprised and delighted. This is Mike's third time seeing me and he remembered my name. Wendy laughs happily in encouragement and pats Mike on the back.

The therapy session is in the school's Robotics club room. The place is full of distractions. More like a storage room than a classroom there are buckets of paint, wood, cabinets, posters, and an assortment of miscellaneous things.

"Let's begin," says Mrs. Laura taking out a piece of paper with pictures on it. Wendy quietly leaves the room as this is a one-on-one session. One important goal for Mike this year is building his vocabulary as this will help his comprehension. Mrs. Laura slowly leads Mike through the words on the page, "sailboat…motorcycle…ship…"

Mike puts his shoes on the table. What? I think surprised. This action is very

different than his behavior in music class. “Put your shoes down and sit nicely,” instructs Mrs. Laura. He obeys reluctantly.

“Look here,” she points to the page trying to focus him. “What is a ship? Draw a line to the word.”

With some effort and prompting, Mike connects the word ‘ship’ to a picture of a ship. Suddenly, he stands and walks to towards the corner of the room, his gaze fixed on a blinking red light, part of the security system. “Mike, sit down please. We are not done with class,” Mrs. Laura calls. “That thing fascinates him. I’m not sure why,” she informs me.

Unlike music class, Mike is off task and distracted. Is it the absence of music or his difficulty with speech and language that is provoking him? This is my first time seeing him behave so poorly.

Mike sits back down with a pout. Firmly and patiently, Mrs. Laura focuses his attention to the task at hand. “What is this?” she asks pointing to a picture on the page.

“Sau…” says Mike.

She places her fingers under his mouth. “*Sail*.” She is working on his pronunciation and diction, saying words correctly.

Mike repeats the word while his therapist pushes her fingers against the bottom of his jaw causing his tongue to rise and touch the roof of his mouth producing the ‘l’ sound. “Sai..l.”

“Try again,” she encourages.

“Saaiil…Sail.”

"Good!" Mrs. Laura puts out her hand for a high five, which Mike returns, enjoying the praise. For the word 'ship,' she gently squeezes the sides of his face, causing the lips to protrude forming the 'p' sound. They proceed like this, word by word through the entire page of vocabulary. Mike patiently endures the process, while Mrs. Laura meticulously checks that Mike's tongue and the shape of his mouth are correct for each specific sound. He is more frustrated and agitated in this class than others. Although Mike really tries to work hard, speech is extremely difficult for him. This may be a reason for his distracted behavior. Throughout the session, Mike will stand up and try to walk away, make noises in his mouth, form shapes with his hands, and play with his pencil. It is challenging for his mind to connect with language. Our language is not his language. Wendy believes "music is his language."

Interestingly, Mike does not have a problem in dictation or pronunciation when singing. Wendy is unsure of why. Nevertheless, Mike has made great improvement. "When he started, it was hard for him to sit for a long time. Now he can sit for most of the period," Mrs. Laura shares, "He's improved so much, is sweet, and works hard. Mike is a good reader. Sometimes he gets he gets confused with pronouns referring to himself as Mike, not "me" or "my." That's something he needs to work on." This is Mrs. Laura's second year working with Mike.

Lunch Time

Mike and Wendy eat lunch in a place separated from other classes, a building surrounded by grass. This is the classroom for "emotionally disturbed" students. Some

have anger issues, others curse, one is partly autistic, one girl speaks badly about her parents. They can be a rowdy group of students. However, they are very sweet and kind to Mike and his mother. Knowing he is different, these students nevertheless accept Mike into their world. Mike and Wendy used to eat by themselves every day because no students wanted to eat with them, but now they have place to go. They like to talk with Mike even though the conversations do not last long. Mike acknowledges them and remembers all their names. I think they are the closest group of students to being his friends at school.

The teacher and aides also welcome Mike and Wendy with open arms. Here, Wendy and Mike find a harbor of safety and acceptance. The educators truly care for their students, being strict when necessary, but giving them freedom for fun. During lunch, the students are allowed to put on music. One girl seems to be in charge of their musical entertainment and often blasts rock music over the speakers. Along with the loud music, the students yell, run around, throw things, and fall to the floor. It is very chaotic most of the time. Interestingly, Mike does not mind the disorganization, noise, and activity around him. Each day, he peacefully sits at one of the tables and eats his lunch. Despite the autism, Mike is comfortable and at ease in this place.

One corner of the room holds a refrigerator, sink, table full of food, and a large trash can. "Feel free to eat anything on the table," Wendy encourages. I look at her puzzled. What exactly does she mean? "The food is for the students. The teachers buy it for them," she explains.

"That's so nice. Why do the teachers buy food?" I glance at the box of instant

noodles, boxes of cereal, cookies, nuts, and hot chocolate.

"They said the students behave better when they're full," she answers with a smile. How amazing, I think, making myself a cup of hot chocolate.

"Do you want whipped cream with that?" Asks one teacher as she walks over and grabs a can of cream from the refrigerator before topping off my drink.

"Thank you," I reply.

An empty instant noodle wrapper flies by Mike's head. "Oops," the student who threw it mumbles with hands over his mouth. The boy he wanted to hit stands beside Mike with wide eyes and a finger pointing at his friend. Mike seems oblivious.

Wendy talks happily with a student. This student loves Asian food and enjoys sharing recipes, what new restaurant he discovered, and where to buy certain things like a rice cooker. Always friendly and open, Wendy likes talking with the students. Mike begins packing up his lunch. "Throw the trash away," Wendy reminds him.

After obeying his mother, he quickly gets up and heads for the door. "Bye, everyone," he calls before walking out the door with a wave of his hand.

"Bye, Mike," the students all respond. There is still ten minutes left for lunch.

"Where does Mike go?" I ask his mother.

"I'm not sure. I think he goes to the office to look at the electronic screen," answers Wendy, "He like to watch the words pass by, disappear, etc."

A couple minutes later, Wendy and I walk out the door after saying goodbyes to the students and their teachers. "They are very kind," comments Wendy, "The students

are very sweet with Mike."

"Yes. They are lovely people," I agree without hesitation.

Electronic Music Class

Mike enters a room filled with computers. Placed in rows of six, each computer is attached to an electronic keyboard and a pair of headphones. This is Mike's electronic music classroom. Many students are already seated at the computers. Some surf the internet, others do their homework. Mike walks toward the end of one row stopping at the last computer. Then, with great familiarity he logs on and opens a music theory program. Working through the theory program is part of the work in this class. Each unit consists of exercises and a test at the end. After passing the test, the student can proceed to the next unit. Students are responsible for their learning because they work individually. Most of the time, the teacher does not teach but rather helps if students have any questions.

As more students file in, I notice other music software running on the computers around us. "What other work do the students do?" I ask Wendy, who sits at the computer next to Mike.

"The students are also working on a great program called Midi protocols," replies Wendy enthusiastically, "But Mike does not do it because it is too complex for him. We just work on the theory program."

"What is Mike learning now on his theory?"

"It's very difficult now. He's learning about harmonizing, improvising, and Jazz

modes."

"Those are quite challenging." How does Wendy do it? How does she help him, when she is learning new concepts herself? I thought.

"Can you help Mike today?" asks Wendy. "I need to reply some emails," she explains, "I'm behind in my work."

"Of course," I answer, happy to help. Pulling a chair, I sit down next to Mike. "Let's read the question." Mike reads aloud as I glance from the question to the multiple choice answers below noting the correct one. However, when he finishes reading, he stares at the screen making no effort to answer the question. Perhaps Mike does not comprehend the question. I rephrase the question with simpler words then lead him through the steps of answering.

While progressing through the next questions, the problem becomes clear. Mike knows the answer, but simply does not fully understand what the question is asking. There is a comprehension issue. Wendy's words pop into my head, "I explain what is needed and simplify the task to fit his ability." Unfortunately, theoretical concepts are much more difficult to explain than practical concerns. Unlike aiding him in band or orchestra, working with Mike in theory is frustrating and tiring. My challenge lies in teaching Mike in a way he understands.

As my mind runs through how to solve this problem, Mike gets restless and starts clicking the answers, trying to figure out the exercise. He gets it wrong signaled by a buzz-like sound. The next question appears on the screen. I begin reading, but am disrupted when Mike clicks again. He grins enjoying the sound, the auditory stimulation

produced by wrong answers. Eventually, this is a game to him as he fixates on the sound. Questions fly by to the point where I cannot finish reading. "Wait, Mike," I state firmly, touching his shoulder. "Let me read the questions first."

Mike looks at me somewhat aloof, but does not click anymore. He plays the electronic keyboard while he waits, amusing himself. Suddenly, he glances at me and taps his chin. This movement is sign language for "good."

"Yes, Mike. You are doing good," I reassure him, tapping my own chin. Hearing my praise, he returns his attention to the keyboard.

Wendy told me previously that children with autism need much praise. "Show me good," she instructed Mike that day, demonstrating for me.

Mike immediately sat up straight and puffed out his chest. Sucking in some air, he said, "Good."

Wendy smiled looking from Mike to me. Mike's innocence and sincere desire to please his mother was childish, yet wonderful. I smile back. Drawing my mind to the present, I focus on the task at hand. Mike and I stumble through the rest of the question until the end, occasionally getting questions correct.

I do not exactly solve how to connect with Mike, but perhaps that comes with time. Now I understand why Wendy works as Mike's aide. Of all people, she knows best how his mind works and how to relate with him. It would take another aide a long period of time to discover how to help Mike successfully.

Seeing we are finished, Wendy calls me over to her computer. "I want to show you Mike's final project. It is a song by Josh Groban, 'You Raise Me Up'." Excitedly

she opens a Midi protocols file and turns up the volume.

"How did you learn how to use this program?" I ask surprised. Although the other students learn to use Midi in their studies, Mike does not.

"I asked another student to teach me. He was very kind." replies Wendy. The final project required the students to arrange a song by adding different instrumental and vocal levels. Mike recorded himself playing each part— a piano accompaniment, the melody, bass, and drums. He also sang the lyrics. Afterwards, Wendy put the parts together creating the song.

As the song begins playing, Mike walks over to us and listens with a smile. When the vocal part enters, Mike sings along. Wendy laughs as she hushes him because they are in class, but she is delighted at Mike's response. I can see his love for music, how it speaks to him and touches him. Even though Mike may not comprehend the words of the song, he sang it because he loved to. "You raise me up so I can stand on mountains. You raise me up to walk on stormy seas. I am strong when I am own your shoulders. You raise me up to more than I can be."

This song is a Christian worship song yet from Mike's lips the song takes on a different meaning. It is as if he is singing to his mother or to music itself. Both have raised him up, been there ever beside him, and given him the hope to achieve.

Mike's Life Outside of School

Mike's life is devoted to music. His extracurricular activities include attending rehearsals, private lessons, and practicing his instruments. As Mike does not have much

homework from school, he is able to pour his time into the art of music. Wendy states, "music opened the doors of his [Mike's] heart."

Piano Tutoring

Roses line the front lawn of a modest two-story house. Stairs lead to the wide front porch containing a rocking chair and stool. Several short bushes decorate one side of the house while a large tree spreads its branches over the other. Once parked inside the garage, Wendy reminds Mike, "You practice piano with Elizabeth." Mike grunts a reply before dashing into the house. "Make yourself a cup of tea, then I want to show you something," Wendy says to me. I find her in the family lounge standing beside a half-completed bust of a child. Hearing me, she turns. "I work on this when I have time. It is a bust of my friend's child," she explains, "He died recently, so I am making this to give to the mother."

"It looks very good," I encourage her, admiring the detail of the work. The art teacher lets Wendy bring molding clay home to work on this sculpture.

Walking into the room, Mike interrupts our conversation saying, "Practice piano," then leaves to find the piano.

Shortly after, the sound of Mike warming up with various scales and chord progressions fills the house. By the time I sit down next to him, he is ready to practice his pieces. "Do you want to play Bach or Beethoven?" I ask.

"Bach," he replies, promptly beginning the piece.

As he plays I quickly flip through his music folder in search of Bach. All Mike's

music is memorized because he does not read music. Unlike band or orchestra, there is no need to point at the score while he plays. Wendy practices with Mike on his numerous instruments every day. However, because she is not a musician, it is difficult for her to check everything. Furthermore, his piano music is by far the most challenging with the greatest number of notes. This is why Wendy asked me to practice with Mike. As a pianist, I can spot wrong notes and rhythms easily while also working on musical expression, dynamics, and phrasing.

Near the middle of the first page, Mike does not hold a note for the correct value. "Wait, Mike." I call, tapping his shoulder. He stops playing and looks at me. "This 'A' is four beats. You need to hold for four beats." I point a few measures before the 'A' note, "Try again from here."

Mike does not say anything or react. He just stares at the place I point. "Is that a hard place to start?" I ask. "Okay, what about here?" It can be strange starting at an unexpected place in the music. Perhaps he needs to hear where I want him to start. I quickly play a measure. After hearing me, he begins playing, now confident.

At first I was a bit skeptical of Mike not being able to read music since he has so much music to learn. Now I am not so sure. "Good, Mike. That's right," I encourage, pleased that he fixed the rhythm problem. Throughout the lesson, I realize that I cannot point at a specific place in the piece and say, "start here." Even with the letter names written in, Mike will not respond. It sometimes works if I sing a specific place. However, music has sequences, repetition, and variation. For example, one section may start like a previous section, but then lead into new music. These times when I sing,

Mike plays a similar sounding section from a different place in the piece. Eventually, I end up playing the beginning of passages each time so that he can understand. "Good, Mike," I exclaim when he finishes playing the piece. "Over here, play this part louder." I point, then demonstrate. He plays again.

Mike is very responsive and attentive during musical engagement in comparison to his normal responses at lunch or non-music classes. Most of the time he does not answer me while playing with his "toys" or forming shapes with his hands. The times he does reply, it seems more like a learned response (to answer) than a sincere reaction to understanding or hearing what I said.

I am at greater ease tutoring Mike in piano than helping him in electronic music class. One reason may be because the practical side of music uses more simple and straight forward language. "Play 'E' two beats, this part play softer, not G but B, rhythm is wrong…it is like this." There are no issues with comprehension. I am able to correct mistakes, work on musicality, dynamics and other aspects simply through speaking and demonstrating.

Mike learns his music by listening. His mini recorder contains all his piano pieces, which his teacher records during the lessons. Taking it everywhere, the recorder is one of the "toys" he keeps in his pocket. He listens to it constantly. According to Wendy, Mike can "get 80% of the notes" after listening to a piece 8-10 times. The rest is "fine tuning" by the teacher and his mother. "Learning music is easier for Mike than anything else," Wendy shares.

Several weeks later, Wendy notices Mike dropping his wrists while playing so

that there is “no strength in his fingers.” To correct this problem she places a plastic hollow tube across the piano, parallel to the keyboard. Held on both ends by wooden stands, this pole supports his wrists.

By the time I meet Mike again, he had already practiced with the pole for one week. There is a new tension and stiffness in his playing that was not there before. Although Wendy means well, I am not convinced or happy this is the best way. I try playing a passage over the pole and feel tension in my hands and arms. Quickly removing the pole and putting it on the ground, I turn towards Mike. “Mike, this pole makes your arms hurt?” I ask.

“Yes,” he replies.

“Yes?” I question, wanting to make sure.

“No,” he now states.

Huh? I am confused. It is as if he thought, “Yes is not the right answer, so I’ll try no.” I try rephrasing the question, asking it in a different way, “Do your arms hurt from the pole?”

All Mike gives is a string of “yes” and “no,” so I do not know his answer.

Recently Wendy told me further uses for the pole, “Mike’s back is crooked. He slouches when playing piano. I raised the pole to under his chin. Now he cannot slouch. It makes sure his posture is good.” She laughs and acts out how he looks. “But now he plays with his eyes looking down.”

I grimace inwardly, imaging how it must feel. “Wow, Mike let’s you do that. He is so obedient.”

"Yes… but it is not painful," she adds quickly sensing my distress, "The pole serves as a reminder." Wendy kept telling Mike to sit up straight, but he forgot when his mother was not there. She continues, "I needed to invent something to take a supervisor's place. When I am not there, the pole is. When he remembers, the device will fade out."

Wendy thinks of different, creative ways to aid his learning because she loves Mike and wants to help him improve. Her methods may seem a bit extreme to some people, but Mike knows his mother is helping him. That is why he is obedient. Wendy states firmly, "most importantly, he knows I'm helping him."

A Piano Lesson

We arrive at a neat, one-story white house. Mike leads the way through a side gate into the back yard. The piano studio sits at the back of the house. This piano teacher has two children. Her oldest child is Mike's classmate in band at Jackson High School. Her youngest child is visually disabled. Wendy has found a teacher who is willing to teach Mike and is sensitive to his needs. Mike's previous piano teacher told him not to come to lessons anymore because she did not want to teach Mike. She did not know how to teach him and said it was too much trouble. Because the present piano teacher has a special needs child, Wendy believes she is more accepting and has the qualities needed to teach her son—patience, understanding, and love.

A round-faced, woman of medium height with long black hair meets us at the door wearing a white sweater. There is kindness in her eyes, but also determination. She

does not “pamper” Mike, but sets high expectations that are within his abilities. Her piano studio is lovely and spacious. A black, grand piano next to shelves of books fills one side of the room. The other side is a raised platform creating a separate section from the piano area. Wooden floors cover the well lit, peaceful room. Wendy sits at the edge of the raised platform while Mike begins his scales at the piano.

This teacher teaches Mike primarily through playing with him or demonstrating how to play something. If there is a part that she would like to hear more, she will play along with Mike at that section. Other times, she will grab his hand helping him produce the sound she wants. To keep his beat steady, she taps her foot against the floor.

Mike is not feeling well. He has been coughing, sneezing, and blowing his nose for most of the day. Usually alert in music class, today he is tired and falling asleep. “Mike is not playing as well as he usually does. He looks sick and tired. He’s falling asleep,” the teacher tells Wendy with concern.

Wendy quickly rises and walks over to the piano to feel Mike’s forehead. “It must be his allergies,” she says. “Mike,” she continues, “if you are sick then we cannot go swimming tomorrow.” This bothers Mike greatly as he starts whining and making noises in his throat. Trying to stop him, Wendy states, “If you want to swim, then you need to play good.” Was it the possibility of his schedule changing that bothers him? Individuals with autism are strict in their routines because it gives them a sense of stability within their chaotic world. Change is distressing for these individuals.

Mike immediately sits up straight, sucks in some air, and puffs out his chest. “Swim,” he says. He will try extra hard to get through today’s lesson. To keep him

awake, Wendy sits next to him encouraging him verbally and through her body movements. This keeps his energy up and helps him focus.

Wendy is usually the one involved in the musical aspects of Mike's life—practicing with him, taking him to lessons and rehearsals, and serving as his aide at school in band and orchestra. Whenever his mom is there, Mike really works hard. It is almost like he is saying "this is the least I can do for everything my mom does for me." Mike tries his best to please his mother and make her happy. He is very obedient. Wendy says, "He will do whatever I ask him to." After the piano lesson, the teacher records some sections on Mike's recorder for him to listen to. She tells Wendy what things he needs to work on.

Music, Motivation, Memory

Lately Mike is learning a Canadian piece for a music competition in Canada. The competition is specifically for individuals with special needs. The piece is extremely challenging and Wendy recalls, "I was going to give up. The song is driving me crazy. It's too hard." Nevertheless, they did not give up and Mike has almost finished perfecting it. Wendy and Mike will be taking several days off from school to put in extra practice. Wendy has even stopped some of his other private lessons so that Mike can concentrate and spend more time practicing piano. "He does not have to win, but I want Mike to try hard and do the most effort." Mike seems to know this, and according to his mother, "Is practicing like crazy." This trip is a reward and motivation for him as he loves to travel.

Mike's musical memory is extremely good. With amazement Wendy states, "He

remembers every song that he has ever played." She describes his mind as a computer. It is very hard to input data (teach him), but once it is in he will not forget it. One day at Mike's house, his mother played a CD of him performing Debussy's "Arabesque" from three years earlier. Mike walked over when he heard the music.

"Mike, is this you playing?" I asked with a smile on my face, wanting to see if Mike remembered his performance.

"Yes," he replied then went straight to the piano and played along with the CD.

I was highly envious of his talent but also sincerely touched that he wanted to perform for me after understanding my question. This was Mike's way of communicating and interacting with me. He wanted to make me happy.

Music as Common Ground

Mike participates in several music groups made up of individuals with special needs. These groups perform in cafes and restaurants, "really entering the community," as Wendy says. Once in an "open mic" cafe, Mike played the keyboard while two others members played guitar, bass, and sang. The other musicians on site "jumped in" and started playing guitar to accompany them. Wendy shares, "it was very touching," because music served as a medium of connection and interaction. The musicians played music together, no barriers or disability between them. Mike and his friends had fun with other musicians through music. But when the music faded, they did not talk afterwards.

Music is something that is natural for Mike. His mother believes that he has untapped potential in music, very few limitations. In math, he tries very hard to learn and

do his work, but it is a struggle and challenge for him. However, music is easier for him to learn than any other subject. It appears that music is something he can grasp, communicate with, and use to interact with others. It helps him function successfully in society and brings him joy. Music is the core of his life—what he lives for every day.

Making Music Together

From the ceiling of the cafeteria flows a beautiful tent of rainbow crepe paper. Each strand of color ends with a flower then connected to the walls. Folding plastic tables fill the entire cafeteria in no particular order. Metal chairs are neatly stacked along the walls under rows of long windows covered with yellow curtains. Two giant American flags hang on either side of the stage giving it all a sense of patriotism and dignity. Once every week, the band members gather together for rehearsal in the cafeteria of "Whitefield Middle School."

The music begins with a wave of the conductor's arm. Although there are no music scores or stands, each musician plays confidently and passionately. "Do they have their songs all memorized?" I ask Wendy who is standing next to me.

"Yes, they don't learn with music anyway," Wendy explains, "They all learn from ear."

"That's just like Mike," I exclaim with surprise.

Wendy laughs. "They know the songs so intimately, they pick it up quickly. Only one or two kids in band can actually read music."

I watch them play song after song with the chords, lyrics, melody, and rhythms of

the music memorized. Amazing. Mike plays the drum set with a smile on his face. He is fully engaged, fully focused on the music. At the front, Mr. Richards, the band director, keeps the beat by waving his arms up and down dramatically. He does not use a podium, but rather walks around the stage, singing and conducting. Sometimes he gestures the action he wants. When Mr. Richards plays a drum pattern in the air for Mike to copy, Mike catches on quickly. This ensemble is formed of individuals with disabilities. Other members play guitar, keyboard, bass, percussion, and sing. There is little talking in this rehearsal, only music.

Wendy does not aide Mike during rehearsal because there is no music involved. She sits at one of the lunch benches correcting tests for Chinese School. However, her work does not stop her from socializing with other parents and being attentive to Mike's needs. When Mike needs encouragement, she walks near the stage and waves her arms in the air signaling him to play louder. Sometimes she stands next to him to keep his energy up and help focus him.

Mike is quite independent in this band. He is able to learn from the conductor without much help from his mother. This may be because he does not need to read music in order to learn the music. Another reason may be because the conductor does not speak much so there are no issues with comprehension. Mike's rhythm is steady on the drums. His eyes are attentive to the conductor's cues. Mike is in our world. Before practice, he walked around aimlessly and expressionless. Now he looks alert, on task, open, and alive.

The band runs through several songs quickly. Then, Mr. Richards plays a song

over the speakers asking them to listen, not play. Section by section, he teaches the different parts of the first section by vocalizing the guitar strumming, demonstrating the drum rhythms, and helping the keyboardist. The ensemble tries their parts together, then listens to the CD once again. Each time they imitated, practiced again, it would sound closer to the original. One time, when they were listening, the music built up to a climatic point. Mike joined in doing a drum roll ending with a cymbal crash even though he was not supposed to be playing. It was as if the music had moved him so much he had to join in. What came out was so spontaneous and natural. Mike had no problems expressing himself through music.

Disabilities are not heard in this band. Each student musician plays at an advanced level. Because of their keen ear and talent in music, little time is spent practicing each song. There is not much for Mr. Richards to say or correct. The only part he really worked on during rehearsal was teaching the vocalists an accapella part. "They sound very good," states Wendy, excited and proud of this group. The band is amazing unified considering the limited communication and interaction between members during and before rehearsal. Their interaction and communication occurs primarily through music-making.

The parents stay for the entire practice. Many socialize, take pictures, and just enjoy each other's company. They feel comfortable being with people who understand and know their daily challenges. Several parents huddle around a table creating a poster that advertises the band. Other parents dance near the stage as the band plays. This really encourages the musicians playing. Watching their parents, the players smile with

increased confidence as they pour themselves into the music.

After practice, Wendy calls Mikes over so that I can talk with him. "Do you like band?" I ask Mike picking words easy to comprehend.

"Yes," he replies sincerely. Mike looks at me but his eyes are not focused. They seem to be on my face, but not at my eyes. Eye contact is difficult for individuals with autism. It is something they must learn. Even after, they may not communicate with it.

I carry on hoping he will talk more, "It is fun."

"Fun," repeats Mike absent mindedly.

"Tell Elizabeth what instrument you play," Wendy encourages placing her hand on his shoulder.

I wait patiently with a smile. After some seconds, Mike speaks, "Drums." At this time a parent walks over and begins talking with Wendy. Seeing his mother diverted, Mike immediately slumps over and looks down at the table.

"Mike, what other instruments do you play?" I ask. He does not answer, but starts a high-pitched hum. "Mike, do you play piano?" There is no response. I ask him several other questions, but he remains in his own world, not wanting to interact. What can I do to communicate with him? I wonder. Before I can think of an answer, Mike quietly slips away.

Ready, Set, Action

Mike is part of another group called "Theatre Arts Group." This group performs different musical play productions. Wendy enjoys the director because she is positive

and has experience. Due to his level of speech, Mike does not act on stage, but plays music in the pit.

Mike also learns at their adapted college of art which teaches theater arts such as acting and singing. Students can earn a certificate or diploma, but Wendy states that the diploma is not important. She mainly wants Mike to learn. "I don't care about the diploma. I just want to see him learn something."

Open House at Mike's

Every once in a while Wendy invites students and teachers from Jackson High to her home for a social gathering. According to the flier she sends out, the purpose of the event is "to make our community work as a family." In welcoming others into her home she hopes to build closer friendships through interaction with Mike and knowing him better. This event is simply a party with food and games. Today, Wendy leaves school around lunch to prepare the house, giving me the responsibility of aiding Mike in both band and orchestra class. When school ends two hours later, she picks us up and we rush home to welcome our guests.

The house is an amazing entertainment center with Wii, Guitar Hero I & II, Rock Band, Nintendo, Dance Revolution, table tennis, air hockey, and a giant trampoline all set out ready to play. One by one the students enter and make themselves at home plopping down on couches, grabbing crackers and cheese, chatting, laughing, and huddling around games. The atmosphere is light-hearted and fun. As most of the games and activities require a team effort, it promotes social interaction.

This is my first time being surrounded by so many games I have never played before. Deciding to try out Rock Band, I walk into the living room towards a group of instruments near the television. As I pick up the case holding the game, I hear someone ask, "Do you want to play? I'll play with you." Turning around I see one of the students, "Caleb," who often carpools with Wendy. He also eats lunch in the classroom for "emotionally disturbed" students along with Mike and Wendy.

"Sure," I reply with a smile. "Do you know how to set it up? I've never played before."

"That's no problem. I can put it in." Caleb takes the game from my hands and cheerfully proceeds to connect the cables and other wires. In the meantime, I pick up a small plastic guitar with colorful buttons. Buttons instead of strings? I think, unsure of how to play. Caleb finishes setting up and grabs the other guitar lying on the chair. While the guitar seems awkward in my grip, he holds it with great familiarity.

"Can you show me how to play? I don't know what the buttons do." I ask. Quickly he explains what to buttons to press and when to strum in accordance with the cues given on the television. Just before we start our first round, Mike appears and sits at the drum set. Picking up the drum sticks he looks at us expectedly, communicating his desire and awaiting our response.

"Yeah Mike, you can play also," Caleb exclaims, joyous for another member in our "rock band." He changes the settings from two players to three players.

I nod my head, happy at how he is including Mike. "Mike, you like to play drums?" I ask brightly.

"Yes," Mike states immediately in a high, abrupt voice. Mike sits next to me at the drum set with his eyes glued to the television screen hitting almost every cue correctly, while I fumble on the guitar getting the timing wrong. I feel my confidence as a musician spiral downward as I struggle in reading this new language of notation.

"I'll save you." Caleb says so engrossed in the game that he is standing up. Yet despite all his efforts, I still do not complete the round. My head spins from looking at the colorful lines running down the screen. Mike and Caleb both receive high scores. Several rounds later, Mike places the sticks back on the drum set and quickly walks away. Another student takes over the drums and a vocalist joins us.

Soon I excuse myself and get a soda. Walking throughout the house I see people intermingling everywhere. In the dining room, Mike is playing Wii, while other students lounge on the sofas surrounding the television. Some watch him play, one is napping, and others talk.

Dinner arrives with the sound of the door bell. Wendy ordered Chinese food from a nearby restaurant. Within a few minutes, students surround the dining table instead of the various games scattered throughout the house. Everyone… except Mike who is still intently playing Wii. Even when everyone is happily eating their food, he is still there in front of the television. Not wanting Mike to go hungry, I walk over to him. "Mike, do you want food? Are you hungry?" I ask.

He looks at me for a moment before replying, "Yes." Putting the game on pause, he sets his remote controller on his seat and follows me to the kitchen. There is no longer anyone in line. I give a plate to Mike, and then get one for myself. However, he stands

there making no effort to get the food himself. He is used to his mother dishing up his food.

Taking the plate from him, I point to the nearest item and ask, “Do you want this?”

“Yes,” he answers abruptly. We go down the food line, with me asking before scooping food on his plate. He accepts the plate and quickly walks back to the family room, to his game. I sit on the couch next to Mike eating food as Wendy walks back in the house.

“Oh, you got your food,” she says when she sees Mike, more to herself than to him as she does not expect him to respond.

After we finish eating Wendy asks Mike to let others play on the Wii. Though reluctant, he obediently changes to another game—Mario Race Cart. Mike gets controllers for me and another student, places batteries in them, then selects a race route. By the end of the round, I am in last place, while Mike is in first place. How did I get so out of touch with contemporary games? I used to be good. A couple rounds later bored with my ineptitude, Mike gets up off the sofa without a word, and switches back to the first game, the one where he plays by himself.

“He’s switching the game back,” the student says with a tone of resigned acceptance. It seems that he is used to Mike having his way—no point in arguing.

“It’s alright. We can play something else,” I reply, a bit sad that Mike excluded us again, but not surprised. It was as if Mike thought, “I obeyed my mother by letting others play for a time.” We leave Mike and move on to play table tennis.

By the end of the day, I am amazed by what I have seen—by all that Wendy does for her son. Not everyone would be willing to open their home, offer free Chinese food, let students play their games and prepare and clean-up the house. However, she is willing so that others can know more about autism and Mike. This is her mission for advocacy. One student describes Wendy as "the most generous person ever." Her open personality, smiles, kindness, and youthfulness make her a friend to all the students. I leave with wonderful memories, new friends, and a warm plate of Chinese food in my hands.

Wendy's Journey

"Life is like a long tunnel…At the side there are many doors. One cannot open all the doors because there is not enough time. But once you open and go in, you discover something, something you've never learned before." This is Wendy's approach and philosophy in helping Mike. As music is basically the only thing Mike can do well, "easier getting him to do compared with everything else," and enjoys doing, she seeks to build his musical skills so that he can "open more doors." Wendy knows the time and commitment she needs to put in to help Mike achieve this goal. "I have to be involved. I learn also. If you go to a lesson, you must practice. *Someone* has to engage. If no one engages in practicing [with Mike], it is a waste of time taking lessons." Within the practice, there are obstacles and challenges to overcome. She quickly describes weakness in Mike's motor skills and how she helped him conquer them.

When Mike was learning the Chinese Sheng this summer, he could not hold and

play the instrument simultaneously. The Sheng is an instrument with many pipes protruding from a hollow "cup" with holes. One is to hold the cup in the palms of the hands, thus supporting the weight of the instrument. Breathing and blowing is fairly easy. Like the harmonica, one can both blow and breathe through the Sheng. However, as Mike blew into the mouthpiece and tried to cover the holes to make different pitches, the instrument would slip from his hands. Mike's difficulty in playing this instrument was a motor skill weakness, the inability to hold the instrument while playing. As Wendy recalls, "He can do it. It is not a hard instrument. I just need to find a way to glue his hands to the cup." For a week, his mother thought of how to overcome this problem. She took two arthritis elastic bandages, cut holes for the thumb, and stuck two strips of Velcro on the gloves. She also taped Velcro to the sides of the cup. With his Velcro "gloves" and Velcro on the instrument, his hands were "totally stabilized." Mike had no more issues playing.

Many parents are not determined or active enough in analyzing why their child cannot do something and merely give up. But Wendy is not like this. As she states, "I put myself in their position to know their difficulty. I will *demand* that they [special needs children] can do it—make them do it. Most people have not got that far." She takes time to break down the problem, play the instrument herself, figure out what she can do and why Mike cannot do it—analyze. "Don't give up. There has to be something. I set my mind to find a way. Mike's dad is supportive." Wendy can do all this because she does not have to work. Mike is her job. Many parents may not have the time or energy to go to such detailed measures. They may not have the choice to help their child

in the fullest way imaginable. Some may admire this mother for her absolute courage and stubbornness in helping her son. Other may think of this mother as over-zealous and too hard on her son. Nevertheless her efforts have produced amazing results.

With Wendy's innovative strategies of helping Mike improve, she is not blind to Mike's limitations. Two years ago she tried to get Mike to learn the recorder. It was too hard for him at the time, so she set it aside. One of the main problems was Mike's drooling. When he blew all the drool would drip down onto the floor. Another problem was difficulty in covering the holes on the recorder tightly enough to produce a pleasant sound. This summer they picked up the recorder again. To counter the drooling, Wendy tied a sandwich bag to the bottom of the recorder to catch the drool. Now, he can play. For the fingering, where as before she had Mike learn from the "C" (cover all holes) this time she taught him "backwards" by playing the "B" (cover two holes). Music teachers know to teach from "B" downwards because it is easier but Wendy figured it out through trial and error.

Despite all the energy and time involved in helping Mike, Wendy loves it. She likes to learn and spend her time doing something of value. "It feels good when I use my mind. I feel happy when I learn something and sad when there's nothing to do. Life is a learning process. I think more positive."

Mike's Voice

"Autism? I don't think he understands," Wendy replies when I ask if Mike knows he has autism, "for his ability, I don't think it is important. I have no intention to tell

him. His comprehension ability is not there. I don't think he knows what it means."

"What kinds of questions can I ask him? Can he express how he feels?" I ask.

Wendy looks at me with a frown as if in deep thought, "How Mike feels, he does not know how to describe. Those with high functioning autism and good language skills can express that. You discover when you read books (Temple Grandin, etc.)."

I nod my head emphatically, "I've read some of them."

"Their [people with autism] sensory system is another zone of the world. Mike was born thinking everyone is like this. Only later he realized 'all these years, people see different than me.'"

"Do you really know how Mike feels, sees, hears…the functioning of his sensory system? Like how you described in the articles you sent me?"

"No, not really. Everything I described is how I imagined he must feel from what I have read—seeing things like through water or the light blinking although it looks stable to us. But, I know that he is happy with what he has. He knows he is in a safe environment and does not worry too much. He has calmness and happiness."

I smile as I think back on all the time I have associated with Mike. Indeed, her description fit Mike well. He is content and happy with what he has. He works hard to achieve and please others. He very rarely throws tantrums; in fact, I have yet to see one.

In her articles about Mike's early years, Wendy calls Mike the "child of a star," gaining inspiration came from the book, *The Little Prince.* She comments, "He doesn't look like he's from *this* planet. He's from outside…somewhere. Like an alien, he doesn't belong to anybody."

As Mike did not understand the things of this world, he did not care. He was content to be in his world filled with stimulations. His sensitivity to the world around him grew with age and maturity. Slowly, he was able to connect and reach out to others. Wendy states, "Mike's feelings are still limited to his own family because he doesn't grasp what other people are thinking." However, Mike knows that people do care for him and "in return he remembers their names." He still remembers his elementary teacher and classmates' names.

Before, Mike was physically here, but his mind was elsewhere. Now, many strings tie him to our world—seeing his mother, being at school, knowing what to do, playing music—slowly stabilizing him. "Finally he becomes not so alien," remarks Wendy. However, despite being his mother, it is still difficult to understand what goes on within Mike's mind, why he behaves or acts a certain way. "He [Mike] is still a mystery," shares Wendy, "I *imagine* what he is thinking." She continues, "I don't know why the blinking light makes him happy. It must be a memory from his past life, a memory from the other planet."

Teaching Mike

Wendy knows she needs to constantly teach and guide Mike. "If I don't give good guidance, he will cause trouble and not even know it." She gives an example from a book she is currently reading, *Of Mice and Men* by John Steinback. The book speaks of two poor, migrant travelers. One is small, smart, and has a good heart. The other is big and has mental retardation. Like autism, the big traveler is attracted to things that

provide stimulations, interest him. However, often he does not know the social inappropriateness of his actions. One time he touched a girl's hair because it was soft and pretty. The girl got scared and started screaming. Frightened, he covered her mouth to stop the screaming but broke her neck due to his strength. Many times, anything that came into his hands met death. Soon, people wanted to kill him.

Wendy provides another example about the necessity of support and guidance. A friend of Wendy's, "Julie," and her daughter, "Gail," came to visit them. Mike was taking a bath at the time. Gail had a disability but looked and acted fairly normal. Since Wendy was talking with Julie, she asked Gail to check on Mike. In her teen years, Gail was happy to help since she thought she was a "big girl." Sauntering into the bathroom, she found Mike playing with the faucet instead of washing. Wanting to stop him, she turned the faucet to the hottest. In reaction, Mike jumped out of the water placing his feet on the sides of the tube and started screaming. Not knowing what she had done, Gail thought Mike was rebelling against her instructions, being plain difficult. She started yelling, pulling Mike down into the hot water. She would have succeeded if Wendy had not rushed in immediately. "If I was not there, Mike could have burned to death," Wendy shuttered, thinking. "There was a lack of judgment, no logic. That's a scary thing. She [Gail] thought, 'I'm bigger, why aren't you listening.'"

Without proper guidance and instruction, like Gail and the Steinback's story, Mike could possibly harm others, himself, and not even know it.

In answer to my earlier question, Wendy replies, "Questions for Mike can be his schedule, the music he plays, instruments he plays, where he's going…it has to relate to

his life." She stresses the importance of using language that he knows, being very direct, not abstract. But even then, Wendy cannot guarantee that Mike will share his own ideas. "He may say what we taught him," states Wendy, "He may repeat learned answers like in ABA therapy sessions."

Mike sometimes has homework, but Wendy tries to make it easy. She thinks before to earlier years. Homework was a painful experience. "He hated reading," Wendy exclaims, "And I would get mad." She speaks in a shocked, guilty tone, "It was a horrible experience, wasting time." Mike did not understand, could not comprehend. One time when reading a book, Mike finally reacted to the word, "nose." It was because he knew the meaning of nose. "After school, there is about 5 hours to work. If I spend it on reading and writing, there is no time for music," shares his mother. Thus, in middle school, Wendy decided to cut everything down. "I needed to know his limit. He did not understand math calculations so I did not force him. In music, he has no limit."

Curious to know if individuals with autism went through an adolescent phrase I ask, "Did Mike have any teenager problems— rebellion, his own thoughts, thinking he's grown up, etc.?"

"Fortunately, no." Wendy laughs relieved. She turns serious and contemplative, "At his age he is the most kneadable dough. He is mellow, will do whatever you ask him. He is so good and nice to teach, motivated, especially if you give him a goal."

"Mike seems very calm. He doesn't scream or throw tantrums. Was he always like this?"

"Oh no, he used to cry and scream. Fear and the unknown will make him cry.

We took him to Disneyland and he was scared to death. Every ride is an unknown."

If Mike is able to predict, he can accept. Wendy found out that he was more willing to accept rides that were outside in the sun. As Mike saw the whole ride, he could memorize the ride and was able to predict what would happen next. In the darkness, there was fear because he could not see what came next.

Some children with autism are rigid because it helps them feel safe, allows them to predict. Change is "tough," triggering tantrums. As long as Wendy tells Mike of changes, he does not get upset. Once she told him that there was no piano lesson today. Mike simple replied, "Piano lesson next week."

Wendy believes in training for varied experiences. "If a child is stuck in a routine, it is harder to break." When she took Mike for walks, they always turned right at the corner of the street. One day, Mike naturally turned right out of habit. That day they turned left.

Wendy also trains Mike for emergency situation by playing "what if" scenarios. For example, if he is lost, he knows to "stay here." Mike has great patience and is able to stay in place for three hours playing his "toys." As Wendy states, "there are a lot of things to think ahead." Mike is more independent through his parent's training. Every morning, Mike can now make his own breakfast "in a messy way." Mike always has a bagel with a cup of milk. He knows how to toast it, spread cream cheese, put the halves together, and cut the bagel in two. He is also learning to blow dry his hair to the side, rather than combing his hair to the front.

Impressions and Perceptions of Others

One challenge these parents and those on the spectrum live with daily is the misconceptions and judgment of others. "How do you deal with the perceptions of others?" I ask.

Wendy cocks her head to the side, thinking before answering, "Fortunately, we are in this country. Americans are more open. Back in Taiwan well…if they are polite they don't know how to interact with you. Rude people think you are crazy! People look at me with a different perspective, mindset, but I ignore them. You need to stand up for yourself, step out, and teach them." She continues, "It would be different at school in Taiwan. Here is a more positive environment. People know and have sympathy for physical disabilities, like Down Syndrome, but don't know about autism. If they have sympathy for autism, they don't know how to act."

Ever since first grade, Wendy has requested each year to speak with the students in Mike's classes about autism. She shares what Mike can and cannot do. Showing a DVD of Mike's life, Wendy attempts to bridge the gap between them—"He's just like us: runs, laughs, plays…he just can't talk." Gradually students are able to see beyond the disability to the person beneath, one who has feelings and fears like them. In addition, Wendy seeks to describe Mike's world, one governed by his unique sensory system. By providing examples, this mother helps these students understand, empathize.

Sitting up straight, Wendy gestures her hands while giving an example, "What he sees is like a camera zoomed in. He sees the spot on your clothes because it is soft, but does not relate it to your body. Or he may only see your nose. He's not being mean or

teasing you by touching your nose, but it attracted his attention." On walks with his parents as a little child, Mike would sometimes sit in the laps of people resting on the sidewalk. With his "zoomed in" vision, he did not see that the lap was connected to a person. He only saw the lap.

Wendy's approach to advocacy is "teaching his friends and environment to know him." This is a reason why the students in Mike's classes are accepting of Mike and his condition. They do not necessarily interact with Mike, but they are not scared of him. I often smile at the way students look at Mike from a distance, an expression of amazement and wonder on their faces.

Personal Issues

Wendy comments on the struggles of serving as Mike's aide, mother, and creating time to do her own work. "At home, even if he is not doing something, he is in front of me…around. Mentally, I cannot rest." Her friends, especially those who are Caucasian, always advise her to take time off, have time for herself. However, she is not content just setting Mike aside to pursue her own pleasures.

"How can I?" Wendy speaks frustrated. "There is no time. I *need* to teach him. His life will be blank for that night, and so will mine."

Mike's father was not greatly involved in Mike's life at the beginning. As Wendy states, "Usually, I have to teach Mike everything. I even go to IEP meetings by myself. My husband thought it was my job."

However, recently Dan started stepping in, taking his share of the load. Having

learned electric guitar in college, Mike's father plays music with Mike every weekend. "This relieves me," Wendy shares, "Now I can do other things, knowing that they are doing something." When Wendy knows that Mike is doing something productive with someone, she is happy. She currently uses her free time to take classes at a community college.

One of Wendy's more recent challenges is having time to complete her master's thesis. As she serves as Mike's aide at school, engages in his practicing, lessons, and rehearsals after school, there is very little time to stay at home, sit down, and write. Wendy can request leave and ask for a substitute aide for Mike, but knows this could have a drastic impact on her son's learning. "If I file leave of absence, they may find a different aide every day. It is hard to find a long-term substitute. He [Mike] will be lost."

Wendy has already extended the due date of her thesis, which was originally last year. A couple weeks ago, she received an email from her teacher asking about her progress. "I almost gave up. Nothing is done," says Wendy raising her hands anxiously, "I have to figure out my priority. Mike is my priority."

"Of course, right now building him, teaching him is most important," I reply knowing her struggle. Could there be no other way? I wonder.

"Yes, I value the learning process more than the master's degree." I get the feeling she is speaking more to herself than me. Looking back at me she smiles, "At my age, a degree is not going to change anything. I must focus on his future."

Wendy's Message to Mike

I take a deep breath before asking my next question, "If Mike had no problem understanding you, what would you like to tell him?" The atmosphere changes as a tender expression comes to Wendy's face.

"Tell Mike I love him. He is doing such a wonderful job really trying so hard to please me…his family. That's not really a 100% good thing, pleasing me, but in the meantime he also gained a lot—his ability, musical sense, enjoys music. He's got lots of things inside. I am really proud of him…I think he's the best I've got." Wendy quickly finishes before breaking into tears, laughing instead.

I laugh along with her at her last statement. To hear that a child with autism is the best she has got is something I thought I would never hear. I was expecting to hear struggles, complaints, hardships, but she saw him as a blessing, a treasure, something to be proud of. I am swept away by her words.

Mike's Future

After high school, Wendy plans on enrolling Mike in post secondary school, another school system that is more oriented toward life skills. Mike will still continue studying music by taking several college courses until the age of 22 years. Afterwards, she would like him to go to the Adult Day programs run by the "Special Needs Community Group." In fact, Wendy is thinking of creating a day program focused on music.

"They can learn to make instruments, learn to fix and clean instruments, practice

together… it will help them get work." Her eyes shine as she continues sharing her new dream. "We can even make a company that collects old instruments to make them useful again…anything with music." All things start with the tiny seed of a dream. I do not doubt Wendy's ability to make it happen. "If we have a group, we can also go and perform," she continues.

"Yes, Mike is already doing that. His future looks bright, surrounded by music." I smile encouragingly. "Will Mike ever be able to live by himself?" I ask.

"No, not by himself," Wendy says shaking her head. "He will live with me or in a group home, supported living. The facility and supervisor will make sure he lives safe and hopefully happy. During the day, he will go the day program, then come home. The caretaker will take them shopping to train their life skills." She pauses in amusement, "Their day goes not bad."

I laugh. "Yes, they have no stress. How nice."

"They are the lucky ones…" Wendy laughs with me.

Epilogue

From a "child of a star," Mike now lives in our world. He is content here. His mother interprets his early childhood behaviors as "trying to return back. Floating— not grounded." Through the efforts and persistence of family, teachers, and friends, Mike recognizes all he would need to leave behind. So, he does not go. He attempts to live here. Music allows him to live amongst us. Mike is 19 years old this year. He will be

graduating from high school next year. What lies ahead is a future bright with hope, as long as music is in his life.

Chapter 5: Ryan

Our First Meeting

As I walk towards the front door, a little face peers curiously through the curtain. Ryan is waiting for me. Today I meet him for the first time. Rachel, Ryan's mother asked me to babysit Ryan while she works on an assignment for her doctorate degree. This is a great opportunity to interact with Ryan. When I draw near, two small dogs meet me at the door, snarling and barking viciously. I freeze when they start jumping on the screen door unsure of what to do.

"Shoo, go away!" Ryan yells running over and pulling the dogs aside. "That's not nice. Bad dogs!" He spanks the dogs simultaneously pushing them towards the back door. As the dogs sulk away, he quickly opens the screen door welcoming me inside.

"Hi Elizabeth," he says. He knows my name? I think, surprised. Looking at the five year old boy standing in front of me, I see no signs of autism in his bright blue eyes, blond hair, and friendly personality. Although autism is a neurological disorder rather than a physical disability, with Mike I recognized the disability through his dull eyes, distant expression, and aloof behavior. On the other hand, Ryan looks and acts like a typical child. He had protected me from the dogs, a very kind and socially appropriate deed. There is no fear in his stance, only sincerity and an expectant look as he waits to be my friend.

"Hi Ryan," I respond cheerfully, "Nice to meet you."

A young woman wearing blue jeans and a light pink top walks into the living

room at this moment. She greets me with a smile; her curly blondish-brown hair frames her friendly face. This is Rachel, Ryan's mother. "I told Ryan you were coming to play. He's been so excited," she says.

"Elizabeth, do you want to play trains?" A small voice interrupts her. Ryan is kneeling on the ground beside a large oval-shaped railroad track looking at me with big eyes, waiting for my answer. There are several trains on the tracks, and more in the box beside to him. Various bridges, trees, signs, and toy people decorate the train route.

"Sure. I'll play trains with you," I answer with a bright tone. His question catches me by surprise. I thought he would be in his own world unaware of my presence, more like Mike, yet here he is asking me to play with him, seeking social interaction. Rachel nods her head, happy at Ryan's behavior and my response.

"I'll leave you two to play," she says before quickly walking back to her room.

I kneel down on the ground opposite of Ryan, placing the train tracks between us. As we drive trains around the tracks Ryan occasionally cries out a phrase I do not understand. I discover weeks later that the phrase came from the movie *Polar Express*. Ryan was demonstrating echolalia, the repetition of other's speech, by copying a line spoken by the conductor of the train. Echolalia can be spoken with the same inflection and intonation of the original speaker. While watching the movie, I noticed immediately, because Ryan's imitation was so similar.

Getting slightly bored by our continuous repetition around the tracks, I decide to try something new. Curious to see Ryan's reaction, I purposely drive my train backwards. "You're going to crash. Stop! You're going the wrong way," Ryan cries in

a realistic tone, as if we are driving in real life instead of playing toys.

"You're right. Oh, no! What should I do?" I ask with a worried voice.

"Go forward. To Herbie."

Following his instructions, I drive my train forward until I reach a toy car parked next to the tracks. Herbie, a car from the movie, *The Love Bug*, is one of Ryan's obsessions. He loves Herbie. Like the "toys" Mike keeps in his pocket, Ryan plays with Herbie all the time, and due to his speech ability, likes telling people about Herbie. Children with autism often have restricted, narrow interests and a tendency to prefer objects over people. Additionally, they may play with a specific part of an object rather than the comprehensive whole. Both Rachel and Wendy noticed their son's unusual play such as spinning the wheels of a bicycle instead of riding on it— fixating on the wheels rather than the whole bicycle— or flipping light switches on and off. The attachments these children form with objects over people is evident in their long period of plays without seeking interaction with actual people. Seeing Herbie, Ryan switches over to playing cars instead. We drive a big Herbie and small Herbie around the train tracks for a while, then move on to play with toy airplanes.

Deciding to use the table outside as the airport Ryan traces the perimeter of the square table with his airplane before blasting off, using one side as a runway. I follow closely behind with a small airplane in hand. We play like this for a long time. Ryan does not seem to get bored. With intense concentration Ryan has his head at plane level with one eye closed and the other in a squint. He slowly leads his plane around the airport before taking off with it in his left hand. Still making blast off noises he transfers

the plane to his right hand, continuing the flight path, his eyes following the plane the whole time. It seems like he is in his own world, but perhaps this is no different than any boy his age.

Tracing the perimeter of the table, a sharp pain shoots up my leg. A small rock is stuck to the bottom of my foot. Quickly brushing the rock off, I am surprised to hear Ryan ask, "Did you cut your foot?"

Huh? I stare at him a couple moments, stunned, before replying. "No, it was just a small rock." He returns back to playing. Ryan's level of socially appropriate, interactive behavior is above what I expected. This may be because I spent a large amount of time observing Mike beforehand. Not only is Ryan interactive and communicative, his awareness of social rules/etiquette is good. I am touched by his concern in asking if I am hurt. Although Ryan gives the appearance of being engrossed in his airplane, he is aware of what is happening around him, what I am doing. Noticing him closely, I find him watching out of the corner of his eyes at me, ever so discreetly. This is how he knows what is happening. Some researchers note that individuals with autism use peripheral vision, looking at people and objects out of the corners of their eyes, to possibly lessen visual stimuli which can be overwhelming. We play a little more, Ryan laughing and smiling as I make blast off sounds. We fly all around the yard then into the house.

Next we play with a spray bottle. Grabbing a bottle from the kitchen counter, Ryan fills it with water and begins spraying me. I run out into the yard as he chases me. A little while later he hands me the bottle and runs off. It is my turn to chase him.

Screaming and laughing, he darts in and out of the house loving this game. I am however, getting breathless from all the running. Stopping by the "airport table" I put the bottle on top and rest.

"Let's wash your hair," Ryan walks over speaking in a robotic voice. Is this another echolalia phrase? I wonder. "Let's wash your hair," he repeats. By now Ryan is kneeling on a chair next to me aiming the spray bottle at my head.

"No, Ryan. My hair isn't dirty," I explain trying to keep him from getting my hair wet. My pants are already soaked. I cover my hair with my hands.

"Let's wash your hair," Ryan begins pulling at my hands.

"Let's wash my feet. You can wash my feet…and my hands!" I suggest eager to divert his plan. My feet and hands are dirty anyway.

"Okay," he agrees climbing off the chair. Ryan bends over and squirts water on my feet. When he is satisfied with washing my feet, he sprays his own feet. After spraying our hands, we go around the yard, spraying all the plants.

Back in the house Ryan opens the faucet and washes his hands with soap. I also wet my hands, squeeze some liquid soap, and scrub them together before rinsing them.

"Wash your hands," Ryan squeezes soap onto my hands.

"Thank you, Ryan." Perhaps he does not know I had washed already or maybe he is being kind and offering more soap. I do not know, but wash my hands again. Just as I finish rinsing my hands he pours my soap into my hands.

"Let's wash your hands," he repeats unaware that we are stuck in a cycle, washing our hands over and over— perseveration. Perseveration is the repetition of activities for

long periods of time. In addition to having restricted interests, individuals with autism demonstrate little variability in their behavior. A child may line up objects in rows or perseverate on his favorite topic for an extended period of time if uninterrupted. Ryan is beginning to perseverate by repeating this hand washing activity again and again. While appearing more normal than Mike in verbal communication and social interaction, Ryan still exhibits extreme autistic behavior in his self-stimulations and odd ways of playing. I wash my hands over and over again hoping he will stop. The bubbles in the sink begin to rise as the water gets higher and higher. I need to quickly find a way to end this.

"I'm done with washing my hands. Let's go play with Herbie," I suggest hoping to distract him. This works and a little later we sit on the living room floor. Suddenly without warning, Ryan hits me on my leg. "Ouch!" I react instinctively.

"Are you going to cry?" Ryan looks at me as if testing, seeing if big people cry. It does not hurt, but nevertheless I start sniffling, pretending to cry. Surprise fills his eyes now huge and round.

"Ryan, can you come here please?" Rachel calls from her room. Ryan knows that his mother is going to scold him and does not go. "Did you hit Elizabeth?" she asks. He starts whining and squirming on the floor, as Rachel walks toward us. "Did he hit you?" she asks me. I nod wanting to tell the truth but also not wishing him to get in trouble. I stern looks comes over Rachel's face as she turns towards him. "Ryan, you know you're not supposed to hit. You need to go to your room," Rachel delivers the consequences firmly.

"No! No, I don't want to go," Ryan whines. He begins rolling on the floor,

crying.

"It looks like you need help." Hauling Ryan up from the ground his mother half drags him to his room, Ryan wiggling and fighting the whole time, not walking properly. Rachel puts him in his room and shuts the door. From within I hear wailing and screaming.

"Excuse him. He just needs some time alone," Rachel informs me apologetically.

Afraid he might get self-injurious, I plead on his behalf, "He just got excited. He didn't do it on purpose."

"He gets in trouble at school for hitting. He needs to learn not to," Rachel firmly states. "Sorry for this. Just give him a few minutes." She walks back to her room, right across from Ryan's. As she passes by, he opens his door and stands at the doorway silently. "Go back into your room. It's not time yet. Close the door," Rachel reminds. He remains standing there. "Okay that's three minutes now." Rachel responds, increasing the length of his time-out period.

"No…" Ryan wails clearly distressed.

"Then go back into your room." Rachel is in no mood for nonsense. He goes back in for another ten seconds before opening the door again. This time, he walks towards his mother's door. "I didn't say you could come out." His time grows to five minutes. Walking back to his room, he stands at the door facing his mom. From his place, he can see his mom working at the table. When he quiets down Rachel calls him to her room and speaks to him. Speaking in hushed tones, I cannot hear what she is saying, but suddenly I hear Rachel say, "You do not push my face." Ryan does not like

the lecture his is receiving. A little while later, Ryan sits down across from me. Wiping his tears away he asks me nicely if I want to play cars with him. I agree and we play with no future problems.

Since Ryan is six years old and high-functioning, it is often challenging to differentiate if his actions are autistic or that of a child. Children at his age also misbehave and throw tantrums, have their obsessions, and play in strange ways. In the time-out scene earlier, I do not know if Ryan demonstrated typical autistic behavior in not wanting to go to his room, pushing his mother's face, and wailing and whining. I only know he understood that he was getting punished.

A little later, Rachel finishes her work and takes me home. "Bye, Elizabeth," Ryan calls cheerfully from the back seat upon arriving at my house.

"That is very kind of you Ryan." I reply warmly, wanting to encourage his good behavior. Next to me, Rachel immediately nods her head, giving him verbal reinforcement. Ryan smiles at the both of us, his eyes shining. Perhaps even more than typical children, children with autism need frequent positive reinforcements. This helps build confidence in their ability, learn what is expected of them, and improve skills such as social interaction, communication, and appropriate behavior. "Bye, Ryan. Bye, Rachel. Thank you!" I walk into my house utterly exhausted.

His Story

Family Background

Rachel, Ryan's mother, holds both a bachelor's and master's degree in Music Education. She is currently studying for a D.M.A. Rachel has worked as a music teacher

for the past fourteen years and currently teaches kindergarten through 8th grade at Roseville Elementary, as well as teaching college level music education courses. She loves spending time with her family and enjoys bike riding.

Ryan's father, Charlie, graduated with a bachelors degree in English. This year, he is entering a master's program in education. Charlie has worked in the hospitality industry and sales for ten years. On the side, he is also a college baseball umpire. He likes to play golf and bike ride, and his favorite NFL team is Pittsburgh Steelers.

Early Years

Ryan was born in the spring, a season of growth and hope, as the first child of his parents. Although he was born six weeks early by a C-section delivery, he was a healthy baby with no physical problems. It was his mother who needed to recover. Rachel had an extremely difficult pregnancy, almost dying in the process. Her left kidney burst, resulting in several radiation treatments. She believes the exposure to radiation may be one of the reasons for Ryan's autism. From the moment Ryan was placed in her arms, Rachel knew something was different, yet could not grasp what it was. Only later would she know what had sparked her instincts.

Ryan was a very unhappy, fussy baby. As Rachel recalls, "He hated being held or put down. It was ridiculous!" Thus, at the time, Ryan was already displaying sensitivity issues. By five months Ryan did not roll over, only at 7 months. He learned to crawl at 12 months and walked by 18 months. In comparison to the normal developing baby, Ryan was delayed in the development of motor skills by a "good six months," Rachel

tells me. Other delays in development included his verbal skills, which at the time were not present.

For Rachel, the biggest characteristic of autism was Ryan's eye contact. He never gave any eye contact "ever." As a baby, whenever his eyes were open, they floated around rather than looking at people. His lack of reaction to people or noises, whether loud or soft, became a source of concern and frustration for his parents. Because he did not react there was "absolutely no communication at all with him," Rachel recounts.

Obsessed with fans, Ryan was quiet when lying under a fan as he watched it spin round and round. Children with autism often display self-stimulatory behaviors and stereotypic behavior. As he gained the motor skills to play toys, Rachel describes that "*Nothing* would ever be used correctly. Ryan liked to spin his toys… everything. At two years old, he could flap his hands, then he started spinning himself." A highly dangerous activity, he showed no signs of pain as he crashed into walls. He would knock into a wall, get up, and do it again. Even today, Ryan will still run into things if he wants attention. His unique sensory system dictated by autism provided a high threshold of pain. He would not feel the pain even though he was sensitive to touch as a baby.

Diagnosis and Early Interventions

Rachel was concerned by Ryan's strange behaviors but did not say anything to the doctors. She thought it was "a crazy first time mother thing." When Ryan turned one year old, Rachel and her husband were required to fill out a developmental chart. This was when they knew something was seriously wrong. All the answers were "no."

Doctors immediately started asking questions—Did he ever do this or this?—which threw them into a spiral of confusion, frustration, and astonishment. Rachel and Charlie had never seen Ryan perform any of the behaviors described by the doctors. For professional help, the doctors sent them to a regional center that provided state funding and help for people with disabilities. Ryan was a year old at this time, rather early to seek state help. At 18 months he was diagnosed with speech and language delays. By two and a half years old it was obvious that Ryan had autism, however doctors did not officially give that label until he was three.

Charlie, Mike's father, was devastated. He could not believe what was happening. His world was falling apart. Rachel felt the same grief as mourning for someone who died. Yet, they were not totally surprised because Ryan displayed problems early on. Rachel was also slightly relieved. It was not her fault that Ryan was like this. She was not a bad parent who did not stimulate him enough or worked too much. Rachel now knew what she was facing. Fueled by a deep sense of urgency, she threw herself into researching. Attempting to learn as much as she could, Rachel "read, read, read, website after website." She was ready to get to work— "What does he need? We have to get it for him *now*."

In attempts to search for a cause, Charlie and Rachel performed genetic tests as well as examining their family tree. Their family had no history of autism. The doctors also reported that there was nothing wrong with their DNA.

When Ryan was 18 months he was placed in applied behavior analysis and speech therapy, intervention programs provided by the regional center. Dedicated to helping

Ryan improve, Rachel and Charlie did all the homework given by the therapists and read continuously. ABA was very difficult and challenging. Ryan hated it. Rachel remembers it as a horrible thing they did; however, it helped manage his behavior. Between the ages of 2-4, Ryan was extremely aggressive and violent. He broke Rachel's nose twice and her front teeth once. She was scared what would happened when he grew up, became bigger and stronger than her. Thankfully, ABA helped set boundaries and rules changing his inappropriate behavior. Rachel and Charlie also learned, began things with Ryan on their own, because interventions were expensive. Rachel shares, "we did things to a higher extent."

Charlie did occupational therapy with Ryan by downloading exercises off the internet, because the regional center would not provide OT sessions. As Rachel was a music teacher and there is "not much music therapy in California," she worked on music with Ryan. Music (singing and piano) was already a significant part of Ryan's life because it seemed to calm him. Autism did not change how she worked with him in music, it simply caused her to increase the intensity of his musical activities. Music was the only thing he reacted to. It was the only time Rachel was able to communicate with Ryan.

Helping Ryan was a challenge because his ability level was not equal in all areas. In addition, like a chameleon, he hid his autism well. Some doctors thought he was a "bratty, little kid." The doctors saw nothing wrong because Ryan could plan ahead. He would try to sneak out of the doctor's office, enjoying the attention when his mother chased him down the halls. Supposedly, children with autism cannot plan ahead. Ryan

however was not really planning ahead. He tried to escape in order to evoke a reaction in his mother which gave him stimulation. The way that Ryan could change his behavior puzzled his parents because "changing all the time" is not an autistic quality. They are still unsure of what causes this.

Ryan is able to mimic people or imitate whatever sound he hears. This is called echolalia. He can mimic an entire movie or song with the same exact inflections and intonation. Rachel thinks that it is because he was taught to do so. For example, ABA is "basically learned responses—mimicking." Music also served to build this skill. The echolalia got to the degree that his parents called him "parrot" for a time. Echolalia was not just for fun, it played an important function in his life. "Echolalia was the only way he communicated," Rachel recalls. Ryan still demonstrates echolalia today. Rachel thinks that this could be a job one day—sound mimicking.

"Everyone has an idea [for helping their kid]," Rachel explains. Now, Ryan does horseback riding and ice skating because he is bigger and able to do it. When he was young there were not lots of things he could do or options to pick from. Ryan took gymnastics to build his core (physical muscles), but the teacher did not cooperate, did not understand his issues. Rachel told me there were not many special education classes, activities Ryan could participate in. The ones she found were for ages six and above, school age. There were not many classes for younger children.

An additional challenge is how Ryan perceives things. "His perspective is always very different than ours when we try things with him," his parents recall. Ryan's idea of doing activities is often different than a typical person. For example instead of playing in

snow or with snow, he is content to lie in it and not do anything. Charlie and Rachel share, “It can be very challenging to do activities with him.

Charlie and Rachel’s lives were turned upside down by the demanding needs of autism. “Everything is dictated by his changing needs,” Rachel tells me. His parents had to change their previous ways of doing things. For example, their house is now kept totally quiet.

Ryan was extremely sensitive to hot foods. Rachel needed to cook then put the food in the refrigerator for one hour before giving anything to Ryan. He has preference foods and has a hard time eating anything else. For example he loves eating chicken nuggets but will not eat plain chicken. Certain foods he wants to buy at the grocery store every time, like pizza. Ryan uses the flavor of sourness as a tool to focus or listen. If he needs to concentrate on doing work, he asks his parents for a sour candy to suck on.

Ryan has extremely sensitive ears. If he hears a loud sound, he will scream louder to block it out. Whenever he goes to the dairy section of a grocery store, he first screams to block out the buzzing sound of the refrigerators. He often screams when his classmates in music class sing loud and out of tune.

Ryan has difficulty recognizing and interpreting facial expressions. His parents will use words to express how they feel. To help him with this, his parents also sing emotion songs to teach him what each feeling is and how to behave. The songs are from a music therapist in New York named Elizabeth Balzano.

Charlie and Rachel are also working on balancing, regulating his sensory input to prevent overstimulation. At home Ryan has a “crash corner” complied of several bean

bags and a mattress. He uses it when his "engine is running too high," when he has too much energy. To release this extra energy he will get "a running start and hurl himself into it [crash corner], 6-8 times." Another tactic used when his engine is too high is to eat food through a straw. In this Occupational Therapy plan, he will, for instance, suck yogurt, which requires a great amount of effort and tires him out. In an effort to help him create an ideal balanced state, his parents often ask him, "How does your engine feel? High? Low? Just right? " This lets them know how he is feeling.

I was interested in how his parents minimized sensory overload or worked around it. They explain, "We can't really minimize the sensory overload— we just try to 'feed his engine' to get it just right." In feeding his engine, they use different tools that match his current state and follow two programs: the Alert program and the Out of Synch Child program. A key in these programs is getting him to recognize how his engine is running and to pair feeling with state of being. His parents use certain language to let him identify how he is feeling and acting so that he can regulate himself to be "just right." An overall goal is to be in the "just right" state as much as possible. When his engine is in that state, they praise him. Feeding, regulating, and balancing Ryan's engine is not an easy task. As his parents explain, "It is very challenging to 'feed his engine' and get it 'just right.'"

Ryan manifested amazing skills sporadically. I do not know if this is a characteristic of autism, but Mike also demonstrated knowledge and skills spontaneously. Ryan was "wacky about puzzles" at the age of three, recalls Rachel. Any puzzle his parent gave him, he could piece together. He could even master puzzles made for ten

year olds. Then all of a sudden the ability disappeared. The puzzles he could do when he was three, he has trouble doing today as a six year old. His parents are not sure why. Ryan also loved saying the alphabet and singing songs forwards and backwards. At first Rachel was confused because she had no idea what he was doing. Then one day it dawned on her, "Oh my gosh! I've got Mozart. He's singing the song backwards!" Then, he stopped. The other day Rachel asked Ryan if he could say the alphabet backwards, but he only got to "X". His mother thinks that perhaps Ryan thought it was funny at the moment, so he did it. She does not truly know because he does not communicate much.

Two years ago, his parents engaged in medical interventions in hopes of defeating autism. Ryan was place on a gluten-free diet with no sugar, no diary, and no protein. He rarely eats meat and fruits (no oranges, some apples) because of slow protein breakdown. Ryan currently takes 18 supplements including vitamin B12 which Rachel believes makes him more responsive and alert. Doctors also found a significant amount of lead and mercury in his blood. Namemda and two other kelatin creams are used to pull the metals out of his body. This is part of the gut medical treatment of Defeat Autism Now.

Ryan's Musical Journey

Ryan has always had music. While in the womb, he and his mother underwent the "music for the unborn program." Ryan's sensory issues made him an "irritating and fussy" baby who cried all the time. The only times he would calm down was when Rachel and Charlie sang to him. Sometimes listening to a CD was enough to pacify him,

but he much preferred a person singing. As a baby, Rachel often took Ryan to her church choir rehearsals. He was amazingly quiet all the way through, content listening to music. However, he screamed all the way home. Ryan would not fall sleep without music. Even today, he still wants three songs sung before sleeping.

Needing a method of communication, Charlie and Rachel began using sign language with Ryan from six months of age. Ryan would show "I want" in sign language followed by pointing to the object he wanted. Then miraculously one day he said his first word and sentence through music by singing "I want a hot dog" to the tune of "I See the Moon," a children's song Rachel often sang to him. Rachel was dumbstruck. Even though he did not like hot dogs, Rachel quickly gave him want he requested. Ryan did not eat it. Rachel thinks that hot dog was probably the only word that popped into his mind at the time. His was three and a half years old. From that point on his parents sought to build this medium of communication. "He needed help to communicate and I know music is a huge communication skill," Rachel told me.

At four and a half, Ryan formed short, two to three word sentences to the delight of his parents. Music served as a key to unlocking the gate to language. Rachel says, "I think singing helped him form thoughts and words in a way that we could understand him." They also noticed his amazing singing voice. Ryan sang in-tune and memorized words quickly if they were put to song.

Not only did music help others understand him, music also provided a way for him to understand the speech of others. Music helped Ryan grasp the meaning of words. He followed directions better when they were sung, complied more easily, and had a

greater attention span. Because Ryan loved music, his parents state that through music, "We turn work into a game."

By five, his parents actively wove music into every part of his life. They connected music with routines, schedules, directions, and learning. "It worked right away," recalls Rachel, "it was a huge leap when we used music functionally." Today, Rachel and Charlie continue singing and engaging music into Ryan's life motivated by the positive changes seen. "When we use music in activities, it all goes much smoother," shares Charlie, "especially if Ryan is an actively participating— singing with, not just listening."

Ryan Goes to School

Ryan started preschool three times a week when he was four years old. Engaged in a good program and supported by a wonderful teacher, half a year later, he began attending school every day. Ryan's teacher was wonderful to Rachel and Charlie—teaching them how to help Ryan, telling them what to do at home, and giving them resources and support.

The following year, the school district surprised Rachel. They wanted Ryan to attend kindergarten in a regular setting with support (aide). The district was aiming for a "least restricted environment" with the idea that they could pull back if needed, put Ryan in special day class if it did not work. "I didn't want it, thought it would be too much for him," Rachel remembers. She considered sending Ryan to special day class instead. She wanted Ryan to "prove himself first," not wipe out two lights, hit a child, and flip a chair

before the school decided to pull him back. Rachel was more cautious.

Ryan did prove himself. When kindergarten came, he sat amongst his typical classmates with his aide by his side. Although Charlie had the time, knowledge, and ability to serve as Ryan's aide, the school district would not allow it. They did not want parents of special needs children involved in special education. Ryan's aide was picked by the school district rather than his parents.

Ryan at School Today

Ryan currently attends "Roseville Elementary School" situated in a quiet, historic town in northern California. He is in kindergarten under full inclusion with his aide, "Hannah." His classes include art, music, physical education, computers, and the kindergarten classroom.

Rachel and I enter one of the three kindergarten classrooms quietly. It is not yet recess so the students are learning. The environment is orderly and comforting. A sit down area sectioned off by bookshelves and a sink is situated in the middle of the room. Self-portraits drawn by the students themselves hang from the walls, and a row of windows at the back lets in much sunshine lighting the room cheerfully. Children sit around colorful tables in groups of five, working silently. After introducing me to the classroom teacher and two assistants, Rachel leads me to one table at the far side of the room. I spot Ryan quickly. Wearing a black sweater, he is busy circling letters on a page with a bright orange marker. He looks peaceful sitting there, seeming no different than the other students at his table. The woman sitting next to him glances up as we approach

the table. This is his aide, Hannah. Middle aged, tall and athletic with short dark hair and glasses, there is a kind and knowledgeable manner about her. After the introductions, Rachel speaks with Hannah. It is important that parents actively communicate with their child's teachers and aide. Through this collaboration, the teacher and aide can structure a way of teaching suitable for the child's specific needs. For example, if a child works better with transitions, parents should share with the aide what transition methods they use—songs, visuals, transitional object, etc. While Rachel and Hannah talk, I observe Ryan.

In short bursts of energy, Ryan erratically presses the tip of the marker heavily against the bottom of his page as if venting or smashing bugs. Hannah patiently redirects him to the task at hand by touching his shoulder to focus him. She places her finger at the first line on the page encouraging him to circle all the "A"s. Ryan circles for a time before going back to dotting his page. Each time, Hannah helps draw his attention back to our world. Not only does Hannah help Ryan, she also encourages and cares for the other students at her table. Glancing around the room, I spot Rachel standing near the windows, at a distance, watching Ryan with love, concern, and a mixture of other emotions on her face. Perhaps the questions and feelings about autism never do go away, even after long accepting the condition. She appears saddened by his outbursts of dot making. Interestingly, the other students at his table are undisturbed by his behavior. They remain focused on finishing the same assignment. I am amazed by how his classmates are comfortable with Ryan's display of autism. We leave the classroom as quickly and quietly as coming in.

Music Class

Rachel and I stand outside near the cafeteria waiting for her next class to arrive. The teachers exchange classes this way, a teacher dropping off his/her class to a fellow teacher waiting to pick up the class. A voice catches my attention.

"Hi Elizabeth." Ryan breaks away from his class running towards me. He gives me a hug.

"Hi Ryan. How are you?" I am surprised by his display of affection.

"I missed you," he says sincerely.

"I missed you too." I glance up to see Hannah walking over, smiling. She had heard his statement.

"That is so kind of you, Ryan. I'm proud of you," Hannah tells him reinforcing his good behavior.

"Yes, Ryan. It was nice of you," I add, giving encouragement.

He looks between Hannah and me with a smile. His eyes shine, liking the praise. "This is my friend, Kate," Ryan continues, introducing me to a girl standing next to him. A sweet-looking girl with dark hair, brown eyes, and a shy smile waves her hand. She is wearing a light blue dress and sneakers.

"Hi Kate. It's nice to meet you," I say warmly.

He puts his hand on her arm and points at me. "Kate, this is Elizabeth."

"Hi Elizabeth," she says softly, dipping her head, then Ryan and Kate run off to join the other children.

At times Ryan amazes me. He had demonstrated social interaction by greeting

me, expressed emotions in saying “I missed you,” practiced social awareness by acknowledging Kate’s presence, and social etiquette by making introductions. All of the above are challenging for individuals with autism because they are often in their own world or have limited speech ability. Additionally, social etiquette and customs are things individuals with autism do not learn on their own as it is usually learned through acculturation. Greeting someone, expressing emotions, making introductions, and an awareness of others are all things that Ryan’s parents taught him.

In the classroom, a row of blue chairs are arranged in one long line facing the front. “Sit on the chairs— boy, girl, boy, girl. Josh, you can be the end of the line,” Rachel instructs. As the students settle in the prescribed order, several girls walk in late. “Girls, over there,” she points to the end.

As the girls sit down, Ryan jumps out of his chair yelling, “Josh is the end of the line.” Running over, he grabs the chair of the last girl and begins dragging it away with the girl still sitting on top.

“Ryan!” Rachel and Hannah get to him at the same time. “You do not do that,” his mother lectures.

“Come, let’s go back to your seat.” Hannah leads Ryan back, softly speaking to him. He listens quietly.

“I’m sorry about that. Are you okay?” Rachel asks the girl.

The girl nods her head, “Yes.”

Ryan can be extremely strict in routines or set patterns. Since the world is a chaotic place, an insistence upon sameness, order, and structure are necessities amongst

individuals with autism. If a teacher decides to change the class routine for the day, be sure to warn the student with autism. When his mother said Josh was the end of the line, he set it in stone and reacted when someone did differently.

The students will play musical chairs today, but first Rachel reviews some songs. Ryan is usually the music stopper, when playing musical chairs, operating the ipod.

As the students starts singing, Ryan runs over the ipod. "Stop singing, freeze!" He yells. He thought they had already started playing musical chairs.

"It's not time yet." Rachel reminds him gently.

Hannah sits behind Ryan helping him focus. She is an excellent aide. Serving more than Ryan's aide, she assists the classroom teacher in managing the other students. She is an extra adult, helping students focus and making sure they obey instructions and behave properly.

In music class, I often sit at the back of the room near the door, at a distance, so I do not distract the students.

One time, a boy turned around and saw me. "What are you doing here? Get out!" he said rudely. I gasped shocked, speechless at his behavior. The other students also turned and looked at me awaiting my response.

Before I could reply, Hannah jumped in and scolded him, "That is not a nice thing to say. We do not say those kinds of things. Turn around."

It is time for musical chairs. Hannah helps rearrange the chairs in two rows back to back while Ryan picks a song to play. He chooses "Dancing Queen" by ABBA, one of his favorites. As the music begins Ryan is excited and content. He does not mind not

playing musical chairs with the students; he enjoys operating the music. A smile fills his face as he watches his classmates circle the chairs and quickly sit when the music stops. At times he is so caught in the music that Rachel needs to remind him to press "stop." Hannah dances along to the music, engaged and happy as the children play. She removes the extra chair with each round making Rachel's life easier.

As Rachel and I walk back to her room after dropping the class at their next lesson, I ask curiously, "Why does Ryan not play musical chairs with his classmates?"

"He might be over stimulated and hurt others or himself," she replies, "He likes playing the music though. He functions better when he has a job in the music classroom, like being the music stopper."

"Yes, he was happy just watching them play. I could see he liked controlling the music."

"I noticed him waiting for the end of phrases to press 'stop' or in the middle of cadences like V-I," she comments thoughtfully, "He would 'stop' on the V then laugh a bit."

"That's interesting," I ponder. Stopping in the middle of cadences is unpredictable, funny, and suspenseful.

"I don't know if he understands," continues Rachel.

I shrug my shoulders. Does this support a natural sensitivity to music? I wonder.

Rachel smiles. "His interest in electronic equipment has grown over this year. He likes to play music on the ipod." Interestingly, Mike also loves electronic objects.

The “toys” in his pocket are primarily electronics devices with numbers—calculator, digital recorder, pedometer, and watch.

Opera Rehearsal

Ryan sits on the choral risers amongst the entire kindergarten class. The kindergarteners will be performing a cute opera about the three little pigs. Today is their last rehearsal, a run through of the whole opera including prop usage. Hannah stands next to him smiling at the large mass of children, but alert to Ryan’s needs. In various places around the room the classroom teachers talk and laugh. Rachel stands in front of the classroom flipping through the script, organizing her thoughts.

Ryan is friendly and interactive with the students around him, smiling as they play a game of cold fingers, touching their fingers to each other’s necks. He raises his shoulders whenever his neck gets cold and laughs. He knows it is a game. Soon rehearsal starts and he concentrates on singing. Standing on the risers he exhibits no disruptive behaviors. I am surprised by the volume and confidence in his voice. He is leading the other students! He has all the words and pitches perfectly memorized. His strong, confident voice is by far the loudest. Ryan is totally focused and happy, in our world, not his. When the main characters sing, Ryan, who is part of the chorus, sits down. With no musical engagement, he now begins thumping his feet against the risers, moving around a lot, and making loud noises. Hannah reminds him to listen and focus. Sometimes the chorus sings softly beneath the main characters’ solos. During these times, Ryan still sings loud. Rachel secretly smiles as Hannah reminds him to sing softer.

In the medium of music, he is happy, engaged, and full of energy.

"I need a break," Ryan declares. What? Now? I think.

Without a word, Hannah quickly takes Ryan's hand and leads him outside. Before closing the door, she nods at Rachel. The exit is smooth and efficient. Rachel carries on as if nothing happened. Ryan must have felt over-stimulated by all the people and activity in the room. It was his way of saying, "Sensory overload! Get me out of here." I am certain a tantrum would have followed if Hannah had not acted right away. It was a great communication on Ryan's part, sharing how he feels and thus preventing an unpleasant scene.

As class ends, Rachel informs me that she did not spend any extra time outside of school with Ryan on the opera. He had learned everything in class. Amazed herself, Rachel shakes her head, "He has all the words and songs memorized. Many students have not got to that point yet."

I grin. "I can't believe it. It was wonderful watching him lead the other students."

"Yes, he's improved a lot this year. He is a great help in music class. He's had a super star week." Each week Ryan receives a number of stars in accordance with his behavior. Super star is seven stars—excellent— the most he can receive. When he reaches a certain amount of stars, Rachel rewards him with a present.

Halloween Music Class

It is a rainy day as the students file into music class. Their shoes squeak against the floor and on the choral risers where they sit. Along with the other students, Ryan

rubs his shoes against the bench smiling. The sound makes me cringe, but interestingly does not bother him. Perhaps it is because he is having fun.

Rachel finishes placing several percussion instruments (shakers, xylophone, flexitone instrument, wood slap, and others) on the carpet in a row, then teaches the children a song about a women that lived near the cemetery. In the middle of the song, without warning, Ryan dashes up to the flexitone instrument, grabs it, and shakes. A strange sound fills the air. "Go back to your seat. I did not give permission to touch the instruments," Rachel orders.

A little later, Ryan tries again. This time he waits until his mother's back is turned, then tip-toes up to the instrument, grabs it, and runs back to his seat. He knows he is disobeying, or maybe he is simply seeking stimulation, a reaction from his mother like at the doctor's office when he was younger. Gleefully Ryan hugs the instrument, stomping his foot up and down with excitement.

"I know you want to play the flexitone, but it's not time yet." Rachel firmly pries the instrument from his hands and places it back in place.

After learning the song, it is time to add the instruments. Hands fly in the air as Rachel picks children to play on an instrument of their choice. One small girl chooses to play the flexitone. As she settles in place, Ryan suddenly runs up hurling his rainbow stuffed frog. The frog is large, about the size of Ryan's upper body, and quite heavy, filled with beans. Hitting its target, the girl falls back with the force of the blow. I am surprised because I have yet to see Ryan violent against his classmates. Usually he just screams and whines, but Hannah is not here today. It is hard for Rachel to both teach the

class and help Ryan. Today when he did not get his way, he acted out.

Rachel does not tolerate this behavior at all. Dragging Ryan by the arm to the side of the room she sits him on a chair facing away from class for a time-out. "Are you alright?" Rachel asks the girl, "I'm sorry."

The class continues. Ryan sits on his chair but turns his body to watch what is happening. When he gets up, Rachel sends him back. After a while, Ryan calms down and is allowed to return.

"He can play. I'll go next," a girl offers.

"No, he needs to learn patience. It is good for him," Rachel replies kindly.

Another round of instrumental playing passes before it is Ryan's turn. He smiles and laughs as he plays. However, when the neighboring thunder drum sounds, he covers his ears yelling, "Too loud. It's loud."

"He is almost done. Yes, it is loud," says Rachel. It seems that she knows Ryan's auditory limit so she does not try to stop the thunder drum. She knows Ryan can take it or she is training him to handle loud noises. The student playing the drum shakes a couple more times before stopping. Ryan does not have a meltdown.

After class, Rachel leads the class to the gym to see pumpkins carved by the student body. The children walk row by row viewing each category. Suddenly, I hear a commotion and turn around just in time to see Ryan push a girl into a table almost knocking over the display. The girl is not hurt, but shocked and scared.

"Are you okay?" Enveloping her in a hug, Rachel pats her back. "Are you hurt?" The girl shakes her head.

"Ryan, say 'sorry' to Jessica. That was not kind."

"Sorry," he mumbles with his head down.

After making sure Jessica is alright, Rachel once again takes Ryan away from the group. He waits by the door while his classmates finish looking at the pumpkins. "What's wrong with you today?" his mother asks him. She rubs his back concerned.

Ryan does not answer.

Several girls walk over. "Is Ryan okay?" they ask.

"I think he's fine," Rachel reassures. Her face brightens, "You know, you can also talk to him when he does wrong things. It's good to also hear from his friends and not only his mom." She walks away to gather the rest of the class. Rachel welcomes peer mentoring, having Ryan's friends teach him when he does wrong. "It works better, hearing it from his peers. It's also more discreet, quiet, and quick, especially in a class situation," shares Rachel.

The girls approach Ryan now standing by himself. "Ryan, next time don't push Jessica."

"She might get hurt," another chimed.

"We should not push people," concludes one.

Ryan looks at them with a troubled expression. Then he nods shyly. Content with his answer, the girls get in the line that is now forming at the door. When all the students are in line, they proceed to their next class. Ryan holds Rachel's hand as they walk down the hallway.

Since Ryan is still young and quite high-functioning, it is at times hard to tell

plain six-year-old behavior and autistic behavior. Typical children also cry, whine, hit people, misbehave when they do not get their way, and throw tantrums. In order to better differentiate between the two, Rachel and Charlie keep in mind the A-B-C paradigm (Antecedent, Behavior, Consequence). For Ryan, tantrums, on a scale of severity, are a "regular occurrence." Since he is quite verbal, his parents are often able to comprehend the source of his tantrums. "He expresses his displeasure by screaming, 'But I don't want to…' or 'I'm not going to…,'" shares his mother. In worst case scenarios, Ryan flops to the floor, kicks, and screams; however, these incidents are not frequent. Sometimes Charlie and Rachel simply do not know what triggers his meltdowns. "He may be tired or hungry, then everything sets him off. We do know what he does not like— bugs, hot foods, foods that fall apart, haircuts, going under water, or if he does not get 'his food' at the grocery store," states Charlie.

Ryan's Life Outside of School

Ryan's parents use extracurricular activities to "keep him [Ryan] socializing, to build his muscles, and exercise," state Rachel. They want to make sure he stays healthy as he grows. Ryan walks his dogs every day and goes bike riding. He often has friends from school come over to his house to play or visa versa. Currently Ryan is not involved in any extracurricular therapies, lessons, or groups.

Camping

It is late afternoon. The sky is overcast, cloudy with light rain. I am in Ryan's car with his family heading for a camping event. Sponsored by one of the parents at school,

the kindergarteners and their parents were invited to camp out at a lovely park nearby. Rachel does not bring sleeping bags, tents, and toiletries because they are not staying overnight. Ryan copes better sleeping at home.

"Want to tell us about your day?" Rachel puts her arm around Ryan.

"Yes."

Rachel waits.

"I had a super star day because I was a good listener and was flexible," Ryan shares sincerely.

Rachel and I both smile. He does not respond to any further questions.

The park is huge. We pass tall trees that seem to touch the sky, small gurgling creeks, numerous hiking trails, and a mother deer with her fawn grazing in the grass. After twenty minutes, we arrive at the camp site with a big, blue tarp set over several long wooden tables for protection against the rain. Charlie, Rachel, and Ryan immediately change into their hiking boots and don jackets. We then join the rest of the group.

The sound of the rain hitting the tarp is quite loud when standing beneath. Appearing more frightened than distressed, Ryan covers his ears but does not scream. After a while, he slowly removes his hands, coping with the noise. Charlie chats with the fathers and helps make dinner while I unpack the food and set up the tables. Rachel helps one family set up a tent, but shortly returns slightly frustrated. On the drive here, Rachel had already told Ryan that they are letting another family borrow their tent overnight. But he did not comprehend sharing his tent with another child or he forgot. Going along

with his mother to set up the tent, he kept asking when he would get it back or saying he wanted to sleep in the tent. Rachel thought of singing the information to help him remember and comprehend, but other parents were around. They would have thought it was weird.

She must sing much at home for these scenarios then, I think. "What melody do you put the words too? Do you make one up?" I ask, curious.

"I usually use the pentatonic scale than the diatonic scale. At his age, the fourth and seventh degrees are a bit tricky," she answers. "Sharing in general is a bit hard for Ryan."

Many of Ryan's friends are here, two of who "tolerate his idiosyncrasies a lot," comments Rachel. Most of the children are nice to him. They do not reject him, but also do not include him, unsure how to interact with him. Pulling on the tarp, the boys send water splashing over the sides onto the ground. They scream and laugh as they get muddy and wet. Ryan stands on the side, not really understanding what they are doing, then starts pushing a chair through the mud like driving a truck. Rachel says Ryan probably thinks he is doing something similar to the boys. Afterwards, Ryan walks back and forth in front of a log by himself. Occasionally he turns towards the log.

"See," Rachel points to Ryan, "it looks like he is having a conversation with the log." She looks sad. Once again, Ryan demonstrates an interest in objects over people, a characteristic of autism, especially in younger children. "He gets upset when I interrupt his flow, when he is doing a cycle in his head (processing something). Maybe that is what he is doing. It's sometime hard to know what he is thinking," shares Rachel.

After a scrumptious dinner of hot dogs, barbequed chicken, fruit, salad, macaroni and cheese, chips, and various beverages, a scavenger hunt follows. Each group is given a list of things to find—pine cones, feather, Y- shaped twig, smooth rock, etc. During the hunt, Ryan starts hugging his fellow classmates from behind. They are all very patient, accepting, and kind about it. None of them try to run away, twist out of his grasp, or be mean. It seems that Rachel's efforts in teaching her students to accept and understand Ryan's condition are not futile. Then, Ryan goes overboard, preventing the children from walking and possibly causing them to stumble.

"That's enough, Ryan," Rachel calls. He hears his mother but continues. She names the consequences, but he does not listen. Firmly taking his hand, Rachel walks beside him. When he calms down, she lets him go. We walk back to camp with no problems.

Although Ryan plays and interacts with others more than Mike, autistic behaviors are still present. He was being friendly with his friends by hugging them, but did not perceive that he was preventing them from walking or perhaps they did not want to be hugged. It appears that contact with another is something *he* decides. As children with autism do not like to be held, Ryan throws a tantrum when someone hugs him without permission. One time when his father picked him up and hugged him, he kicked and screamed to be put down. Maybe Ryan was caught off guard, but he did not connect that his friends might feel the same way.

There is music planned for tonight. Rachel will be leading songs around the campfire accompanied by a father who can play the guitar. However, Ryan begins to get

tired. Noticing this, Rachel asks, “Do you want to sit on my lap?”

Ryan climbs on his mother’s lap. “Mommy, I want to go to the car.” Was this another signal communicating “I need to get out of here before I have a meltdown.”? Ryan has no problem communicating his needs verbally.

“But we haven’t sung the songs yet. Alice’s dad even brought his guitar,” Rachel tries to persuade him. She suggests several songs they could sing now while waiting.

Ryan picks one and starts singing. “I got two dogs…”

“He has done a great job memorizing this song. It is very long, but he knows all the words,” she tells me. During the chorus, Rachel joins in. “He sings this song in the same key all the time.”

Ryan likes singing songs in the same key he first heard them. I think this provides him a sense of stability, something children with autism seek to help them function in our world. Sometimes when Rachel is tired, she unconsciously sings in a different key.

“No,” Ryan will cry, seeming distressed, “It starts like this.” He then sings the starting pitch. Rachel had to change the key of the kindergarten opera after she already started teaching the class. This really upset Ryan until he got use to the new key.

Rachel talks to me while Ryan sings. He suddenly stops. I cannot see the expression on his face. “Oh, I’m sorry. I threw you off, didn’t I?” Rachel waits for him to start again then talks softer. Another time at the chorus she forgot to sing because she was speaking to me. Ryan looked at her, waiting. “Oh, that’s my cue,” replies Rachel. When it is the next chorus, she makes sure to sing along with him. It is still hard for

Ryan to sing along with others because unless the person is singing in-tune, the sound of various pitches upsets him. Autism creates this unique sensitivity issue. Thus, when he wants someone to sing with him, it is rare and special.

We leave early that night because Ryan starts misbehaving due to fatigue. Before leaving, Rachel hands the music over to the guitarist. Ryan is quiet on the ways home as he leans against his mother.

"Making Circles"

Rachel leads me into the kitchen to where Ryan is on the floor playing with his trains. I am babysitting Ryan today because his mother will be running some errands. He does not look up when we enter or acknowledge our presence, but continues driving his plastic train in circles around him, spinning himself in the process. He is the picture of intense concentration with his head tilted and eyes in a squint. He is in his own world where everything spins, from the wheels, to the train, to himself. Over and over again he spins, oblivious to anything around him. Rachel walks over to a nearby table and plays ABBA's "Dancing Queen," one of Ryan's favorite songs, on the ipod. Immediately, Ryan glances up at the sound of music, his trains momentarily forgotten. He looks in our direction but does not see Rachel and me. He is looking for the source of the music. Once he finds it, he returns back to playing. Although Ryan did not react to our presence, he responded to the presence of music. Music momentarily drew him back into our world.

"He loves ABBA," Rachel explains. "I was also able to connect with another

child with autism by playing ABBA."

"It's really interesting." I had never heard of this band before.

A thoughtful expression fills her face. "I wonder if there is something special about this group." Rachel gets ready to leave, and a few minutes later walks out the door.

Ryan does not notice or react to his mother's departure, engaged in weaving his train in circles on the ground.

I sit on the ground, pick up another set of trains, and start leading my train in a wide circle around me, rotating my body 360 degrees. Perhaps if I play the same way he does, I can reach him and interact with him. As my train passes his in our circle making, Ryan does notice my train, glancing at it out of the corner of his eyes. However, he does not look at me, the person driving the train. Although Ryan does not give any degree of eye contact, I am able to "play" with him as we make circles around each other and weave patterns on the floor. We continue nonstop for about thirty minutes. Suddenly he looks at me and says, "Follow me." I follow the path of his train with mine. Stopping his train at the door leading to the back yard he gets up and goes outside. Ryan walks to a blue, small, plastic pool leaning against the side of the house. The big air-blown pool had popped after Ryan threw a chair at it. Now it lay as a table cover on the rectangular plastic table outside. Ryan drags the little round tub several steps towards a hose.

"Do you want to fill it up?" I ask.

"Yes."

Placing the pool on the grass, I hand him the hose and turn on the water. When the pool is full he runs inside the house and back out with three model sports cars in

hand. He puts the cars inside the water, happily watching bubbles rise as the cars fill with water. Sharing his cars, Ryan lets me drive one in the water world. He then stands in the tub swirling his feet in the water, pushing his cars with his feet. Squatting down, Ryan forgets about being inside the pool. The water gradually soaks his pants and shirt as he plays with his cars.

"I'm wet," he cries surprised. Leaping out of the pool he runs into the house screaming, "I'm wet! I'm wet."

Confused I follow him to his room. He stands in the middle of the room distressed. "Let's put on dry clothes," I suggest helping him undress and finding dry clothes in his closet.

"I want Mommy," he begins to whine.

I try comforting him, "Mommy is not home. She will be back later. Let's put on your clothes." I walk towards him with his clothes in my hand.

"No! No, I want my mommy!" Ryan backs away from me unsettled and runs about the room.

He does not seem scared of me. Does he want his mother for reassurance? Getting wet was probably a curve ball, leaving him off balanced. It was unexpected, a shock. Or perhaps it has something to do with sensory issues. I am not sure. However, I do know Ryan is clearly about to have a meltdown as he begins stomping around his room agitated. I rush out of the room and arrive back with my cell phone, "Do you want to call Mommy?"

"No! I want mommy home," Ryan runs to his book case looking ready to throw

something, getting aggressive.

"Okay, you don't need to wear clothes," I compromise. "Let's do something else. Do you want to eat?" Rachel had said that one of their approaches to helping Ryan focus when he had tantrums was redirecting his behavior, his focus to other things.

This seems to work, capturing his attention. Knowing now that I am not forcing him to wear clothes Ryan runs out of his room, throughout the house, into the back yard, before coming to rest on the couch in the living room. I quickly close the front door so that the neighbors or other people will not see a naked child.

"I want to play games," he states pointing to a game connected to the television. Giving him the remote control, I turn on the game, then walk to the kitchen for a cup of water. By the time I am back, Ryan is well into his game, his eyes fixed on the screen. He is no longer is aware of me. Knowing he is content playing by himself I watch television in his parent's room needing time to rest. Occasionally, I check on him, but he remains in the same place happily playing.

Forty minutes later, Ryan walks into his parent's room, climbs on top of the bed, and snuggles beneath the covers. He does not say anything, but watches golf on the television with me. A couple minutes later, he comments, "I'm hungry. Can I have rainbow goldfish?"

Rachel had said before that holding a conversation with Ryan is difficult because his comprehension is still limited. Ryan's communication revolves primarily around basic necessities such as hunger or pain. Indeed, most of the time, I do know how Ryan feels and what he wants. Interestingly, his request this time was so specific that I am

confused. “Okay, I’ll go find some,” I answer. Was there such a thing as rainbow goldfish? I only know of goldfish crackers. In the kitchen I open cupboard after cupboard looking for goldfish to no avail. Goldfish are like crackers. Maybe crackers will do the trick. I grab a box of crackers from off the refrigerator and head back to the room. “Is this is what you want?” I hold out the box for him to see.

“No,” he replies simply then turns back to watching television.

Returning to the kitchen I flip through more cabinets and spot Fruit Loops, rainbow colored cereal. Maybe Ryan got the names wrong, perhaps he wanted Fruit Loops. Back in the room, I wave the box of cereal in the air. “Is this rainbow goldfish?”

He cocks his head looking at box. “Not really…,” he states.

“Do you know where the rainbow goldfish are?”

“No.”

I open the last cabinet in the kitchen without much hope and cannot believe my eyes. There on the middle shelf lies a box of rainbow goldfish with individually wrapped portions. Ryan knew what he was asking for. He did not get the names wrong and could communicate, differentiate when I gave him the wrong thing. I hand him the goldfish relieved, “Here you go.”

Ryan munches on his snack, his eyes on the television screen. How long has it been? He is still intensely concentrated on watching golf. Charlie likes playing golf, so maybe Ryan is use to watching golf. Nevertheless, I find his unusual focus surprising since most children would find golf boring. Ryan happily finishes eating his snack, then gives me the empty bag. Still wearing no clothes, he returns to the living room.

“Elizabeth, can you turn on this game for me?”

“Alright, I’m coming.” The television is already on with the disc inside. Grabbing the remote controller, I attempt to activate the game. Nothing works. Suddenly, a red little box pops on the screen.

“That’s the game. Press it!” he calls from the couch.

“How do I press it? Can you please come show me what to press?” I have no idea what he is talking about. With a sigh Ryan leaps off the couch, runs forward, and jabs his finger at the red box. I still do not know how to start the game.

“Damn you. Damn you!” Ryan begins screaming.

“Who are you mad at?” I am confused and surprised.

“I’m mad at Elizabeth.” Jumping up and down he yells, “Damn you!” Although Ryan has problems recognizing other people’s emotions, he is able to communicate his emotions clearly. I am fairly certain he is using echolalia again. Rachel said that echolalia was one of Ryan’s means of communication when he was younger.

I turn around, speaking firmly, “That is not a nice thing to say. You need to speak nicely or we are not going to play.” This seems to calm him down. “I don’t know how to work this game. I’ll ask your mom to help when she comes back.”

He does not reply. Outside a car door closes. Rushing to the windows I breathe a sigh of relief as Rachel walks towards the house. Meeting her at the door, I apologetically state, “He’s not wearing any clothes.” Rachel nods her head, not at all bothered or surprised. Once inside she quickly helps him get dressed. “Is everything alright?” she asks kindly.

I tell her briefly what we did then share our most recent scene, “He got mad when I didn’t know how to work the game. He said some not so good words.”

“I’m sorry,” she replies sympathetically. Turning towards Ryan she lightly scolds him, “Ryan you know how to work this game. You don’t need Elizabeth to do it for you.”

When Ryan is settled, Rachel rushes out the house again. She is going to pick up Charlie at the airport. As a college baseball referee he is invited to different cities in the U.S. for baseball games. He was gone four days this time. On the kitchen table sits his welcome home present prepared by Rachel and Ryan— a vase of flowers, a card, and a box of chocolates.

A little later, the front door opens. “Daddy’s home,” Charlie exclaims striding towards us. Picking up Ryan in a big hug, he rocks his son back and forth in his arms saying, “Daddy missed you so much.”

Ryan does not show the same affection. He starts squirming, screaming, and kicking to the extent that his father has to put him down. There is a hurt look on Charlie’s face. After not seeing each other for several days, any parent and child should be happy. Not always with a child with autism. I am sad that this father could not receive the display of love he deserved from his child.

As if feeling the same way as me, Rachel calls Ryan over. She kneels down to his level, looks him in the eye, and sternly said, “You need to go and give daddy a hug.”

Ryan obeys, but he does not seem down to earth. Was his mind still processing his environment? His father caught him off guard and perhaps he needed time to adjust.

Ryan does not seem like he knows what was going on.

"Show daddy our present for him," Rachel encourages.

Ryan leads his father over to the table filled with gifts.

"Thank you," Charlie says placing his hand on Ryan's shoulder. Then walks over to Rachel and gives her a kiss.

Rachel is driving me home today. Before we leave she asks Ryan, "Do you want to stay home to help daddy unpack?"

"No, I want to go with you," Ryan says.

Charlie's happy face dissolves into weariness as he hears Ryan's words. He wants to interact and communicate with his son, but Ryan remains distant. With a tired, strained look and a forced smile, Charlie thanks me for staying to watch Ryan.

As I leave I remind myself that these parents need a heart that loves unconditionally—one that does not store up on hurts. While Charlie is affected by Ryan's behavior, he needs to remind himself that Ryan's actions were results of autism and not really personal. I hear a joyful exclamation from the back seat when we reach the end of the street.

"Daddy!"

Next to me, Rachel says with a laugh in her voice, "*Now* you know daddy is home. Do you want to go home and be with Daddy?"

"No" Ryan replies. However, he is no longer confused or uncomfortable.

Play Date

Today, one of Ryan's classmates from school, Carrie, is coming over to his house to play. Rachel calls her the "autism whisperer" as she has a knack for understanding Ryan in a mysterious way. "She [Carrie] is willing to follow his lead and go along with his games and silliness," shares Rachel. With a maturity way beyond her years, Carrie is also a wonderful role model and teacher for Ryan. She provides reason when Ryan is lost in his tantrums and desires. When he is having trouble, she teaches him manners and good behavior. She is a good friend to Ryan, accepting his strange behaviors and tolerating his obsessions.

While we wait for Carrie at school, church bells from across the street start ringing. Ryan runs a few steps closer to the sound then begins swaying his body and waving his arms to and fro.

"Oh, you're conducting the bells," Rachel says.

"Mommy, sing!" requests Ryan.

The bells are playing a church hymn. As Rachel sings, her demeanor changes becoming more childish and stress-free. She joins Ryan's world, making music with him. Ryan smiles as he conducts and his mother sings. I smile along, observing his love of music and natural response to it.

When Carrie arrives we pile our bags into the car and head home. In the car, Rachel plays music therapy songs by Elizabeth Balzano, a music therapist from New York. The CD is a collection of songs about emotions—happy, mad, sad, etc. As Ryan has trouble recognizing facial expressions and understanding emotions, these songs help

teach him how to express emotions properly—what we can do when we are for example, happy. One of the verses states "when I am happy, I can hug my mom." During these songs, Rachel often turns around to see if Ryan has any response.

Does Ryan understand what the therapist is singing? Is he even listening?

"What do you like to do when you're sad?" The therapist asks.

"Eat ice cream," replies Ryan aloud.

Good answer, I think.

"I like to eat ice cream when I'm sad," the therapist shares.

The next verse speaks about eating ice cream. Although Ryan's answer sounded genuine, it was most likely learned from listening to the CD. At least he answered the question. He is listening.

"Ryan, let's sing. We love this song…" encourages Rachel singing, "'it's not so bad, when sad turns to glad.'"

"No."

"Don't you want to sing? You like singing this song."

Ryan remains quiet, content with just listening.

Once at home, Rachel rushes into her room to type up an assignment for her D.M.A. class. Charlie and I stand outside watching Ryan and Carrie ride a toy 4x4 car up and down the sidewalk in front of their house.

"The purpose is to see if Ryan will let Carrie drive the car. Not just let her sit in the driver's seat, but actually drive."

I nod my head. Ryan was practicing sharing his toys.

"Sometimes he will still try and control the car by putting his hand on the wheel or getting out and pushing the car."

I smile imagining the scene he describes as I walk behind the car. "I'll follow them."

"I'll just stand here," Charlie calls from under a tree. "They'll be doing this for quite some time."

He is right. Twenty minutes later, I choose a tree of my liking and rest. Up and down the sidewalk, Ryan drives the car over and over again—perseveration. Angie sits next to Ryan without complaint, happy letting him drive.

Seeing that Ryan had not yet let Carrie drive, Charlie states, "At the end of the street, it's Carrie's turn to drive."

"No…!" wails Ryan. He begins whining and stomping, throwing a tantrum.

"Would you like to drive, Carrie?" Charlie asks.

"I just want Ryan to have a good time," she replies simply.

Charlie nods his head and does not pursue the issue further, as Ryan quickly drives away with Carrie by his side. I am touched by her answer. Although young, Carrie is willing to put Ryan first.

Sometime later, I decide to try something new, to engage myself in their play. As they drive towards me, I stick out my hand. "High five," I call encouragingly. Both Ryan and Carrie slap my hand when they pass by. Ryan really likes this so that eventually it becomes routine. Each time they come around, I stick out my hand for a "high five." In the beginning stages of this new game, Carrie will turn around giving me

a “thumbs up” with a smile while Ryan drives on after the “high five.” Her smile tells me I am doing the right thing, encouraging me. It is as if she is teaching me how to “play” with Ryan.

Ryan soon sets up a “high five” station with his father, about twenty meters away. While Charlie talks on the phone, Ryan puts out his hand for a “high five.” Ryan is not tired of driving or doing “high fives” again and again. Carrie does not complain either. We play like this for over an hour. Then, Ryan drives around the corner back home without a word. Although this may demonstrate autistic behavior, it is possible that a typical child will do the same thing. I am not very surprised as I do not expect Ryan to communicate his plans. Walking back to his house, I notice Charlie following behind still talking on the phone. His nonchalant expression indicates no surprise or anger.

They are in the backyard playing with trucks, airplanes, and trains. Ryan amuses himself by digging in the sand with his truck. He is not really playing with Carrie, but she does not mind. Carrie happily plays with airplanes by herself. However, if she does something incorrect such as putting the airplane wrong in the blast off station, he will jump up and fix it. I am beginning to think that Ryan is actually very aware of his environment, but chooses to react or not react to things. Although Carrie and I are next to him, most of the time he chooses not to respond or acknowledge us. Thus, it is difficult knowing when he is in his own world or appearing to be in his world. This is a manifestation of his chameleon ability— hiding his autism so well at times.

Sitting on a chair several meters away, I try taking some pictures of him as he plays with his truck, but am only able to take side profiles because he never once looks at

me.

"Ryan, can I take a picture of you?" I ask.

He does not respond.

I call him again.

No answer.

Dejected, I unconsciously sing two pitches (sol-mi) quietly. Ryan immediately looks straight at me, pausing in his play as if expecting something, me to sing a song or tell him something. I have his full attention for a couple of seconds. I am so surprised I do not say anything or react fast enough to get the photo. He returns back to playing with his truck.

I did not know what I sang until I analyzed it later. The descending interval of the fifth to the third (interval of a minor third) is one of the first intervals children learn. This interval is found in many children songs and playground taunts around the world. When words could not get into his head and evoke a response, he was attentive when I merely hummed two pitches softly. His sensitivity to music was incredible. The music went straight to his brain.

Beauty and the Beast

A Roseville school tradition, every year the graduating eighth grade class performs an opera. Rachel invited me to join this event with them. Not wanting to be late for dinner, we are one of the first people to arrive at school. Ryan and his friend Carrie run around taking pictures in the inner court yard situated between two long

hallways. Sitting at one of the round tables, I watch them play. Rachel and Charlie talk and intermingle with other parents. Classrooms surround us on each side. To the left, several plastic tables are set in a L-shaped formation, some food already on top—fruit, salad, and bottles of beverages. The main meal, pizza from Costco, is not yet here. Rachel warned me on the drive to school that Ryan loves pizza. It is one of his food obsessions, something that he wants each time they are grocery shopping.

"He can probably eat a whole pizza by himself if we give him one," Rachel says with a laugh. Oh, the kid loves pizza, I think. There's nothing wrong with that. Little did I know.

Glancing towards the sound of scurrying footsteps, I see many mothers carrying boxes of pizza. They head for the tables and minutes later, the food is ready to be served. "Sit at the table and wait. Daddy and I will get food," Rachel instructs Ryan. Soon, we dig in happily to our pizza.

"They are eating all my pizza," Ryan suddenly whines in a distressed tone.

What? What does he mean? I wonder.

"That's *my* pizza," he says a bit louder.

"No, your pizza is here." Rachel points to the three slices of cheese pizza on his plate plus the one in his hand. "When we go out, we often order a kid's size pizza just for him to eat," she explains to me, "He doesn't seem to understand that a big pizza can be divided and eaten by many people. It's something he needs to learn— to share."

I nod my head. Little or big made no difference, Ryan wants to eat the whole pizza. In fact, he wants all the pizzas.

“Get away from the pizza!” Ryan begins screaming across the court yard to the people getting their food. There are over fifteen boxes of pizza stacked at the tables. I am not sure why Ryan has a hard time with sharing. Is it an issue that every child needs to overcome or is it because pizza is one of his food obsessions? I have not read that difficulty with sharing is an autistic quality.

“Ryan, stop. We will go home and miss the opera if you don’t stop,” Rachel warns.

“But that’s my pizza.”

“Don’t look at the pizza. Just eat your food.” His temptation is great as he sits facing the direction of the food table. He can see each person who takes a slice of pizza.

“Look Ryan.” Carries point to his plate reminding him. “This is your pizza.”

It seems to calm him down, but shortly he hollers again. People look at us from the surrounding benches disrupted from their pleasurable meal. Others at the food table frown, puzzled. By now, I am slightly embarrassed and eat with my head down hoping to ignore the eyes directed at our table. However, Charlie and Rachel do not seem embarrassed. They are more used to it by now. “Both Charlie and I have learned to become humbler,” shares Rachel, “We have big egos, lots of pride. When Ryan screams and runs down the aisle with a shopping cart, others perceive it as bad parenting. They don’t know that he actually thinks it’s a race car. The battle still definitely goes on. You get sweaty, embarrassed, red faced, breathe it out, and talk with him. Ryan’s speech is obviously not like a typical kid, so others can figure out after a while.” I am tasting what these parents experience on a daily basis.

“Ryan, do you remember what happened at the pool?” prompts Rachel. Ryan had gone swimming at the pool with his aunt and become possessive of the pool, screaming for the people to get out. As he continued to do this, his parents eventually took him home.

“I don’t want to go home. I don’t want to go home!” Ryan whines remembering.

“Then eat your pizza, bud,” advises Charlie.

“You have four pieces of pizza. Daddy has one and mommy has none,” Rachel reasons with him or tries to evoke an emotional response.

“Oh, maybe you’ll get some tomorrow,” Ryan answers innocently.

“Thanks” replies Rachel with a slightly sarcastic tone. Ryan made it sound as if it was his mother’s fault that she did not get any pizza. He does not truly comprehend that his parents sacrificed their pizza, let him have their slices.

A little later Roseville’s physical education teacher joins us with her plate of food. Rachel chats about Ryan not wanting to share the pizza and another incident at a river. “He wouldn’t let other children play in the river. I can’t believe it.” Rachel laughs perplexed.

The other teacher does not really reply.

“Sharing is something he needs to work on. We still have to find a way to teach him,” Rachel comments.

It is very open of Rachel to talk about her son’s condition with others. She is not afraid of what others think, their judgments and perspectives. I admire that. The teacher does not stay long and soon leaves.

"Is today a normal day with Ryan?" I ask Charlie.

He pauses and nods wearily, "Autism is a challenge every day."

There is a little more time before the opera starts, so Charlie buys us some treats from the snack table. While eating outside, we meet Hannah, Ryan's aide. She has a friend with her and happily talks with Rachel. Ryan dances with a cupcake in hand between his mother and aide. Hannah keeps dodging him, whenever he gets too close to her.

"I don't want cupcake on my clothes," she explains apologetically with a smile.

Rachel laughs in understanding.

Hannah is very open and committed to her job. She is always cheerful, full of energy, and works hard. "She really cares about Ryan," says Rachel.

Next we meet Sara, the other music teacher at Roseville. Despite their differences in age, Rachel and Sara are very close, great friends. Taking a bite from Rachel's chocolate chip cookie, Sara jokes about her day. Our conversation is cut short with the sound of a bell, signaling the start of the opera.

My seat is several rows behind Ryan, his parents, and Carrie since Rachel bought my ticket at a different time than theirs. Sara sits in the row behind me.

The music starts, barely audible at first, a mysterious opening piece depicting the prince's castle. Unfortunately the audience does not get the message—the opera has started. Behind me, I hear a mutter, "Don't they know that when the music starts, the performance starts?" Turning around, I smile at Sara's reaction. The distinction between musicians and non-musicians is obvious. It seems like there will be no silence until an

actor appears on stage. However, despite the noise around me, I happily immerse myself in the music without a care.

Ryan is absorbed in the performance the entire time. Keeling upon his chair, his shoes sticking out from the back opening, he has no problem comprehending the story. Before the opera, Charlie shared his concern of how Ryan might react to the opera. He thought the Beast might be too scary for Ryan. As a backup plan, Charlie was going to set up a movie on a portable electronic device for Ryan. Rachel's backup plan was to sit near the aisle and dash out the doors with Ryan if anything went wrong. Their backup plans do not come to pass. Ryan is thoroughly engaged. He loves it. After Beauty's father gets lost in the forest and is put in jail by the Beast, Beauty asks the Beast if she can take her father's place. When the Beast threatens to let the father die in jail (followed by an evil laugh), a distressed "No!" pierces the air. Where did that come from? I wonder. That scream did not sound like it was part of the opera. Glancing around I see Ryan half off his chair with his hands over his mouth. Was it Ryan? My answer reveals itself in the numerous heads that are looking at him. Smiles light their faces. Ryan is now in his mother's arms.

During intermission, I overhear a conversation of Sara talking with a friend. This friend is speaking about Ryan. "I sat in the chair behind Ryan. His feet stuck through the back of the chair and he was kicking me the whole time," she shares in a good-humored tone, "He was so excited he couldn't sit still!" The second half the opera passes quickly and pleasantly.

Tonight Ryan exhibited his love of music and music's ability, its lyrics and

accompanying drama, to touch him. He understood the story; he could comprehend the words set to music. His response to the Beast's threat was sincere. The eighth graders did a splendid job. I leave this performance alive and joyous. It is an amazing accomplishment.

Rachel's Journey

Lessons Learned

"It is very typical to have a negative 'why me, God?' attitude, but I never hated having a special-needs child," says Rachel, "Ryan has taught me so much." He reminds his mother, who moves at a fast pace, to slow down and enjoy life more often saying, "Mom, slow down. I want to talk to you." Rachel smiles as she recalls these memories, "Each time I wonder, 'what is my kid teaching me now?' I don't know if a typical kid will do that for me." While her students at school never comment when she rushes through a lesson too fast, on the other hand, Ryan will say, "Mom what the heck are you doing?" "I love that about him," states Rachel, "he has helped me be a better teacher—knowing where they [her students] are and where they need to be."

Advice for Other Parents with Special Needs Children

"It's frustrating at the beginning because you don't understand [about autism]. When you think you've found something, it changes," shares Rachel, "I was scared to be the mom who screams and hollers because I thought I would get less. But the truth is, the moms that do, get more. We need to be more of an advocate and not just accept what

people give." As a teacher, Rachel teaches each student in her class about autism— why Ryan acts the way he does and how to help him. Like Wendy, she teaches her environment to understand Ryan. The students are absolutely amazing in their acceptance of his condition and their ability to work with him. I am surprised each time I observe this, and believe the other children may get more from the arrangement than Ryan does.

Ryan's Future

Even though Ryan is more high functioning than Mike, his parents still worry what he will be like as an adult, how to support him financially, and other concerns. This year, he told his parents he wanted to be a race car driver; however, Rachel knows he may not even be able to get a license because of his tunnel vision. "The reality is there… I don't know what God will provide," states Rachel. "However, we should not lose hope. Ryan is still young and has already made substantial improvement. He has gone so far so fast," she shares. Additionally, his biomedical doctors believe Ryan is on the road to recovery. As they straighten out the imbalances in his body, they believe he may be close to typical one day.

Epilogue

Ryan is in first grade this year. In comparison to his previous teacher, his current teacher is very structured, caring, and inclusive of Ryan's condition. Hannah remains his aide. He has made "leaps and bounds," states his mother and "is having a good year so far." Ryan's future looks very bright as music remains present in his life.

Chapter 6: There and Back Again

My journey took me into a different world, the lives of children with autism. While not all questions posed at the beginning of this study were answered, I returned with renewed insight, a deeper understanding of how music serves in Mike and Ryan's lives. Certain themes emerged in this study revealing connections between music and autism in: speech and communication, memory, learning, social interaction, stimulus and musical ability, and confidence and self-esteem.

Speech and Communication

Communication is noted by many researchers as the area that presents the most difficulties for children with autism.[1] Even Leo Kanner, the first to recognize autism, wrote in extreme detail about their language deficits, including "muteness, repetitions, immediate and delayed echolalia, pronoun reversals, word substitutions, and literalness."[2] Autism researcher, Uta Frith, concludes that more is written about the language impairment of children with autism than any other deficit.[3] Music, however, can serve as a vehicle for communication, a bridge, between our verbal world and the nonverbal world of children with autism.

Music was the key that allowed Ryan to communicate verbally with his parents.

---

1. Alice-Ann Darrow and Tammy Armstrong, "Research on Music and Autism: Implications for Music Educators," *Update: the Applications of Research in Music Education* 18, no. 1 (1999): 16. See Hargrave & Swisher (1975) and Lovaas et al. (1974).

2. Darrow and Armstrong, "Research on Music and Autism," 16. See Kanner (1946).

3. Darrow and Armstrong, "Research on Music and Autism," 16. See Frith (1989).

As a baby, Ryan did not react to people, sounds, or his environment. Rachel recalls "no communication at all" because of his lack of responses. From six months until four and a half years old, his parents communicated with him in sign language. Communication revolved around basic necessities such as hunger and pain. However, Rachel always used music with Ryan because he loved music. It seemed to calm him and bring him joy. When Charlie and Rachel sang to him he would stop fussing and be quiet. Temple Grandin, a well known author with autism, shares how some children with autism are able to sing a response although they cannot speak it.[4] This was the case with Ryan.

At the age of four Ryan sang "I want a hot dog," to the tune of a children's song Rachel sang to him. He said both his first word and sentence that day. From then on, he sang when communicating with his parents. Ryan could speak short sentences by the age of five. Today he speaks quite well. Rachel believes music helped him organize his thoughts in a way she and Charlie could understand. According to music therapist, Michelle Lazar, music organizes speech by "chunking" phrases into predictable patterns. Music also "offers timing clues" which assists with pacing in speech. Finally, because many similarities exist between singing and speech, Lazar suggests using music as an alternative way to practice functional communication.[5]

Unlike Ryan, Mike never used music as a means of verbal communication. His verbal communication and comprehension is limited. Speaking, reading, and writing are

---

4. Darrow and Armstrong, "Research on Music and Autism," 17. See Grandin (1988).

5. Michelle Lazar, "Music & Communication," www.tunedintolearning.com (accessed April 14, 2009).

painful for him. As a child it was difficult for him to complete his school assignments, especially those from English classes. Because Wendy saw the energy and time spent on his homework were not fruitful, beginning middle school she began focusing Mike's life on music, something he could do successfully. According to Wendy, music is easier for Mike to learn and do than anything else. She believes music is his language.

Mike first communicated and interacted with people through the medium of music. At the age of eight, Mike played his first piano performance. When he heard the audience's applause and saw their smiles, he knew they were clapping for him. He loved it. Now, whenever Mike plays music, his eyes are focused on the audience rather than down at his hands. He is no longer in his own world. He is interacting and communicating—nonverbally— seeking people's approval and praise. In return, he gives them music.

Memory

Mike and Ryan both have an incredible musical memory. Ryan can memorize music and accompanying words quickly and easily. For example, while other students struggled with the music and lyrics on the day of the opera performance, Ryan had everything memorized weeks before. The songs he learns also remain in his brain for an extended period of time. Several weeks after the performance, Ryan was still singing the songs.

Mike can play from memory every piece he has ever learned. While visiting Mike's house, Wendy put on a recording of him playing Debussy's Arabesque at a

performance two years ago. I asked Mike if he was the one playing the piano. He replied "yes," then walked straight to the piano and began playing along with the CD from memory.

Mike has difficulty with pronouncing and articulating words clearly when speaking. However, Mike can sing fluently and clearly. The issues he has while speaking are minimized while singing. Wendy does not know why. Through singing Mike comes the closest to speaking, but unfortunately his mother believes most of the time he does not comprehend what he sings. I asked Wendy if Mike understood the lyrics of "You Raise Me Up," a song he sang for his electronic music final project. Wendy said he did not comprehend, and she did not know how to explain the meanings of the words. It is difficult knowing if Mike truly understands because he does not speak much. Besides improving his speech, like Ryan, Mike can memorize the lyrics of a song easily through music. He memorized all the words for his electronic music project. When Wendy showed me his final during class, Mike started singing along to the music. It is like he was led by the music and naturally responded to it.

According to Michelle Lazar music helps organize information making it a useful mnemonic device to aid learning and recalling information.[6] Alvin and Nordoff and Robbins similarly confirm the ability of music to help individuals with autism memorize material.[7] Diagnosed with autism as a child, melodies were the only thing Temple

---

6. Michelle Lazar, "Music & Academics," www.tunedintolearning.com (accessed April 14, 2009).

7. Darrow and Armstrong, "Research on Music and Autism," 16. See Alvin (1978), Hairston (1990), Michel (1985), Nordoff & Robbins (1977), and Oppenheim (1974).

Grandin could remember as a child without a visual image. She credits music as a reason for helping her receive a doctorate degree in animal science.[8]

Music is a key to accessing Ryan's mind. To input and store information in Ryan's brain, Charlie and Rachel often sing. Routines and schedules for the day are sung on a daily basis. His parents also sing when he has trouble understanding, comprehending what they tell him. Somehow music helps Ryan connect with language and speech. At the camping event, he started irritating Rachel because he could not understand or remember why they were letting another family borrow their tent. He kept saying, "I want to sleep in the tent tonight." or "When are we getting the tent back?" Rachel already explained the reasons while setting up the tent and even on the drive to the camp site. Finally, as the last straw, Rachel wanted to sing to Ryan. However, she did not because other families were present. They would have thought it was weird—singing to a six year old about a tent.

Learning

The special musical interest and unusual sensitivity in individuals with autism creates the possibility of using music as a tool for learning.[9] Two functional uses of music in Ryan's life are songs that assist memorization and sequencing of events. Every day Hannah, Ryan's aide, sings a playground song before he goes to recess with the

---

8. Darrow and Armstrong, "Research on Music and Autism," 16. See Toigo (1992).

9. Nicole Allgood, "Parent's Perceptions of Family-based Group Music Therapy for Children with Autism Spectrum Disorders," *Music Therapy Perspectives* 23, no. 2 (2005): 93.

following words: “Never, never push on the playground. Never, never hit on the playground.” The song helps him remember proper social behavior and conduct. Hannah notes that he always behaves much better when the song is sung before he goes out the play. Rachel thinks this is because the song constantly runs through his head (repeats itself) reminding him while he plays. The song is also repetitive in nature.

Ryan’s routines and schedules are also sung to help him memorize the sequence of events. Almost any task that involves multiple steps is put into song. For example Ryan has a bedtime song embedded with the following steps: 1) go to the bathroom, 2) put on your pajamas, 3) brush your teeth, and 4) go to bed. If his parents speak the order of steps, he will not respond. However, when they sing, Ryan acts immediately. Songs helped Ryan learn and remember important multi-step life skills such as using the toilet and washing his hands.

On the other end of the spectrum, Mike does not use music as a tool for memorization. He can quickly memorize information spoken to him such as directions and schedules. When Wendy sang to him, he focused more on the music than the words. This may indicate a high level of musicianship. Many musicians are unable to work with background music because they will analyze and focus on the music. However, a television program playing in the background will not distract them. Perhaps, this is the case with Mike.

Music therapist, Michelle Lazar states that many students with special needs show an increased response to instructions presented in melodic or chanted form.[10] Similarly,

---

10. Michelle Lazar, “Tunes for Tasks,” www.tunedintolearning.com (accessed April

Buday reports that children with autism are more responsive to instructions accompanied by music than without.[11] Ryan follows instructions better, complies easier with greater enthusiasm, when his parents ask him to accomplish a task or job through singing. His parents do not really know why, but Rachel thinks that "music is a tool to order his head. It connects the dots for him. He has a musical mind."

Music also helps Ryan transition between activities, allowing him to "find an end to activities," shares his mother. Transitional songs and songs that help him follow directions are used by Ryan's parents and Hannah at school, home, and elsewhere.

Engagement in music-making can serve in building motor skills, a fun way to practice and exercise muscle movements.[12] When Wendy discovered weakness in Mike's motor skills she set him on a journey of learning and practicing various instruments. Mike does not speak clearly and often drools. He is currently starting saxophone lessons in hopes of strengthening the muscles around his mouth and cheeks as well as exercising his breathing. Mike also plays piano, cello, drums, timpani, Yangqin (Chinese dulcimer), Sheng (Chinese mouth organ), and recorder. His motor skills improved greatly through what Wendy calls, daily "occupational therapy at home."

Ryan does not formally play any instruments because he is young, six years old. While singing is an integral part of his life, he occasionally plays piano for fun. His parents work on building his muscles through bike riding, walking the dogs daily, dance

---

14, 2009).

11. Darrow and Armstrong, "Research on Music and Autism," 17. See Buday (1995).

12. Michelle Lazar, "Music & Motor Skills." www.tunedintolearning.com (accessed April 14, 2009).

class, horseback riding, and other extracurricular events.

Studies reveal positive outcomes in using music as a reinforcer or motivator.[13] Music is Mike's motivation, his goal in life. He works hard daily in building his skills because he knows music is his future. Wendy describes music's role as, "filling his life with color." Music brought Mike a more meaningful, joyful life.

Social Interaction

Music is a social activity that increases levels of engagement between children with autism and typical children. As music-making primarily occurs in a group setting, it encourages social interaction, drawing these children out of their preferred social isolation.

Mike learns to interact, communicate, and work with other people through participation in various ensembles during school and out of school. Even though he does not interact and communicate verbally, he is aware of his surroundings, the members in his ensemble and the conductor. When he does not play during long periods of rests, he looks at the rest of the band or orchestra and smiles. Mike also listens while playing music. One time I observed him grin in amusement when the band was not playing together. Wendy also teaches him to watch the conductor for cues and instruction. In all this he practices self and group awareness.

Mike also interacts and communicates with his audience through music. Since his first piano performance when he truly noticed the audience, now he looks at his listeners

13. Darrow and Armstrong, "Research on Music and Autism," 16. See Toigo (1992), Jorgenson (1974), and Watson (1979).

while he plays music, seeking their praise and applause. He no longer looks down at his hands, in his own world. Music further allows Mike to play with others, with no barriers or disability in-between. Recently, Mike and two other children with disabilities played at open mic café. "It was very touching," recalls Wendy when the other typical musicians joined in upon hearing Mike and his friends play. These musicians could play together because music provided a nonverbal means of interaction and communication. Music was the common ground (common interest) for engagement.

More social and communicative than Mike, Ryan can associate with people in settings without music. He does not need music as a medium for interaction. However, music can serve as common ground, especially when he is older, allowing him to join music ensembles and make new friends.

Stimulus and Musical Ability

Music is an engaging stimulus for children with autism. Autism literature states that children who do not respond to speech will often respond to music. In fact, they respond more frequently and appropriately to music than any other auditory stimulus.[14] Mike and Ryan support these findings.

Mike liked to be in his own world, one filled with color, light, spinning objects, and sound. Mindless of everything else around him, he would not respond when people called his name. He only responded to music. As a child, whenever his mother sang a

14. Elizabeth Starr and Krista Zenker, "Understanding Autism in the Context of Music Therapy: Bridging Theory and Practice," *Canadian Journal of Music Therapy* 6, no. 1 (1998): 1.

scale, Mike immediately turned in her direction. Wendy believed that even at these times Mike was not truly seeking her; he was searching for music. Mike loved it when his mother sang to him. He also sometimes cried, especially during sad songs. "Music touched him," recalls Wendy.

Sensitivity issues created by autism made Ryan an extremely fussy baby. However, he would stop crying when his parents sang to him. He was quiet and calm when there was music. Playing music on a CD sometimes worked, but Ryan much preferred a person singing. As a baby, Rachel often took him to her church choir rehearsals. Ryan was silent throughout the entire rehearsal, but screamed on the way home.

In addition to responding positively to music, children with autism often exhibit a high level of musical ability.[15] Mike and Ryan both have perfect pitch and an excellent ear. Mike learns his music solely through listening to recordings. After listening eight to ten times, Wendy states that he has approximately 80% of the notes. Mike can identify the letter and quality of a chord (example, B minor) in his electronic music aural exams as a result of his perfect pitch, amazing his teacher who only expects students to name the chord quality. Mike's musical talents also enable him to perform numerous instruments at an advanced level.

Ryan has a wonderful voice and sings pleasantly in tune for his age. Because he has perfect pitch, he cannot stand when his classmate sing out of tune. It also distresses

15. Ibid., 1-2.

him if Rachel sings a song in a different key than when she first sang it for him. Ryan learns songs quickly, often faster than the other children in his class. He had all the words and music of the kindergarten opera memorized several weeks before the performance, while many students struggled with the words on the day of the performance. Rachel states that she did not work on the opera with him outside of class. He learned everything during music class along with his classmates.

Confidence and Self-esteem

Through participation in music-making and performances, children with autism gain confidence and self-esteem. Music reinforces their abilities and minimizes their deficiencies, bringing out their strengths than weaknesses.

Mike loves the praise he receives from his audience. Whenever he plays music, he now looks at his listeners. Through music, he interacts and communicates with us. He is present in our world. As he gains acknowledgement and approval from people around him, Mike's confidence in his musical abilities grows along with greater self-esteem. Increased confidence and self-esteem as notable improvements seen by Wendy in Mike since his first piano performance at the age of seven.

According to Rachel, music has not yet reached the stage of building Ryan's confidence and self-esteem. She does not think Ryan realizes his talent in music. He only knows when others cannot do something in music such as when a student sings out of tune. Interestingly, his classmates at school recognize his musical abilities. They often tell him he has a great voice, but he does not respond. Perhaps Ryan will experience

what Mike loves later in life as he develops his musical skills and joins various ensembles.

A Final Refection

A connection between the nature of music and the natural aptitude for music in children with autism are evident in this study. Music is able to reach Mike and Ryan in ways other stimulus and interventions cannot. It was the only thing that drew them out of their world into our world. As a bridge into their hearts and minds, their parents use music functionally in their lives. Mike and Ryan also love music and can engage in it successfully. A structured use of music helped these children build skills essential to function successfully in our society. Music aided with communication, social interaction, appropriate behavior, motor skills, and academics in each participant to varying degrees.

As each child on the spectrum is different, it is important to discover the role and importance of music in a child's life. Music should be used according to the needs and abilities of the child. Music assists Ryan in his routines, transitions, accomplishing tasks, and appropriate behavior because songs remain in his memory for a long time. He also better comprehends words set to music than spoken. It is a tool that provides stability, helping him function smoothly in life. On the other hand, Mike uses music as a goal and purpose in life. He builds his skills and abilities in music so that he can have a future. Although Mike's abilities in other areas are limited, he can learn and perform music successfully. Music is his medium for interaction and communication with others because unlike Ryan, Mike has narrow speech, comprehension, and social skills.

The stories of Mike and Ryan show music's potential in helping individuals with autism live a more fulfilling life. As music accommodates different levels and abilities, it has the potential to bring out the best in all children with autism. Music can highlight their abilities rather than their disabilities. With successful experience these children gain confidence, self-esteem, learn a skill, establish a socially approved hobby, and acquire outside acknowledgement and praise. The success of my participants is also attributed to their parents who recognized the power of music and actively incorporated music into the lives of their children. Through their stubborn persistence, determination, and love, music brought change and improvement.

It is my hope that by looking "to the specific" I may bring "something grander than the case to the attention of others."[16] In the U.S. today, every one in 91 people are diagnosed with autism.[17] This rate continues to rise as scientists scramble to find a cause or cure. On the most basic level, music can bring happiness and comfort when other things cannot. It also serves in positive ways when used functionally. Music is valued and effective in enriching the lives of children with autism, helping these individuals experience the closest to normal living.

---

16. Corrine Glesne and Alan Peshkin, *Becoming Qualitative Researchers: An Introduction* (White Plains: Longman Group Ltd., 1992), 148.

17. "Autism Speaks Responds to New *Pediatrics* Autism Study Putting Prevalence at 1 in 91 American Children, Including 1 in 58 Boys," http://www.autismspeaks.org/press/autism_nchs_prevalence_study_1_in_91.php (accessed October 5, 2009).

Bibliography

Accordino, Robert, Ronald Comer, and Wendy Heller. "Searching for Music's Potential: A Critical Examination of Research on Music Therapy with Individuals with Autism." *Research in Autism Spectrum Disorders* 1, no. 1 (2007): 101-115.

Ackerman, Paul, Robert Jaeger, and Anne Smith. "History of Special Education." http://www.answers.com/topic/history-of-special-education (accessed September 14, 2009).

Adamek, Mary, and Alice-Ann Darrow. *Music in Special Education*. Silver Spring: The American Music Therapy Association, 2005.

Aigen, Kenneth. *Paths of Development in Nordoff-Robbins Music Therapy.* Gilsum: Barcelona Publishers, 1998.

Aldridge, David. *Music Therapy Research and Practice in Medicine: From Out of the Silence.* London: Jessica Kingsley Publishers, 1996.

Allgood, Nicole. "Parents' Perceptions of Family-Based Group Music Therapy for Children with Autism Spectrum Disorders." *Music Therapy Perspectives* 23, no. 2 (2005): 92-99.

Alvin, Juliette. *Music Education for the Autistic Child*. New York: Oxford University Press, 1978.

———. *Music Therapy for the Autistic Child.* New York: Oxford University Press, 1991.

Ansdell, Gary. *Music for Life*. London: Jessica Kingsley Publishers, 1995.

Antrim, Doron. "Music Therapy." *The Musical Quarterly* 30, no. 4 (1944): 409-420.

Applebaum,E., A. Egel, R. Koegel, and B. Imhoff. "Measuring Musical Abilities of Autistic Children." *Journal of Autism and Developmental Disorders* 9 (1979): 279-285.

Atterbury, Betty. *Mainstreaming Exceptional Learners in Music*. Englewoods Cliffs: Prentice-Hall, Inc., 1990.

Autism Society of America. "Educating Students on the Autism Spectrum." www.autism-society.org (accessed October 5, 2009).

"Autism Speaks Responds to New *Pediatrics* Autism Study Putting Prevalence at 1 in 91 American Children, Including 1 in 58 Boys,"

http://www.autismspeaks.org/press/autism_nchs_prevalence_study_1_in_91.php (accessed October 5, 2009).

Bailey, A., P. Luthert, A. Dean, B. Harding, I. Janota, M. Montgomery, M. Rutter, and P. Lantos. "A Clinicopathological Study of Autism." *Brain* 121 (1998): 889-905.

Bauman, M., and K. Kemper, "Neuroanatomical Observations of the Brain in Autism." In *The Neurobiology of Autism*. Edited by M. Bauman and K. Kemper. Baltimore: The John Hopkins University Press, 1994: 119-145.

Ben-Arieh, Josefa, and Helen Miller. *The Educator's Guide to Teaching Students with Autism Spectrum Disorders*. Thousand Oaks: Corwin Press, 2009.

Bonnel, A., L. Mottron, I. Peretz, M. Trudel, E. Gallun, E., and A. Bonnel. "Enhanced Pitch Sensitivity in Individuals with Autism: A Signal Detection Analysis." *Journal of Cognitive Neuroscience* 15, no. 2 (2003): 226-235.

Brown, Sandra. "Autism and Music Therapy- Is Change Possible, and Why Music?" *Journal of British Music Therapy* 8, no. 1 (1994): 15-25.

Brown, W., K. Cammuso, H. Sachs, B. Winklosky, J. Mullane, R. Bernier, S. Svenson, D. Arin, B. Rosen-Sheidley, and S. Folstein. "Autism-related Language, Personality, and Cognition in People with Absolute Pitch: Results of a Preliminary Study." *Journal of Autism and Developmental Disorders* 33, no. 2 (2003): 163-7.

Brownell, M. "Musically Adapted Social Stories to Modify Behaviors in Students with Autism: Four Case Studies." *Journal of Music Therapy* 39, no. 2 (2002): 117-144.

Bruscia, Kenneth, ed. *Case Studies in Music Therapy*. Gilsum: Barcelona Publishers, 1991.

Buday, E. "The Effects of Signed and Spoken Words Taught with Music on Sign and Speech Imitation by Children with Autism." *Journal of Music Therapy* 32, no. 3 (1995): 189-202.

Bunt, Leslie. *Music Therapy: An Art Beyond Words.* London: Routledge, 1994.

———. "Music Therapy." In *Grove Music Online*. *Oxford Music Online*, http://www.oxfordmusiconline.com.libaccess.sjlibrary.org/subscriber/article/grove/music/19453 (accessed September 5, 2009).

Burleson, S., D. Center, and H. Reeves. "The Effect of Background Music on Task Performance in Psychotic Children." *Journal of Music Therapy* 32 (1989): 198-205.

Carr, E., and Durand, V. "Reducing Behavior Problems through Functional Communication Training" *Journal of Applied Behavior Analysis* 18 (1985): 111-126.

Čeponienė, R., T. Lepistö, A. Shestakova, R. Vanhala, P. Alku, R. Näätänen and K. Yaguchi. "Speech-Sound-Selective Auditory Impairment in Children with Autism: They Can Perceive but Do Not Attend" *Proceedings of the National Academy of Sciences of the United States of America* 100, no. 9 (2003): 5567-5572.

Christian, Julie, and the Autism Program Staff at the University of South Dakota. *Autism and Related Disorders Handbook.* www.usd.edu/cd (accessed October 5, 2009).

Clandinin, D., and F. Connelly, *Narrative Inquiry: Experience and Story in Qualitative Research*. San Francisco: Jossey-Bass Publishers, 2000.

Courchesne, E. (and 15 others). "Unusual Brain Growth Patterns in Early Life in Patients with Autistic Disorder: A MRI Study." *Neurology* 57 (2001): 245-254.

Creswell, J. *Qualitative Inquiry and Research Design*. Thousand Oaks: Sage Publications, 1998.

Crowe, Barbara J. "The Profession of Music Therapy in the United States." *Open Ear Journal: Dedicated to Sound and Music in Healing and Education*, (2000):170-173.

Darrow, Alice-Ann. *Introduction to Approaches in Music Therapy.* Silver Spring: American Music Therapy Association, 2005.

Darrow, Alice-Ann, and Tammy Armstrong. "Research on Music and Autism: Implications for Music Educators." *Update: the Applications of Research in Music Education* 18, no. 1 (1999): 15-20.

Daveson, B., and J. Edwards. "A Role for Music Therapy in Special Education." *International Journal for Disability, Development, and Education* 45, no. 4 (1998): 449-457.

Davis, Kim. "Aspects of Support for Learning." *The Reporter* 11, no. 1 (2006): 10-11.

———. "Reframing Our Thinking and Getting to Know the Child." *The Reporter* 8, no. 3 (2003): 22-27.

———. "Tips to Consider when Including a Student with ASD in Art, Music, or Physical Education." *The Reporter* 12, no. 3 (2007): 7-10.

Davis, William, Kate Gfeller, and Michael Thaut. *An Introduction to Music Therapy: Theory and Practice*, 2nd ed. USA: McGraw-Hill Companies, Inc., 1999.

Degmecic, Dunja, Ivan Pozgain, and Pavo Filakovic. "Music as Therapy." *International Review of the Aesthetics and Sociology of Music* 36, no. 2 (2005): 287-300.

Dorita, Berger. *Music Therapy, Sensory Integration and the Autistic Child.* London: Jessica Kingsley Publishers, 2002.

Duerkson, G. *Music Education: Helping Other to Use Music. Music Therapy: Using Music to Help Others.* University of Kansas: Unpublished paper, 1978.

Edgerton, C. "The Effect of Improvisational Music Therapy on the Communicative Behaviors of Autistic Children." *Journal of Music Therapy* 31, no. 1 (1994): 31-62.

Evers, Stefan. "Music Therapy in the Treatment of Autistic Children: Medico-sociological Data from the Federal Republic of Germany." *International Journal of Child and Adolescent Psychiatry* 55, no. 3 (1992): 157-158.

Fein, Deborah, and Michelle Dunn. *Autism in Your Classroom: A General Educator's Guide to Students with Autism Spectrum Disorders*. Bethesda: Woodbine House, Inc., 2007.

Frith, Uta. *Autism*. Cambridge: Basil Blackwell, 1989.

———. "What Do Imaging Studies Tell Us about the Neural Basis of Autism?" In *Autism: Neural Basis and Treatment Possibilities*, edited by M. Rutter. Chichester: Wiley, 2003.

Frith, Uta, and Francesca Happe. "Language and Communication in Autistic Disorders." *Philosophical Transactions: Biological Sciences* 346, no. 1315 (1994): 97-104.

Gaston, Thayer, ed. *Music in Therapy.* New York: Macmillan, 1968.

Gilliland, Esther. "The Healing Power of Music." *Music Educators Journal* 31, no. 1 (1944): 18-20.

Gillingham, G. *Autism: Handle with Care!* Arlington: Future Education, 1995.

Glesne, Corrine, and Alan Peshkin. *Becoming Qualitative Researchers: An Introduction.* White Plains: Longman Group Ltd., 1992.

Goldstein, C. "Music and Creative Arts Therapy for an Autistic Child." *Journal of Music Therapy* 1 (1964): 135-138.

Grandin, T. "Teaching Tips from a Recovered Autistic." *Focus on Autistic Behavior* 3 (1988): 1-8.

Hadley, Richard, Wynton Hadley, Virginia Dickens, and Earlyn G. Jordon. "Music Therapy: A Treatment Modality for Special-Needs Populations." *International Journal for the Advancement of Counselling* 23, no. 3 (2001): 215-221.

Hairston, M. “Analyses of Responses of Mentally Retarded Autistic and Mentally Retarded Nonautistic Children to Art Therapy and Music Education.” *Journal of Music Therapy* 27 (1990): 137-150.

Heaton, P., B. Hermelin, and L. Pring. “Autism and Pitch Processing: A Precursor for Savant Musical Ability?” *Music Perception* 15, no. 3 (1998): 291-305.

———. “Can Children with Autistic Spectrum Disorders Perceive Affect in Music?: An Experimental Investigation.” *Psychological Medicine* 29, no. 6 (1999): 1405-1410.

———. “Musical Processing in High Functioning Children with Autism.” *Annals of the New York Academy of Sciences* 930 (2001): 443-444.

Heaton, P. “Pitch Memory, Labeling, and Disembedding in Autism.” *Journal of Child Psychiatry and Psychology* 44, no. 4 (2003): 543-551.

Heflin, L., and Donna Alaimo. *Students with Autism Spectrum Disorders: Effective Instructional Practices*. Upper Saddle River: Pearson Education, Inc., 2007.

Hill, Elisabeth, and Uta Frith. “Understanding Autism: Insights from Mind and Brain.” *Philosophical Transactions: Biological Sciences* 358, no. 1430 (2003): 281-289.

Hoelzley, P. “Communication Potentiating Sounds: Developing Channels of Communication with Autistic Children through Psychobiological Responses to Novel Sound Stimuli.” *Canadian Journal of Music Therapy* 1 (1993): 54-76.

Horden, Peregrine, ed. *Music as Medicine: The History of Music Therapy Since Antiquity*. Brookfield: Asgate, 2000.

Hourigan, Ryan, and Amy Hourigan. “Teaching Music to Children with Autism: Understandings and Perspectives.” *Music Educators Journal* 90, no. 1 (2009): 40-45.

Hughes, Charles. “Science, Magic, and Continuity in the History of Music Therapy: On Rhythm and Health.” *Nordic Journal of Music Therapy* 10, no. 2 (2001): 188-190.

Hume, Kara. “Clean Up Your Act! Creating an Organized Classroom Environment for Students on the Spectrum.” http://www.iidc.indiana.edu/irca/education/CleanUp.html (accessed May 6, 2009).

———. “Transition Time: Helping Individuals on the Autism Spectrum Move Successfully from One Activity to Another.” http://www.iidc.indiana.edu/irca/education/TransitionTime.html (accessed May 6, 2009).

Iseminger, Scott. “Keys to Success with Autistic Children.” www.menc.org (accessed April 15, 2009).

Iwata, B., M. Dorsey, K. Slifer, K. Bauman, and G. Richman. “Toward a Functional Analysis of Self-injury.” *Analysis and Intervention in Developmental Disabilities* 2, (1982): 3-20.

Kanner, L. “Follow-up Study of Eleven Autistic Children Originally Reported in 1943.” *Journal of Autism and Childhood Schizophrenia* 10 (1971): 119-145.

Kaplan, R., and A. Steele. “An Analysis of Music Therapy Program Goals and Outcomes for Clients with Diagnoses on the Autism Spectrum.” *Journal of Music Therapy* 42, no. 1 (2005): 2-19.

Kemper, K., and M. Bauman. “Neuropathology of Infantile Autism.” *F. Neuropathol. Exp. Neurol.* 57 (1998): 645-652.

Kern, P., and D. Aldridge. “Using Embedded Music Therapy Interventions to Support Outdoor Play of Young Children with Autism in an Inclusive Community-based Child Care Program.” *Journal of Music Therapy* 43, no. 4 (2006): 270-294.

Kern, P., L. Wakeford, and D. Aldridge. “Improving the Performance of a Young Child with Autism during Self-care Tasks Using Embedded Song Interventions: A Case Study.” *Music Therapy Perspectives* 25, no. 1 (2007): 43-51.

Kern, P., M. Wolery, and D. Aldridge. **“**Use of Songs to Promote Independence in Morning Greeting Routines for Young Children with Autism.” *Journal of Autism and Developmental Disorders* 37, no. 7 (2007): 1264-1271.

King, Betsey. *Music Therapy: Another Path to Learning and Communication for Children in the Autism Spectrum.* Arlington: Future Horizons, 2000.

Knoll, Cathy, Dellinda Henry, and Dwight Knoll. *Autism Handbook #1 for Music Therapists.* Stephenville: Music Works Publications, 2008.

Kolko, D., L. Anderson, and M. Campbell. “Sensory Preference and Overselective Responding in Autistic Children.” *Journal of Autism and Developmental Disorders* 10 (1980): 259-271.

Lainhart, J., J. Piven, M. Wzorek, R. Landa, S. Santangelo, H. Coon, and S. Folstein. “Macrocephaly in Children and Adults with Autism.” *F. Am. Acad. Child Adolescent Psychiatry* 36 (1997): 282-290.

Lane, Deforia. *Music Therapy [sound recording]: A Gift Beyond Measure*. Chautauqua: RB Media, 2006.

Lathom, W. “An Overview of Music Therapy.” In *The Use of the Creative Arts in Therapy*. Washington: American Psychiatric Association, 1980: 36-38.

Lazar, Michelle. “Music & Academics.” http://www.tunedintolearning.com/why (accessed April 14, 2009).

———. “Music & Motor Skills.” http://www.tunedintolearning.com/why (accessed April 14, 2009).

———. “Music & Autism.” http://www.tunedintolearning.com/why (accessed April 14, 2009).

———. “Music & Communication.” http://www.tunedintolearning.com/why (accessed April 14, 2009).

———. “Tunes for Tasks.” http://www.tunedintolearning.com/why (accessed April 14, 2009).

Ma, Y., J. Nagler, M. Lee, and I. Cabrera. “Impact of Music Therapy on the Communication Skills of Toddlers with Pervasive Developmental Disorder.” *Annals of the New York Academy of Sciences* 930 (2001): 445-447.

Marwick, C. “Leaving Concert Halls for Clinic Therapists New Test Music’s ‘Charms.’” *Journal of the American Medical Association* 275 (1996): 267-286.

McClellan, Randall. *The Healing Forces of Music: History, Theory and Practice.* San Jose: Toexcel, 2000.

Merriam, S. *Case Study Research in Education: A Qualitative Approach*. San Francisco: Jossey-Bass Publishers, 1992.

Mottron, L., I. Peretz, and E. Menard. “Local and Global Processing of Music in High-functioning Persons with Autism: Beyond Central Coherence?” *Journal of Child Psychology and Psychiatry* 41, no. 8 (2000): 1057-1065.

Nelson, D., V. Anderson, and A. Gonzales. “Music Activities as Therapy for Children with Autism and Other Pervasive Developmental Disorders.” *Journal of Music Therapy* 21 (1984): 100-116,

Nordoff, Paul, and Clive Robbins. *Creative Music Therapy.* New York: John Day, 1977.

O’ Connell, T. “The Musical Life of an Autistic Boy.” *Journal of Autism and Childhood Schizophrenia* 4 (1974): 223-229.

Oppenheim, R. *Effective Teaching Methods for Autistic Children*. Springfield: Charles C. Thomas, 1974.

Organization for Autism Research. *A Journey Through Autism: An Educator's Guide*. Silver Spring: Danya International, Inc., 2004. www.researchautism.org (accessed April 14, 2009).

Osteen, Mark, ed. *Autism and Representation*. New York: Taylor and Francis Group, 2008.

Pavlicevic, Mercedes. *Music Therapy in Context: Music, Meaning and Relationship*. London: Jessica Kingsley Publishers, 1997.

Peters, Jacqueline. *Music Therapy: An Introduction*. Springfield: Charles C. Thomas Publisher, 1987.

Pontiff, Elizabeth, ed. *Spotlight on Making Music with Special Learners*. Reston: MENC, 2004.

Pratt, Cathy, and Scott Bellini. "Educating Students with Autism: Are There Differences in Placement?" *The Reporter* 1, no. 5 (1996): 8-10.

Pratt, Rosalie. "Music Education and Medicine: A Renewed Partnership." *Music Educators Journal* 77, no. 5 (1991): 31-36.

Priestley, Mary. *Music Therapy in Action*. London: Constable and Company Limited, 1975.

Provonost, W. "The Speech Behavior and Language Comprehension of Autistic Children." *Journal of Chronic Diseases* 13 (1961): 228-233.

Roehmann, Franz. "Making the Connection: Music and Medicine." *Music Educators Journal* 77, no. 5 (1991): 21-25.

Scott, Jack, Claudia Clark, and Michael Brady. *Students with Autism*. San Diego: Singular Publishing Group, Inc., 2000.

Sewell, Karen. "Educating Children with Autism." www.autism-society.org (accessed October 5, 2009).

Shamshoian, Sara. *Music Therapy as a Treatment for Children with Autism.* San Luis Obispo: MPI Microfilm Service, 2005.

Shapiro, T., I. Chiarandini, and B. Fish. "Thirty Severely Disturbed Children." *Archives of General Psychiatry* 30 (1974): 819-826.

Sloboda, John. *The Musical Mind: The Cognitive Psychology of Music*. New York: Oxford University Press Inc., 1985.

Smith, D., and M. Hairston. "Music Therapy in School Settings: Current Practice." *Journal of Music Therapy* 36, no. 4 (1999): 274-292.

Stake, R. "Case Studies." In *Handbook of Qualitative Research*. Edited by N.K. Denizen and Y.S. Lincoln. Thousand Oaks: Sage Publications, 1994.

Stake, R. *The Art of Case Study Research*. Thousand Oaks: Sage Publications, 1995.

Starr, Elizabeth, and Krista Zenker. "Understanding Autism in the Context of Music Therapy: Bridging Theory and Practice." *Canadian Journal of Music Therapy* 6, no. 1 (1998): 1-19.

Stuart, R. "Motivating Students Who Have Autism Spectrum Disorders." *The Reporter* 1, no. 3 (1996): 1-3.

Thaut, M. "Visual Versus Auditory (Musical) Stimulus Preferences in Autistic Children: A Pilot Study." *Journal of Autism and Developmental Disorders* 17, no. 3 (1987): 425-432.

———. "Measuring Musical Responsiveness in Autistic Children: A Comparative Analysis of Improvised Musical Tone Sequences of Autistic, Normal, and Mentally Retarded Individuals." *Journal of Autism and Developmental Disorders* 18, no. 4 (1988): 561-571.

Mahan, Margaret. *The Chicago Manual of Style: The Essential Guide for Writers, Editors, and Publishers*, 15th ed. Chicago: The University of Chicago Press, 2003.

Turnbull, R., M. Shank, and S. Smith. *Exceptional Lives: Special Education in Today's Schools*, 4th ed. Upper Saddle River: Pearson Education, Inc., 2004.

Walworth, D. "The Use of Music Therapy within the SCERTS Model for Children with Autism Spectrum Disorder." *Journal of Music Therapy* 44, no. 1 (2007): 2-22.

Watson, D. "Music as Reinforcement in Increasing Spontaneous Speech among Autistic Children." *Missouri Journal of Research in Music Education* 4 (1979): 8-20.

Wheeler, Barbara. *Music Therapy Research*. Gilsum: Barcelona Publishers, 2005.

Whipple, Jennifer. "Music in Intervention for Children and Adolescents with Autism: A Meta-analysis." *Journal of Music Therap*y 41, no. 2 (2004): 90-106.

Wigram, Tony, Inge Pedersen, and Lars Bonde. *A Comprehensive Guide to Music Therapy.* London: Jessica Kingsley Publishers, 2002.

Wigram, T., and C. Gold. “Music Therapy in the Assessment and Treatment of Autistic Spectrum Disorder: Clinical Application and Research Evidence.” *Child: Care, Health and Development* 32, no. 5 (2006): 535-542.

Wolfberg, Pamela. *Play and Imagination in Children with Autism*. New York: Teachers College Press, 1999.

Zhao, L., ed. *Autism Research Advances*. New York: Nova Science Publishers, 2007.

APPENDIX A

GLOSSARY

Glossary

Adaptations. "Modifications or alterations of the curriculum, the support systems, the environments, or the teaching strategies to match individual needs (strengths and deficits). The adaptations ensure that the student can participate actively and as independently as possible."[1]

Aide. A paraprofessional who is hired to give 1:1 educational support in a school setting.[2]

Assessment. "The process of testing and observing the child in order to understand the nature, personality, learning style and abilities of the child to help make decisions about the kind of educational programming required."[3]

At-risk. A "term used to describe children who are considered likely to have difficulties in school because of home-life circumstances, medical difficulties at birth or other factors, and who may need early intervention services to prevent further difficulties."[4]

Behavior. "Observable actions and responses to environmental stimuli. These actions and responses are also influenced by internal factors such as understanding, feelings, and emotions related to stimuli."[5]

Behavior Modification. "A method for changing specific human behaviors that emphasizes regular encouragement or discouragement of behaviors that can be seen and for observing what happens both before and after the behavior."[6]

---

1. Julie Christian and the Autism Program Staff at the University of South Dakota. *Autism and Related Disorders Handbook,* 2002. 52. www.usd.edu/cd (accessed October 5, 2009).

2. http://www.wrightslaw.com/info/relsvc.aide.steedman.htm (accessed October 17, 2009).

3. Mary Adamek and Alice-Ann Darrow, *Music in Special Education* (Silver Spring: the American Music Therapy Association, 2005), 295.

4. Ibid.

5. Christian and the Autism Program Staff, *Autism and Related Disorders Handbook,* 52.

6. Adamek and Darrow, *Music in Special Education*, 296.

Case Conference. "The meeting held to discuss evaluation results, determine if there is a need of special services and plan for the student's educational future by developing the IEP."[7]

Communication. "An interactive process that conveys information and ideas from one person to another. Communication is a social skill that has potential for influencing others and gaining some control over one's environment."[8]

Due Process. "A legal term that assures that people with disabilities have the right to challenge any decision make on their behalf."[9]

Discrete Trial Format. "A specific method of instruction in which a task is isolated and taught to an individual by repeatedly presenting the same task to the person."[10]

Early Intervention. "Programs and services provided to infants and children with disabilities from birth to aged five."[11]

Echolalia. "The repetition of speech produced by others. The echoed words or phrases can include the same exact inflections as originally heard, or they may be slightly modified."[12]

Evaluation. "The process of collecting and interpreting information about a child." It "consists of a variety of tests, observations, and background information, and is done by a group of qualified people called a 'multidisciplinary team.'"[13]

Functional education. "Instruction about basic skills needed in everyday life."[14]

---

7. Adamek and Darrow, *Music in Special Education*, 296.

8. Christian and the Autism Program Staff, *Autism and Related Disorders Handbook*, 52.

9. Adamek and Darrow, *Music in Special Education*, 297.

10. Christian and the Autism Program Staff, *Autism and Related Disorders Handbook*, 53.

11. Adamek and Darrow, *Music in Special Education*, 297.

12. Christian and the Autism Program Staff, *Autism and Related Disorders Handbook*, 53.

13. Adamek and Darrow, *Music in Special Education*, 297.

14. Ibid., 298.

Functional routines. "The set or sequence of steps or procedures directed to achievement of a practical purpose; for example, a routine for washing dishes or going to the movies."[15]

Hypersensitivity. Overtly sensitive— acute, often painful reaction— to sensory input (touch, smell, sound, etc.).[16]

Hyposensitivity. Dull in responses (little or no reaction) to sensory input.[17]

Inclusion. "A situation in a school or community setting where children with disabilities are included with children without disabilities."[18]

Individualized Education Program (IEP). "An individualized special education program designed to meet each child's educational needs."[19]

Least Restrictive Environment (LRE). "One of the principles of normalization, it requires that people with disabilities receive services and support in environments that do no limit their life activities un-necessarily."[20]

Mainstreaming. "The selective placement of special education students in one or more "regular" education classes." [21]

Multidisciplinary Team. "An assessment team which has professional members from various disciplines (education, speech pathology, psychology, medicine) to evaluate the total child."[22]

---

15. Christian and the Autism Program Staff, *Autism and Related Disorders Handbook*, 53.

16. Ibid.

17. Ibid., 54.

18. Ibid.

19. Ibid.

20. Adamek and Darrow, *Music in Special Education*, 299.

21.http://www.weac.org/Issues_Advocacy/Resource_Pages_On_Issues_One/Special_Education/special_education_inclusion.aspx (accessed October 17, 2009).

22. Christian and the Autism Program Staff, *Autism and Related Disorders Handbook*, 54.

Music therapy. "An established health profession in which music is used within a therapeutic relationship to address physical, emotional, cognitive, and social needs of individuals. After assessing the strengths and needs of each client, the qualified music therapist provides the indicated treatment including creating, singing, moving to, and/or listening to music. Through musical involvement in the therapeutic context, clients' abilities are strengthened and transferred to other areas in life. Music therapy also provides avenues for communication that can be helpful to those who find it difficult to express themselves in words."[23]

Occupational Therapist. A "therapist who specializes in improving the development of the fine motor and adaptive skills."[24]

Overgeneralize. "The tendency of those with autism to use a skill in all settings just as it was taught, without modifications that reflect the differences in a situation."[25]

Perception. "The process of organizing or interpreting information received through the senses, such as auditory or visual thoughts, ideas or impressions. A level of learning that can be described as existing in the mind."[26]

Perseveration. "Redundant repetition of a word, thought, or action without the ability to stop or move on."[27]

Placement. "The services and classes chosen by the case conference committee that will provide the most appropriate program for the student. The IEP is the planning document used to describe all the details of the student's program or placement."[28]

Referral. "The process of directing a person to another person or service agency that can provide needed services. Referral is also the term used to start the educational evaluation process."[29]

---

23. http://www.musictherapy.org/quotes.html (accessed October 5, 2009)

24. Christian and the Autism Program Staff, *Autism and Related Disorders Handbook*, 54.

25. Ibid, 53.

26. Adamek and Darrow, *Music in Special Education*, 299.

27. Christian and the Autism Program Staff, *Autism and Related Disorders Handbook*, 55.

28. Adamek and Darrow, *Music in Special Education*, 300.

29. Ibid.

Response. "An action or behavior that is triggered by a preceding cue or stimulus (object, action, or event)."[30]

Sensory Integration Therapy (SI). "Treatment involving sensory stimulation and adaptive responses to it according to the child's neurological needs. The goal of therapy is to improve the way the brain processes and organizes sensations."[31]

Social Skills. "Positive, appropriate, social behaviors that are generally considered necessary to communicate and interact with others."[32]

Special Education (Sp. Ed., S. E.). "Instruction designed for one person's needs, specially planned to satisfy or address the needs of a person with a disability".[33]

Speech and Language Pathologist/Therapist (SLP/ST). A "therapist who works to improve speech and language skills as well as oral-motor activities."[34]

Stereotypic Behavior. Prolonged repetition of a behavior[35]

Transitional Cue. "An object that serves as a reminder of the targeted destination."[36] For example, a playground song serving as a reminder to prepare for recess.

Visual Adaptations, Visual Support Systems. "Written schedules, lists, charts, picture sequence, and other visuals that convey meaningful information in permanent format for later reference. Visual adaptations allow the person with autism to function more independently without constant verbal directions."[37]

---

30. Christian and the Autism Program Staff, *Autism and Related Disorders Handbook*, 55.

31. Ibid.

32. Ibid.

33. Adamek and Darrow, *Music in Special Education*, 301.

34. Christian and the Autism Program Staff, *Autism and Related Disorders Handbook*, 56.

35. Ibid.

36. Ibid.

37. Ibid.

APPENDIX B

PERMISSION LETTERS FOR RESEARCH

Consent Forms from Participants (Adult and Child)

Consent Form for Adult Participants

Agreement to Participate in Research

Dear Participant,

You have been asked to participate in a research study investigating the use of music in the lives of children with autism. This project is being conducted by Elizabeth Fang at San Jose State University with the supervision of Dr. Diana Hollinger for a Master's Degree in Music Education. Your participation in this project is greatly appreciated and will involve interviews and observations. If you decide to participate, you will be asked to meet with me for audio taped interviews from January 2009-April 2009. We will talk about how and why you use music with your child. How does music benefit/help your child? What is the importance of music to you and your child? Because I am interested in exploring children with autism in relation to their personal history, I may ask you questions dealing with the past to provide a context in which to observe the child. During these discussions, you may decline to answer any questions or talk about any topics that you would prefer not to address, without the need for explanation. I may also wish to observe you with your child in various settings, such as therapy sessions, with prior notice to you and the therapist. These observations will be audio recorded.

I hope that you will participate in this research project, as it allows the voice of autism to be heard. Music helps us discover new ways of understanding children with autism.

Although the results of this study may be published, no information that could identify you will be included. Your involvement in this project will be kept as confidential as legally possible. All information and data will be reviewed and read only by Dr. Diana Hollinger and I. Pseudonyms will be used to maintain confidentiality.

Questions about this research may be addressed to Elizabeth Fang at Lfiazng817@yahoo.com. Complaints about the research may be presented to Dr. Diana Hollinger, Director of Music Education at San Jose State University at (408) 924-4631. Questions about a research subject's rights, or research-related injury may be presented to Pamela Stacks, Ph. D., Associate Vice President, Graduate Studies and Research, at (408) 924-2427.

No service of any kind, to which you are to otherwise entitled, will be lost or jeopardized

Initial

if you choose not to participate in the study. Your consent is being given voluntarily. You may refuse to participate in the entire study or part of the study. You have the right to not answer questions you do not wish to answer. If you decide to participate in the study, you are free to withdraw at any time without any negative effect on your relations with San Jose State University or Friends of Children with Special Needs.

At the time you sign this consent form, you will receive a copy of it for your records, signed and dated by the investigator.

Thank you very much for your time.

Sincerely,

Elizabeth Fang

_____

Participant's Signature Date

_____

Investigator's Signature Date

Consent Form for Child Participants

Agreement to Participate in Research

Dear Adult,

Your child or ward has been asked to participate in a research study investigating the use of music in the lives of children with autism. This project is being conducted by Elizabeth Fang at San Jose State University with the supervision of Dr. Diana Hollinger for a Master's Degree in Music Education. Your child or ward's participation in this project is greatly appreciated and will involve interviews and observations. If your child or ward decides to participate, he/she will be asked to meet with me for audio taped interviews from January 2009-April 2009. You will be asked to be present or nearby. We will talk about what music means to the child. What is his/her experience living with autism? What are his/her thoughts and views towards himself/herself, others and the world? Because I am interested in exploring children with autism in relation to their personal history, I may ask him/her questions dealing with the past to provide a context in which to observe the child. During these discussions, he/she may decline to answer any questions or talk about any topics that he/she would prefer not to address, without the need for explanation. I may also wish to observe your child or ward with you in settings, such as therapy sessions, with prior notice to you and the therapist. These observations will be audio recorded.

I hope that your child or ward will participate in this research project, as it allows the voice of autism to be heard. Music helps us discover new ways of understanding children with autism.

Although the results of this study may be published, no information that could identify your child or ward, your family or you will be included. His/her involvement in this project will be kept as confidential as legally possible. All information and data will be reviewed and read only by Dr. Diana Hollinger and I. Pseudonyms or a coding system will be used to maintain confidentiality.

Questions about this research may be addressed to Elizabeth Fang at Lfiazng817@yahoo.com. Complaints about the research may be presented to Dr. Diana Hollinger, Director of Music Education at San Jose State University at (408) 924-4631.

Initial

Questions about a research subject's rights, or research-related injury may be presented to Pamela Stacks, Ph. D., Associate Vice President, Graduate Studies and Research, at (408) 924-2427.

No service of any kind, to which you and/or your child or ward is otherwise entitled, will be lost or jeopardized if you choose not to participate in the study. Your consent is being given voluntarily. You may refuse to allow his or her participation in the entire study or part of the study. Your child/ward has the right to not answer questions he/she does not wish to answer.

If you allow his/her participation, you are free to withdraw your child or ward at any time without any negative effect on your relations with San Jose State University or Friends of Children with Special Needs.

At the time you sign this consent form, you will receive a copy of it for your records, signed and dated by the investigator.

Thank you very much for your time.

Sincerely,

Elizabeth Fang

_____

Name of Child or Ward

_____

Parent or Guardian Signature Date

_____

Relationship to Child or Ward

Initial

_____

Full Mailing Address

_____

Investigator's Signature Date

APPENDIX C

SAMPLE INTERVIEW QUESTIONS

Adult Participants (Wendy, Dan, Rachel, Charlie)

Child Participants (Mike, Ryan)

Teachers (School, Private lessons, Band directors, etc.)

Adults Participants (Parents, Older siblings, etc.)

1. When was your child diagnosed autistic? What was your reaction?

2. Did he exhibit an early interest in music?

3. Please describe your child for me (his strengths, weaknesses, behavioral patterns...)

4. How have you adjusted your life style to include and support your child?

5. How has your perceptions/attitude toward autism changed since the birth of your child?

6. What therapies/intervention has your child undergone and/or is currently receiving? What was/are his reactions/responses to them?

7. What is your child's level of communication? Speech ability? Eye contact?

8. Please discuss methods of communication between your child and you/ others.

9. Please talk about your child's sensory system. Hyper-acute or hypo-acute? What senses are your child most reactive toward or completely insensitive toward?

10. What sort of things upset your child? What triggers his/her meltdowns? How do you help your child focus again?

11. How do you help your child with routines/schedule? Accomplishing tasks? Do you use visuals, speak, sing, etc.?

12. How independent is your child? How do you work on increasing his/her independence? What skills is he/she currently learning?

13. Where does your child to school?
    Is he mainstreamed, full inclusion, special day, class?
    If mainstreamed, in what areas?

14. Does your child have an aide? What process did you go through in requesting an aide? What qualities do you look for in an aide?

15. What is the role of music in your child's life? Please describe how music is use with your child.

16. Would you recommend that other parents use music to help/benefit their child?

17. What is a typical day like working with your child? How does music fit into the day?

18. When was music first introduced to your child? How was it introduced? (music therapy class, learning an instrument, singing to your child, etc.)

19. When did your child begin to show an interest in music? How were you able to perceived this interest?

20. What musical activities did/does your child participate in? (music at school, singing in the church choir, etc.)

21. Do you think music helps/benefits your child? If yes, in what ways (how)?

22. Why did you decided to engage/involve/bring music in your child's life?

23. What changes do you notice/see in your child with the use of music? Or since the use of music?

24. What is one of the greatest advice/message you can give to parents struggling with a child with autism?

25. What message can you give to others uninformed/puzzled—"in the dark" about autism.

26. What are your plans for equipping your child for the future?
    What worries do you have? How do you set out to break those worries?

27. Do you participate in any organizations involving individuals with special needs? If so, which ones?

28. What changes have you seen in your child over the years? What caused those changes?

29. Please share some experiences of success in your child. Stories of challenges?

30. If your child had no problem understanding you, what would you like to tell him? Something from the heart…

31. Is there anything else you would like to tell me about your child, autism, or music?

Child Participants (with Autism)

1. Tell me about yourself. What is your name? How old are you? Do you like music? Do you play any instruments? Sing?

2. What is your favorite part of school?

3. What food do you like to eat? Don't like?

4. Do you play any sports?

5. Do you like listening to music? What is your favorite song/piece?

6. What do you like to do when you have free time?

7. What are you good at doing? (skills, talents)

8. How often do you go into your own world? What does it feel like to be in your own world?

9. Do you think in pictures? Words? Sounds?

10. Tell me about your family.

11. How do your parents help you? What can others do to help you?

12. What do you want to be when you grow up?

13. What experiences do you have with music?

14. What sort of things upset you?

15. What are you most proud of? Musical accomplishments?

16. If anything were possible, what would you hope for?

17. How do you feel about how other people treat you? Are they mean or nice?

18. What do you think about yourself— how do you view yourself? How do you see others?

19. Is there anything else you would like to tell me about yourself? About music?

Teachers (School, Private lessons, Band directors, etc.)

1. What is your approach to teaching/working with a student with autism?

2. Have you made any adjustments in your teaching style to better teach children with autism? Have you made any other changes, such as classroom layout?

3. Do you use music in your classroom? If yes, how and when is it used?
   What type of music is used?
   Why did you decide to include music in your classroom?

4. Does the student with autism in your class have an aide?
   If yes, how do you incorporate an aide in you classroom?
   Does the aide act as a second teacher and also help other students?

5. What is the student's behavior in rehearsals/lessons (ex. totally focused, responds well to instructions, plays with his toys, etc.)?

6. Please describe the student's personality and attitude.

7. How do you help him learn and accomplish tasks (grow as an individual and a musician)?

8. What is a typical rehearsal/lesson like working with a child with autism?

9. Does the student exhibit an interest in music? If yes, in what way?

10. Do you see music as one of his strengths? Why?

11. Has music helped him grow in positive ways (ex. increased confidence, interaction with others, better motor skills, etc.)?

12. How would you describe his relationship with/responsiveness to music (ex. he loves it, it makes him happy, he is more focused and alert, etc.)?

13. How does he learn his music (he can read music, learns by ear, learns by rote)?

14. What are the student's strengths and weaknesses (musical and non-musical)?

15. How independent is he in music (he is able to keep up, learns quickly, he needs much attention, etc.)?

16. How does he interact with you as a teacher and/or with the other members in the ensemble/classroom?

17. Do you have any experiences/stories to share about children with autism you have taught or are teaching?

18. What new insights have you learned about children with autism? If any?

19. Have your views/ideas of autism changed in any way?

20. Please share some challenges you experienced and/or obstacles to overcome. What was one of the hardest parts being the student's teacher?

21. If the student had no problem understanding you, what would you like to tell him? Something from the heart…